National Institute for Health and Care Excellence

Final

Supporting Adult Carers

RQI Evidence reviews for supporting carers during changes to the caring role

NICE guideline NG150

Evidence reviews

January 2020

Final

These evidence reviews were developed by the National Guideline Alliance, part of the Royal College of Obstetricians and Gynaecologists

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Supporting carers during changes to the caring role

Review question

What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult carers during: (i) changes to the setting in which caring is performed; (ii) the transition of the person receiving care to adulthood; and (iii) change of carer status or circumstances?

Introduction

Caring is seldom static and many carers will find themselves facing changing and sometimes increasing needs for care and support over time. The Care Act 2014 introduced a process of identification, assessment, support plan and regular and ongoing review to identify and meet carers' assessed needs. Guidance emphasises that this process should be ongoing and dynamic, regularly reviewed and should take account of whether the outcomes proposed in the carer's support plan need change or modification. Over the past decade, demographic change, greater complexity of disabilities and health conditions and a shift from hospital to home for long term care have impacted on carers and the support they might need at different stages. Carers may be supporting several family members and increasingly are likely to be distance carers, with family members living within different local authority areas.

Carers organisations emphasise the importance of appropriate information and practical and emotional support at key transition stages, including changes in the family's circumstances such as a return to employment, family breakdown or divorce or possible changes in the health of the carer (including the need for the carer to go into hospital or have longer term treatment for a health problem). Carers UK and the Carers Trust note the importance of acknowledging changes and transitions over time in many caring roles, emphasising that carers do not necessarily relinquish their caring role when a relative moves into a residential or care home or long term NHS provision. However, both also recognise the challenges of managing transitions well. Age UK (2018) underlines the importance of preparation and advance planning for increasing levels of inter-dependency as carers and those they support age. The Parkinsons Society and the Alzheimer's Society (2019) also stress the need for information, advice and support when the person being cared for begins to deteriorate and the carer's role changes. Particular concerns have been noted with regard to the impact on the whole family of escalating care needs, in particular on young adult carers and their future education and career prospects.

Principle 7 of the NHS England Carers Toolkit states that 'the support needs of carers who are more vulnerable or at key transition points will be identified early', reinforcing the Care Act's similar expectations that key transition points will be identified early to avoid crisis situations. However, there is currently varying agreement about how best to manage key transition points in care pathways and how best to ensure that the changing circumstances of both carer and the person being cared for are acknowledged at key stages.

Summary of protocol

Please see Table 1 for a summary of the Population, Intervention, Comparison and Outcomes (PICO) characteristics of this review.

Table 1: Summary of the protocol (PICO table)

Population	Adult carers who provide unpaid care for: • ≥ 1 adult(s); or • ≥ 1 young people aged 16 - 17 years with ongoing needs AND: • where the setting in which care is provided has changed; or • whether the person receiving care becomes and adult; or • when the person who has provided care ceases to do so • social care, healthcare and other practitioners involved in providing care will also be considered.
Intervention	• As outlined in protocols for key areas 4, 5, 6 and 7.
Comparison	• As outlined in protocols for key areas 4, 5, 6, and 7.
Outcomes	Quantitative outcomes: • as outlined in protocols for key areas 4, 5, 6 and 7. Qualitative outcomes: • Expected themes might include: ○ need of carer to be involved in decisions regarding changes to the setting in which care takes place ○ need for practical support/advice to prepare for changes to the caring role ○ continuity of support during transitionary periods ○ need for comprehensive information about support available ○ return to work/education after carer ceases to be a carer

For full details see the review protocol in appendix A

Evidence

Included studies

This is a mixed method review which includes both qualitative and quantitative study designs. The objective of this review is to establish whether there are any types of any interventions for supporting carers during changes to the caring role that are effective, cost-effective, and acceptable to them.

For the quantitative part of the review, we looked for systematic reviews and randomised controlled trials (RCTs). For this question, the guideline committee agreed to exclude quantitative data from research conducted in the United States. They argued that the interventions would have been conducted in the context of a welfare system that is not sufficiently comparable with the UK for the purposes of drafting recommendations.

For the qualitative part of the review, we looked for studies that collected data using qualitative methods and analysed data qualitatively (including thematic analysis, framework thematic analysis, content analysis etc.). Survey studies restricted to reporting descriptive data that were analysed quantitatively were excluded.

Quantitative component of the review

An overview of the 5 included RCTs is provided in Table 2. The studies were from Canada (3 studies: Cameron 2015, Ducharme 2011, and Ducharme 2015;) and the United Kingdom (2 studies: Forster 2013, and Kalra 2004). Five RCTs looked at education/skill based practical support (Ducharme 2011, Ducharme 2015; Forster 2013, and Kalra 2004), and 1 study evaluated a multicomponent practical support intervention (Cameron 2015).

Overall the included RCTs provided data on 1543 adult carers. The smallest sample size was 31 adult carers of people with stroke (Cameron 2015), whilst the biggest study sample was 928 carers –of people with stroke (Forster 2013). The 5 included RCTs focused on carers of people with the following conditions:

- stroke (Cameron 2015; Forster 2013; and Kalra 2004 –for a total of 1259 carers)
- Alzheimer’s disease (Ducharme 2011, Ducharme 2015, n=111 carers of which 103 participated in both studies). These 2 RCTs included the same cohort of carers: in the first study (Ducharme 2011) 111 carers were randomised between the intervention group (the “Learning to Become a Family Caregiver” programme) and control group (usual care); in the second study (Ducharme 2015) the intervention carers were randomised between 2 subgroups (receiving or not receiving a booster session) while the control carers were kept as in the first study (Ducharme 2011).

The following outcomes were reported for the different interventions:

- For education or skills based practical support for interventions for carers the outcomes were carer knowledge/confidence/ efficacy about supporting person receiving care, impact of caring on carer, caring-related morbidity and resource use.
- For respite or practical support interventions for carers the outcomes were caring-related morbidity, social capital and carer control.
- For the intervention with a psychological/emotional component of practical support for carers, the outcomes were impact of caring on carer and caring-related morbidity.

Within this group 2 economic evaluations were identified, and included in the review.

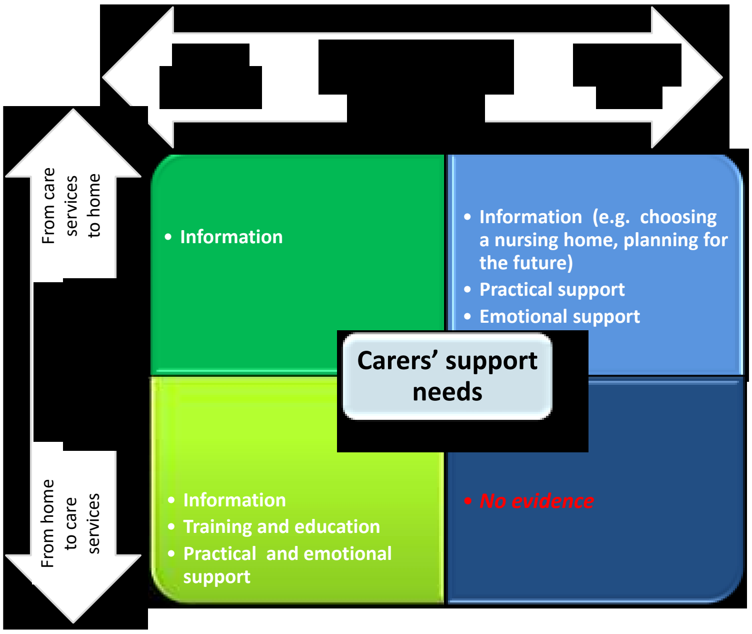
Qualitative component of the review

Four qualitative studies were included (Cobley 2013, Davies 2004, Ryan 2012, and Salisbury 2010). Table 3 provides a summary of the 4 included qualitative studies. They were published between 2004 (Davies 2004) and 2013 (Cobley 2013). They focused on carers either of stroke survivors (Cobley 2013, and Salisbury 2010) or of older people with an unspecified condition (Davies 2004, and Ryan 2012). All studies were conducted across the UK. Two studies recruited carers across England (Cobley 2013, and Davies 2004), 1 study took place in Northern Ireland (Ryan 2012), and 1 in Scotland (Salisbury 2010). All studies focused on the experiences, feelings and motivations of adult carers (n=101), ranging from a sample size of 9 (Salisbury 2010) to 48 carers (Davies 2004).

The included studies collected data via face-to-face semi-structured interviews (Table 3). Data analysis methods included constant comparative analysis using the 'Paradigm model' (Ryan 2012), inductive constructivist method (Davies 2004), interpretative phenomenological analysis (Salisbury 2010), and thematic analysis (Cobley 2013), with the latter being the most common method across included studies. Data collection and analysis were performed until the emerging concepts and categories reached saturation or data sufficiency in 2 studies (Cobley 2013; and Ryan 2012).

All included studies focused on the overall experience of carers with interventions for supporting them during changes to the setting in which care was provided (Table 3), while we did not identify any qualitative study focusing on the acceptability of interventions for supporting adult carers during the transition of the person receiving care from childhood to adulthood or changes of carer status or circumstances. As shown in the theme map (Figure 1), the concepts have been explored in a number of central themes and subthemes.

Figure 1: Theme map of carers' support needs during changes to the setting in which care is provided.



Excluded studies

Studies not included in this review with reasons for their exclusions are provided in appendix K.

Summary of studies included in the evidence review

A summary of the quantitative and qualitative studies that were included in this review is presented in Table 2 and Table 3.

Quantitative component of the review

Table 2: Summary of included quantitative studies

Study	Population	Participants	Intervention groups evaluated (as named in the paper)	Comparison in the review
Cameron 2015	**Setting** • Canada **Study type** • 3 group mixed-method RCT. This was a feasibility trial. **Aim of the study** • To examine feasibility of conducting a randomised controlled trial of the Timing it Right Stroke Family Support Program (TIRSFSP) and collect pilot data **Study dates** • NR **Follow-up** • 1,3, 6 months	N= 31 **Carer characteristics** • Age - Mean (SD): Self-directed intervention 57 (14.9); Stroke support person directed Intervention 57 (19.4); Control 55 (10) • Gender (% female)- Self-directed intervention (80%) ; Stroke support person directed Intervention (73%); Control 80% **Carer recipient characteristics** • First episode of stroke	• Intervention 1- Stroke support person directed • Intervention 2 –Self-directed support • Control- Standard care	B
Ducharme 2011	**Setting** • Canada **Study type** • 2 group RCT **Aim of the study** To test the efficacy of a psycho educational individual program conceived to facilitate transition to the caregiver role following diagnosis of Alzheimer disease in a relative. **Study dates** • NR **Follow-up** • Post-test, 3 months	N= 111 **Carer characteristics** • Age - Mean (SD): intervention =60.37 (13.12); control= 62.75 (13.22) • Gender - intervention: 79% female ; control: 79.6% female **Carer recipient characteristics** • Alzheimer's	• Intervention- Psychoeducational program • Control – Usual care	A
Ducharme 2015	**Setting** • Canada	N= 103	• Intervention 1- Booster group	A

Study	Population	Participants	Intervention groups evaluated (as named in the paper)	Comparison in the review
(Follow-on booster session study from Ducharme 2011)	**Study type** • 3 group RCT **Aim of the study** • To evaluate the efficacy of a booster session offered 2 weeks after the 6 month post-program assessment. **Study dates** • NR **Follow-up** • 6 months from booster	**Carer characteristics** • "caregivers had a mean age of about 60 years and approximately 80% were women **Carer recipient characteristics** • Alzheimer's	• Intervention 2- Non booster group • Control- Control	
Forster 2013	**Setting** • United Kingdom **Study type** • 2 group Cluster multicentre RCT **Aim of the study** • To evaluate whether or not a structured, competency-based training programme for caregivers [the London Stroke Carer Training Course (LSCTC)] improved physical and psychological outcomes for patients and their caregivers after disabling stroke, and to determine if such a training programme is cost-effective. **Study dates** • 2008- 2010 **Follow-up** • 6, 12 months	N= 928 **Carer characteristics** • Age - Mean (SD): intervention =61.1 (14.64) ; control= 60.8 (13.91) • Gender - intervention (n): 140 male ; control (n): 153 male **Carer recipient characteristics** • Stroke	• Intervention – London Stroke Carers Training Course (LSCTC) • Control – Usual care	A
Kalra 2004	**Setting** • United Kingdom **Study type** • 2 group RCT **Aim of the study** • To evaluate the effectiveness of	N= 300 **Carer characteristics** • Age: (IQR): Intervention 76 (70-80) years, Control 76 (70-82) years	• Intervention- Caregiver training • Control – Conventional care	A

Study	Population	Participants	Intervention groups evaluated (as named in the paper)	Comparison in the review
	training care givers in reducing burden of stroke in patients and their care givers. **Study dates** - NR **Follow-up** - 3, 12 months	- Gender: Intervention (n): 86/151, Control (n):74/149 **Carer recipient characteristics** - Stroke		

A: Education/ skill based practical support intervention. B: Practical support intervention.
F: Female; IQR: Inter quartile range; M: Male; N: Number; NR: Not reported; SD: Standard deviation; TAU: Treatment as usual; RCT: Randomised controlled trial.

Qualitative component of the review

Table 3: Summary of included qualitative studies

Study and aim of the study	Participants	Methods	Themes
Cobley 2013 **Aim of the study** The aims of this qualitative study were to explore the carers' experiences of 'Early Supported Discharge' services for stroke patients in the UK, and inform future Early Supported Discharge service development and provision.	N=15 adult carers **Carer** - Carer age - years = Mean (SD): 72.8 (14.1) - Carer gender (M/F:n)= 2/13 **Care recipient** - Condition= stroke	- **Recruitment period:** N/R - **Data collection & analysis**: ○ Data were collected through semi-structured interviews (duration ranged from 30 to 45 minutes). ○ Interview data were analysed using inductive thematic analysis performed in parallel by 2 researchers.	- Transition to a short-term care facility ○ Information needs - Transition to home from a short-term care facility ○ Information needs ○ Training and education needs ○ Practical and emotional support needs

Study and aim of the study	Participants	Methods	Themes
Davies 2004 **Aim of the study** The aim of this qualitative study was to explore experiences of nursing home placement from the viewpoint of carers of older people, around the time of the transition, in order to enable nurses and other healthcare practitioners to better meet their needs.	N=48 adult carers **Carer** • Carer age = Range, years: 45 - 84 • Carer gender (M/F:n)= 21/27 **Care recipient** • Condition= people admitted to nursing homes (no condition specific)	• **Recruitment period**: N/R. • **Data collection & analysis**: ○ Data were collected through semi-structured interviews. ○ Data were analysed using inductive constructivist method	• Transition to a long-term care facility ○ Information needs: planning for the future ○ Practical support needs: health and social care professionals ○ Emotional support needs
Ryan 2012 **Aim of the study** The aim of this qualitative study was to explore the rural family carers' experiences of the nursing home placement of an older person.	N=29 adult carers **Carer** • Carer age = Range, years: N/R • Carer gender (M/F:n)= N/R **Care recipient** • Condition= Stroke, dementia and immobility (no condition specific)	• **Recruitment period**: 2003 to 2006 • **Data collection & analysis**: ○ Data were collected through semi-structured interviews. ○ The interviews continued until the emerging concepts reached saturation. ○ Interview data were analysed using a constant comparative analysis following the 'Paradigm model' ○ Analysis was performed in parallel by 2 researchers, until data saturation.	• Transition to a long-term care facility ○ Information needs: choosing a nursing home ○ Practical support needs: health and social care professionals ○ Emotional support needs
Salisbury 2010 **Aim of the study** The aim of this qualitative study was to explore the carers' perceptions of a Functional	N=9 adult carers **Carer** • Carer age = Range, years: 57 - 73 • Carer gender (M/F: n)= 2/16 **Care recipient**	• **Recruitment period**: April to May 2007 • **Data collection & analysis:** ○ Data were collected through semi-	• Transition to a short-term care facility ○ Information needs • Transition to home from a

Study and aim of the study	Participants	Methods	Themes
Electrical Stimulation out-patient Clinic.	- Condition= stroke	structured interviews. ◦ Interview data were analysed using the framework of Interpretative Phenomenological Analysis. ◦ No details on data saturation/sufficiency were reported	short-term care facility ◦ Information needs

F: Female; M: Male; N: Number; N/R: Not reported; SD: Standard deviation.

Quality assessment of outcomes included in the evidence review

See the evidence profiles in appendix F.

Economic evidence

Included studies

Two studies were identified relating to the cost-effectiveness of interventions for supporting carers during changes to the caring role (Forster 2013; Patel 2004). Table 4 provides a brief summary of the included studies.

See also the economic evidence study selection chart in appendix G.

Table 4: Summary of included studies (economic evidence)

Study	Population	Intervention/Comparison	Perspective and cost year	Comments
• Forster 2013 • Cost-utility analysis conducted alongside an RCT • UK.	• Carers of inpatients after stroke	• Structured training programme – the London Stroke Carers Training Programme • Usual care	• Health and social care perspective; Societal perspective • 2009-10 prices	• Sensitivity analysis were undertaken to explore the impact of imputing missing data and using the replacement cost method to estimate the costs of informal care
• Patel 2004 • Cost-utility conducted	• People who have had a stroke	• Training carers in basic nursing and facilitation of personal care • No training of carers	• Health and social care perspective • 2001-02 prices	• Sensitivity analysis was used to vary assumptions about length

Study	Population	Intervention/Comparison	Perspective and cost year	Comments
alongside an RCT - UK	and their carers			of hospital stay and using the replacement cost method to cost the time of informal care

RCT: Randomised controlled trial.

See the economic evidence tables in appendix H and economic evidence profiles in appendix I.

Excluded studies

Studies not included in this review with reasons for their exclusion are provided in appendix K – Excluded studies.

Summary of studies included in the economic evidence review

A UK economic evaluation (Forster 2013) reported the results of a cost-utility analysis that compared a structured training programme, the London Stroke Carer Training Course (LSCTC), for carers of people with stroke to usual care. The LSCTC consisted of 14 training components (6 mandatory) that were considered to provide important knowledge and skills that would be needed by carers of stroke survivors following transfer to home. Carers received the LSCTC training whilst the person with stroke was an inpatient in the stroke rehabilitation unit. A further ‘follow through’ session was provided after hospital discharge either in person or by telephone.

For costs the analysis adopted societal and health and social care perspectives. Costs from the health and social care perspective included the costs of nursing/residential care; hospital inpatient, outpatient, day hospital and accident and emergency services; and primary care/community-based health/social care services. For the societal analysis all these costs were included along with the costs of informal care (for example carers' time). All costs were presented in UK pounds sterling and were estimated using 2009-10 prices. No discounting was necessary as all costs were incurred within a 1 year time horizon. Both resource use and effectiveness evidence were derived from a cluster single RCT including 930 carers, with a follow-up of 1 year (Forster 2013).

No significant difference between carers receiving training versus no training were observed in levels of self-reported burden, anxiety, depression, social restriction or QALYs (quality-adjusted life years), at 1 year follow-up. In addition, health and social care costs were found to be similar in carers who received the structure training programme and carers who did not receive training. Both univariate and probabilistic sensitivity analyses were performed and confirmed the findings of the base-case analysis, that LSCTC was not cost-effective compared to usual care.

Annother UK study (Patel 2004) compared the cost-utility of a training programme for carers of people who had had a stroke compared to no caregiver training. The training programme comprised instruction in basic skills of moving and handling, facilitation of activities of daily living, and simple nursing tasks. Carers received training over 3 to 5 sessions, each lasting from 30 to 45 minutes, and a follow-up session at home. The analysis costing was undertaken from a societal perspective. The costs included in the study were community-based care costs (for example respite care); social services costs (for example social services day care centre); costs of initial admission for stroke, and costs of other secondary care services and the costs of informal care (estimated by valuing carers' time using the opportunity cost method). All costs were presented in UK pounds sterling at 2001-02 prices. Discounting of costs was not undertaken as all costs were incurred within 1 year of the intervention. Both resource use and effectiveness evidence were derived from a prospective single-blinded RCT (Kalra 2004), with a follow-up of 1 year.

No significant difference in QALYs was found between carers receiving training and those receiving no training, at 1 year follow-up. The authors queried whether the EQ-5D measure was sufficiently sensitive to changes in carer health related quality of life since statistically significant differences were found between the groups using a visual analogue scale (Kalra 2004). Total health and social care costs were found to be lower for people whose carers received training than for those whose carers did not receive training. One-way sensitivity analysis was used to examine the impact of varying the cost of unpaid care and the length of stay. This analysis showed that the use of higher costs or longer length of stay increased the total costs in both groups, but did not affect the comparison of the total costs. Therefore, the authors concluded that the training of carers of people with stroke reduced the costs associated with stroke rehabilitation, without worsening the carers' quality of life.

Economic model

No economic model was undertaken for this review because although this was identified as medium priority there was published economic evidence that was included in this review and a lack of effectiveness data on which to base new modelling.

Evidence statements

Each evidence statement has an identifying code to ensure ease of reference to the data during presentation and committee discussions. The code is derived from the title of the review and in this case is 'SCT' and then a number. SCT stands for support (during) caring transitions.

Quantitative and qualitative components of the review

Evidence statements from the included studies are organised by intervention category and then by outcome within each category, starting with quantitative data and then relevant themes from the qualitative studies.

Work, education and training [Relating to RQD]

- **SCT1.** No evidence (neither quantitative nor qualitative) was identified about this intervention category

Training to provide practical support [Relating to RQE]

Caring-related morbidity

- **SCT2.** Low quality evidence from 1 multicentre cluster RCT from the UK including 928 adult carers of people after stroke could not differentiate perceived levels of anxiety (Hospital Anxiety and Depression Scale – Anxiety subscale) and mortality rates (Number of Caregiver Death) between carers receiving the intervention (the "London Stroke Carers Training Course" –LSCTC) versus usual care (as recommended in national guidelines) at 6 and 12 months follow-up. This educational/skills intervention is a structured training programme for caregivers, which includes assessment of competencies in knowledge or skills essential for the day-to-day management of disabled survivors of stroke.
- **SCT3.** Very low quality evidence from 1 UK RCT including 300 adult carers of people after stroke suggested potential benefits in levels of perceived burden of depression or anxiety (Hospital Anxiety and Depression Scale) in carers receiving the intervention (multicomponent training programme targeted on carers' needs) combined to usual care versus usual care alone (in this case information on stroke and its consequences + involvement in goal setting for rehabilitation and discharge planning + encouragement to attend nursing activities to learn about informal instruction on facilitating transfers, mobility, and activities of daily living tasks + advice on community services, benefits, and allowances) at 12 months follow-up. This educational/skills intervention started when the people who'd had a stroke's rehabilitation needs had stabilised and discharge was contemplated. Carers received 3 to 5 sessions depending on need; each session lasted 30-45 minutes.

Impact of intervention on caring-related accidents/incidents

- **SCT4.** No data reporting on this outcome

Carer skills, knowledge/confidence or efficacy about supporting person receiving care

- **SCT5.** Very low to low quality evidence from 1 RCT from Canada showed that there was conflicting evidence about the effectiveness of a manual-based skills intervention on perceived levels of knowledge/confidence or efficacy in adult carers of people living with dementia following diagnosis. Low quality evidence from this RCT including 111 carers found improved levels of preparedness

(Preparedness for Caregiving Scale) and knowledge of services (The Knowledge of Services Scale) in carers receiving the skills-based training intervention (the “Learning to Become a Family Caregiver” programme) versus usual care (such as putting carers in contact with local community service centres and offering a range of available services) at 3 months follow - up from intervention completion. However, the same RCT could not differentiate perceived levels of self-efficacy (Revised Scale for Caregiving Self-Efficacy), or knowledge of future needs (Planning for Future Needs Scale) between intervention groups. This manual-based intervention consists of 90-minutes individual sessions once a week for 7 weeks, it targets only carers, and consists of 7 sessions covering a number of topics (carer perceptions of the care situation; coping strategies for dealing with difficulties and averting psychological distress; how to communicate and enjoy time spent with the relative living with dementia; how to use one’s strengths and experiences to take care of the relative; how to get family and friends to help; knowledge of services and how to ask for them; and planning ahead for the future)

- **SCT6.** Very low quality evidence from 1 follow-up RCT from Canada showed that there was conflicting evidence about the effectiveness of a manual-based skills intervention on perceived levels of knowledge/confidence or efficacy in adult carers of people living with dementia following the diagnosis of dementia of their relative, with or without a booster session. Low quality evidence from this RCT found improved levels of preparedness (Preparedness for Caregiving Scale) in carers receiving the booster session after the skills-based training intervention (the “Learning to Become a Family Caregiver” programme) versus usual care (in this case putting carers in contact with local community service centres and offering a range of available services). However, the same RCT could not differentiate levels of knowledge of services, planning for future care needs, and use of reframing as a coping strategy, perceived informal support, and family conflicts between interventions groups. This 90-minute booster session was delivered 6 months and 2 weeks after the initial intervention; and was aimed to consolidate what carers learned during participation in the skills-based training intervention, to make adjustments relative to intervention components, and to consolidate or improve carers’ ability to transfer learning to different problem situations in their daily life as a caregiver.

Impact of caring on carer

- **SCT7.** Low quality evidence from 1 UK multicentre cluster RCT including 928 adult carers of people after stroke could not differentiate levels of Health Related-Quality of Life (HR-QoL) (EuroQol VAS) and self-reported levels of burden (Caregiver burden Scale) between carers receiving the intervention (the “London Stroke Carers Training Course” –LSCTC) versus usual care (as recommended in national guidelines) at 6 and 12 months follow-up. This educational/skills intervention is a structured training programme for caregivers, which includes assessment of competencies in knowledge or skills essential for the day-to-day management of disabled survivors of stroke.
- **SCT8.** Very low quality evidence from 1 UK RCT including 300 adult carers of people after stroke suggested potential benefits in terms of carers’ perceived burden of HR-QoL (EuroQol VAS) and self-reported levels of burden (Caregiver burden Scale) in carers receiving the intervention (a multicomponent training programme targeted on carers’ needs) combined with usual care versus usual care alone (in this case information on stroke and its consequences + involvement in goal setting for rehabilitation and discharge planning + encouragement to attend nursing activities to learn about informal instruction on facilitating transfers,

mobility, and activities of daily living tasks + advice on community services, benefits, and allowances) at 12 months follow-up. This educational/skills intervention started when the stroke survivor’s rehabilitation needs had stabilised and discharge was contemplated. Carers received 3 to 5 sessions depending on need; each session lasted 30-45 minutes.

Resource and service use (health or social care)

- **SCT9.** Please see evidence statements under “Economic component of the review” below.

Qualitative themes

- **SCT10. Perceived carers' training and education needs during transition to home from a short-term care facility**. There is low quality evidence from 1 UK study that many adult carers of people with stroke expressed the need for education on how to manage care in the home. In most cases, the training of carers in how best to physically support the stroke survivor after transfer from hospital, was described as inadequate. After the person’s discharge from healthcare services some carers also highlighted difficulties in coping with the person’s emotional and psychological needs.

Practical support [Relating to RQF]

Caring-related morbidity

- **SCT11.** Very low quality evidence from 1 feasibility RCT from Canada including 31 adult carers of people after stroke could not differentiate levels of depression (Center for Epidemiological Studies-Depression), or levels of psychological well-being (Positive Affect Scale) in carers receiving the intervention (the “Timing it Right Stroke Family Support Program” –TIRSFSP) versus standard care (not reported) at 1, 3 and 6 months follow-up. This manual-based practical intervention aimed to provide carers with support tailored to their needs and corresponding to their care recipient’s phase of recovery; was composed of 3 components (information about stroke, treatment options, and services; emotional support to carers; and guidance about ways to have their support needs met). This multicomponent intervention has been delivered in 2 ways: 1) carer self-directed or 2) professional-led.

Impact of caring on carer

- **SCT12.** No data reporting on this outcome.

Social capital

SCT13. Very low quality evidence from 1 feasibility RCT from Canada including 31 adult carers of people after stroke could not differentiate levels of social support (Medical Outcomes Study Social Support) in carers receiving the intervention (the “Timing it Right Stroke Family Support Program” –TIRSFSP) versus standard care (not reported) at 1, 3 and 6 months follow-up. This manual-based practical intervention was aimed to provide carers with support tailored to their needs and corresponding to their care recipient’s phase of recovery; was composed of 3 components (information about stroke, treatment options, and services; emotional support to carers; and guidance about ways to have their support needs met). This multicomponent intervention has been delivered in 2 ways: 1) carer self-directed or 2) professional-led.

Carer quality of life

- **SCT14.** No data reporting on this outcome.

Carer choice/control/efficacy

- **SCT15.** One feasibility RCT from Canada including 31 adult carers of people after stroke could not differentiate levels of mastery (Pearlins Mastery Scale) in carers receiving the intervention (the "Timing it Right Stroke Family Support Program" – TIRSFSP) versus standard care (not reported) at 1, 3 and 6 months follow-up. This manual-based practical intervention was aimed to provide carers with support tailored to their needs and corresponding to their care recipient's phase of recovery; was composed of 3 components (information about stroke, treatment options, and services; emotional support to carers; and guidance about ways to have their support needs met). This multicomponent intervention has been delivered in 2 ways: 1) carer self-directed or 2) professional-led.

  Rating the overall certainty in evidence reported in this RCT was not feasible (because it was impossible to judge the precision of the estimates of effect).

Qualitative themes

- **SCT16. Perceived carers' information needs during transition to a long-term care facility: choosing a nursing home**. There is very low quality evidence from 1 UK study that many adult carers seeking a nursing home for the older person they were supporting reported that the following factors influenced their choice of a nursing home: familiarity, rurality and the recommendations made by friends. Other carers felt that the decision-making was further influenced by the expressed wishes of the older relative. All carers said they rarely needed to consult any formal channels for advice on the choice of home
- **SCT17. Perceived carers' information needs during transition to a long-term care facility: planning for the future**. There is very low quality evidence from 1 UK study that many adult carers of older people recently admitted to a nursing home reported that they had not been provided with much information to help them to plan for the future.
- **SCT18. Perceived carers' practical support needs during transition to a long-term care facility: role of health and social care professionals.** There is low quality evidence from 2 UK studies that many adult carers of older people recently admitted to a nursing home highly valued the support received from health and social care professionals, particularly in the absence of family support – or in the presence of limited family support. Professionals were seen as playing the central role of carer advocate. During the move to the nursing home, many adult carers expressed the need for a more active interaction with staff. In particular nursing home staff frequently failed to draw upon the knowledge and expertise of family caregivers in developing plans of care for residents. In this context, carers were left to their own initiative to improvise ways of ensuring that staff got to know the older person.
- **SCT19. Perceived carers' information needs during transition to a short-term care facility**. There is low quality evidence from 2 UK studies that many adult carers of people admitted to acute care after a stroke expressed needs for detailed 'disease-specific' information, for example including stroke diagnosis, current and future treatment and care needs, availability and how to access community resources, and prognosis.
- **SCT20. Perceived carers' information needs during transition to home from a short-term care facility**. There is low quality evidence from 2 UK studies that many adult carers of people with stroke had a negative experience of discharge planning, most of these carers reported being poorly informed regarding the extent of support available after discharge.

- **SCT21. Perceived carers' practical and emotional support needs during transition to home from a short-term care facility**. There is low quality evidence from 1 UK study that, after the person they care for had been discharged from healthcare services, many adult carers described a reduction in time for leisure and social activities that, in turn, limited their opportunities for much needed social support. Many of these carers, indicated that they felt thrown into the caring role without receiving enough support from the community stroke teams. They stressed the need for services to consider and address carers' issues, including practical and emotional support. Most of them reported feelings of exhaustion and physical strain.

Psychological and emotional support (Relating to RQG)

- **SCT22.** No quantitative evidence was identified about this intervention category

Qualitative themes

- **SCT23. Perceived carers' emotional support needs during transition to a long-term care facility**. There is low quality evidence from 2 UK studies that many adult carers of older people recently admitted to a nursing home felt that the key to a successful transition appeared to be the availability of a confidant, often a social worker, who could support, listen, and offer advice and comfort. Many adult carers reported that professionals showed no interest in their own needs and the absence of any assessment meant that many relatives were left to work through their feelings and emotions at this time without support. The change of care setting itself was a traumatic experience for many adult carers, some of whom described overwhelming feelings of guilt and loss. During the move to a nursing home, they alternated between feelings of reassurance that their relative would now receive appropriate care and despair that they were no longer able to provide this care.

Economic component of the review

- **SCT24** One partially applicable cost-utility analysis from the UK found that a structured training programme (the London Stroke Carers Training Programme) was not cost-effective for carers of inpatients after stroke. This analysis was characterised by minor limitations
- **SCT25** One partially applicable cost-utility analysis from the UK found that training carers of stroke survivors in nursing and facilitation of personal care was cost-effective with savings in health and social care costs achieved without a reduction in the carers' quality of life. This analysis is characterised by potentially serious limitations.

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

This evidence review includes both qualitative and quantitative outcomes.

In terms of quantitative outcomes, prioritisation was as outlined in the protocols for the reviews about work, education and training (RQD), the review about training to provide practical support (RQE), the review about practical support for carers (RQF), and the review about psychological and emotional support for carers (RQG).

Quantitative evidence was identified on most of the outcomes considered critical for supporting carers during changes to the caring role.

In terms of qualitative outcomes, the committee focussed their discussion on 3 themes: transition to a long-term care facility - carers' support needs (including information, practical support, and emotional support needs); transition to a short-term care facility - carers' support needs (including information needs); and transition to home from a short-term care facility and carers' support needs (including information, training and education, practical support, and emotional support needs).

The quality of the evidence

In terms of quantitative evidence, 5 RCTs were included. The quality of the quantitative evidence was assessed using the GRADE methodology. The quality of the evidence across all outcomes ranged from very low to low and was commonly downgraded because of design limitations (risk of bias) of the studies and high to very high rates of imprecision in the effect estimates, due to small number of events. Common study limitations included: performance bias (with many RCTs not blinding carers, personnel and outcome assessors to the support interventions provided, potentially creating systematic differences between groups in the care provided); attrition bias (with many RCTs reporting incomplete –or missing– outcome data); and selective reporting bias. Two RCTs (Kalra 2004, and Cameron 2005) presented their results as medians and interquartile differences, therefore it was not possible to judge the precision of their estimates of effect, and so rating was automatically downgraded here.

In terms of qualitative evidence, 4 qualitative studies were identified. Quality of the qualitative evidence for the themes identified in the review ranged from very low to moderate quality, according to GRADE-CERQual. The quality of the included qualitative evidence was mostly downgraded due to adequacy of data, as there was enough data for only a few themes to develop an understanding of the phenomena of interest, either due to insufficient studies (offering inadequate data) or lack of diversity of carers (for example, all the qualitative evidence focused on carers either of stroke survivors or of older people with an unspecified condition). For all themes, the overall quality of evidence was also downgraded due to design limitations in the studies (for example recruitment, data collection and analysis methods, and lack of disclosure of the relationship between researcher and participants).

Synthesis of quantitative and qualitative data

During their discussion of the evidence, the committee synthesised the quantitative and qualitative data, making judgements about the extent to which the combined findings could be used as a basis for recommendations.

Five RCTs provided quantitative evidence about the effectiveness of interventions for supporting carers during changes to the caring role. However the findings were generally conflicting and the quality of the data were rated as low or very low quality. The committee therefore made limited use of these findings in drafting recommendations, focussing more on the strength of the qualitative component. This is described in detail below under 'benefits and harms'.

Benefits and harms

Training carers to provide practical support during changes to their caring role

The quantitative evidence showed that there were conflicting results in levels of carer knowledge/confidence or efficacy, impact of caring on carer and caring-related morbidity in carers receiving structured training programmes to deal with changes to their caring role compared to those carers receiving no intervention. Furthermore the committee expressed concern that the findings from this area of the review were low to very low quality, and only covered some specific carers' circumstances. Therefore, the committee agreed not to draft any recommendations on training interventions to improve carers' skills during changes to their caring role.

Practical support for carers during changes to their caring role

One RCT was identified about the effectiveness of practical support interventions for carers during changes to their caring role, demonstrating no improvement in morbidity, levels of social support, and levels of mastery in carers receiving the intervention. The committee noted that the findings from this trial only covered some specific carers' circumstances (in this case, carers of stroke survivors); they also highlighted concerns about the overall quality of the evidence for these findings, which was graded as very low, and with incalculable imprecision ratings. Therefore, the committee agreed not to use the quantitative evidence to draft any recommendations on this area of the review.

They focussed more on the strength of the qualitative evidence in drafting recommendations about practical support for carers during changes to their caring role. The committee concurred with the qualitative evidence that for many carers of people recently admitted to a nursing home, receiving information was important to help them plan for their needs around the transition. Professionals were seen as playing the central role of carer advocate, with many carers expressing the need for more active interaction with staff, during the move from home settings to a residential care home. The committee used this evidence to recommend that health and social care professionals should provide information and emotional and practical support to help carers prepare for and adjust to the change in their caring circumstances, specifically, when the cared-for person moves away from home. The committee also noted an absence of evidence about young adult carers' experiences during transitions in the caring role and they considered this subgroup of carers to be particularly important in this context. They therefore reached consensus agreement that information and emotional and practical support should be provided to carers in a range of circumstances, including when a person moves from being a young carer to an adult carer.

Some other key times of change considered by the committee for reference in the recommendations included when the person being cared for becomes terminally ill or dies unexpectedly, when the carer themselves becomes bereaved or experiences a decline in their own ability to care as they get older. These circumstances are likely to have a significant emotional impact, and will require a review of the current practical support and care giving arrangements that are currently in place.

One of the transition points that the committee discussed was the move to or from hospital. The committee agreed about the importance of having a professional from the hospital-based team responsible for providing carers with information and practical and emotional support at the moment of transition from hospital (including practical information of who to contact about medicine and equipment problems that occur in the 24 hours after discharge). They noted that this was partially confirmed by the evidence, but to avoid overlapping with existing NICE guidance, they referred to

NICE's guideline on transitions between inpatient hospital settings and community or care home settings, to recommend support and training for carers during this process.

Psychological and emotional support for carers during changes to their caring role

No quantitative evidence was identified about the effectiveness of psychological and emotional support interventions for carers during changes to their caring role. However, based on qualitative evidence, the committee discussed that for many carers of people recently admitted to a nursing home the availability of a professional, who could support, listen, and offer advice and comfort was key to a successful transition. Based on this evidence, they also agreed that the change of care setting itself could be a traumatic experience for carers and that support during this period is essential. Although the person may no longer be living with them the committee noted this certainly does not mark the end of the carer's role. On this basis they drafted a recommendation emphasising the importance of being aware that caring responsibilities may not end when the cared-for person moves away from home.

Related to other topics within this guideline

Evidence from this review alongside the review about end of life support for carers (RQH) suggested that carers appreciate being recognised for the work they do in order to improve the life of the cared-for person. The wealth of knowledge that carers have about the person they care for, their needs and their preferences helps services provide better support. In light of this evidence the committee discussed that carers should be recongised and valued both for their own sake and because of its significance to the person they care for. They therefore drafted a recommendation about recognising the benefits of identifying carers, which is in the section of the guideline on identifying carers.

Finally, overall, no quantitative evidence was located by this review about interventions to support adult carers to enter, remain in or return to work or interventions for providing emotional support to adult carers during changes to their caring role. The committee agreed not to recommend further research in these areas. They considered them a low priority for research funding, compared with other evidence gaps identified during development.

Cost effectiveness and resource use

Whilst some cost-effectiveness evidence was found the results were either inconclusive or difficult to generalise, given the very specific populations (adult carers of stroke survivors) and the interventions analysed (in this case structured training programmes). Therefore, it was still necessary for the committee to make additional qualitative assessments of cost-effectiveness given the breadth of recommendations drafted on the support needs of adult carers during changes to their caring role.

The committee's recommendations emphasised the importance of providing information, emotional and practical support to carers during changes to the care role. These recommendations were informed largely by the committee's own experience and existing NICE guidance. The committee considered that the recommendations largely reflected current practice and were unlikely to have a significant resource impact. They acknowledged that some providers would need to improve the information and support given to carers during transition but this was likely to be cost-effective as it could mitigate the “downstream” impact on services arising from transitions which can often be a traumatic experience to the carer.

Other factors the committee took into account

In drafting recommendations on the basis of this review, the committee also took account NICE’s guideline on transitions between inpatient hospital settings and community or care home settings (NICE guideline [NG27]) which includes support for carers.

References

Quantitative component of the review

Cameron 2015

Cameron JI, Naglie G, Green TL, Gignac MA, Bayley M, A feasibility and pilot randomised controlled trial of the "Timing it Right Stroke Family Support Program". Clin Rehabil 2015;29(11):1129-40

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Ducharme 2015

Ducharme F, Lachance L, Lévesque L, Zarit SH, Kergoat MJ. Maintaining the potential of a psycho-educational program: efficacy of a booster session after an intervention offered family caregivers at disclosure of a relative's dementia diagnosis. Aging Ment Health 2015;19(3):207-16

Forster 2013

Forster A, Dickerson J, Young J, Patel A, Kalra L, A cluster randomised controlled trial and economic evaluation of a structured training programme for caregivers of inpatients after stroke: the TRACS trial. Health Technol Assess 2013;17(46):1-216

Forster A, Dickerson J, Young J, Patel A, Kalra L, A structured training programme for caregivers of inpatients after stroke (TRACS): a cluster randomised controlled trial and cost-effectiveness analysis. Lancet 2013;382(9910):2069-76

Kalra 2004

Kalra L, Evans A, Perez I, Melbourn A, Patel A, Training carers of stroke patients: randomised controlled trial. BMJ 2004;328(7448):1099

Patel A, Knapp M, Evans A, Perez I, Kalra L. Training care givers of stroke patients: economic evaluation. BMJ 2004;328(7448):1102

Economic component of the review

Forster 2013

Forster A, Dickerson J, Young J, Patel A, Kalra L, A cluster randomised controlled trial and economic evaluation of a structured training programme for caregivers of inpatients after stroke: the TRACS trial. Health Technol Assess 2013;17(46):1-216

Forster A, Dickerson J, Young J, Patel A, Kalra L, A structured training programme for caregivers of inpatients after stroke (TRACS): a cluster randomised controlled trial and cost-effectiveness analysis. Lancet 2013;382(9910):2069-76

Patel 2004

Patel A, Knapp M, Evans A, Perez I, Kalra L. Training care givers of stroke patients: economic evaluation. BMJ 2004;328(7448):1102

Qualitative component of the review

Cobley 2013

Cobley CS, Fisher RJ, Chouliara N, Kerr M, Walker MF. A qualitative study exploring patients' and carers' experiences of Early Supported Discharge services after stroke. Clin Rehabil 2013;27(8):750-7

Davies 2004

Davies S, Nolan M. 'Making the move': relatives' experiences of the transition to a care home. Health Soc Care Community 2004;12(6):517-263

Ryan 2012

Ryan A, McKenna H, Slevin O. Family care-giving and decisions about entry to care: a rural perspective, Ageing and Society 2012;32:1-18

Salisbury 2010

Salisbury L, Wilkie K, Bulley C, Shiels J. 'After the stroke': patients' and carers' experiences of healthcare after stroke in Scotland. Health Soc Care Community 2010;18(4):424-32

Appendices

Appendix A – Review protocols

Review protocol for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult carers during: (i) changes to the setting in which caring is performed; (ii) the transition of the person receiving care to adulthood; and (iii) change of carer status or circumstances?

Table 5: Review protocol

Field (based on PRISMA-P)	Content
Review question	What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult carers during: (i) changes to the setting in which caring is performed; (ii) the transition of the person receiving care to adulthood; and (iii) change of carer status or circumstances?
Type of review question	Mixed, quantitative and qualitative review
Objective of the review	This review aims to establish whether there are any interventions for supporting carers during changes to the caring role that are effective, cost-effective, and acceptable to them
Eligibility criteria – population/disease/condition/issue/domain	Adult carers who provide unpaid care for: ≥ 1 adult(s); or ≥ 1 young people aged 16 – 17 years with ongoing needs AND: where the setting in which care is provided has changed; or whether the person receiving care becomes and adult; or when the person who has provided care ceases to do so. Social care, healthcare and other practitioners involved in providing care will also be considered.
Eligibility criteria – intervention	As outlined in protocols for key areas 4, 5, 6 and 7.
Eligibility criteria – comparator(s)/control or reference (gold) standard	As outlined in protocols for key areas 4, 5, 6, and 7.
Outcomes and prioritisation	As outlined in protocols for key areas 4, 5, 6 and 7.

Field (based on PRISMA-P)	Content
	Expected themes might include: • need of carer to be involved in decisions regarding changes to the setting in which care takes place • need for practical support/advice to prepare for changes to the caring role • continuity of support during transitionary periods • need for comprehensive information about support available • return to work/education after carer ceases to be a carer. Results of the qualitative evidence synthesis will be determined by thematic analysis and the use, if appropriate, of thematic maps. The quantitative and qualitative data will be presented together as the overall result of this mixed methods review. Where they allow, data will be grouped around the protocol interventions.
Eligibility criteria – study design	See the corresponding section in the protocols for review questions 4, 5, 6, and 7. Generally there will be no restrictions on the types of studies that will be considered for inclusion.
Other inclusion exclusion criteria	Additional inclusion criteria: setting of intervention can be people’s own homes and any other health and social care setting (including neighbourhood and community) in which adult carers provide care and support only studies from the following geographical areas/countries will be included: UK, Australia, Canada, Europe, Japan, New Zealand, South Africa, and USA. Studies from other countries will not be included due to substantial differences in their carer populations and/or social or healthcare systems - for qualitative evidence, only studies from the UK will be considered full-text English language articles published in or after 2003. full-text reports of complex or multicomponent interventions will be assessed for relevance to this review questions Exclusion criteria: interventions to support carers during periods of crisis will be excluded, as these interventions will be assessed as part of question 6 conference abstracts will be excluded as they typically do not provide sufficient information to evaluate risk of bias/quality of study non-English language studies.

Field (based on PRISMA-P)	Content
	A step-wise approach to the included evidence will be used if required: although only studies published in or after 2003 will be initially included, subsequent modifications to the inclusion criteria may be warranted, subject to ratification by the GC, if the volume of studies to examine is very high. For example, studies may be restricted to those conducted in the UK or a more recent date of publication may be used. If changes to the initial inclusion criteria are deemed necessary, reasons for these will be explicitly noted in the methods section of the guideline.
Proposed sensitivity/sub-group analysis, or meta-regression	Not applicable
Selection process – duplicate screening/selection/analysis	Selection of articles will be from the searches for review questions 4, 5, 6 and 7. Dual screening will not be performed for this review question.
Data management (software)	Pairwise meta-analyses, if appropriate, will be conducted using the Cochrane Review Manager (RevMan5). GRADEpro will be used to record (and assess) the quality of quantitative evidence for outcomes relevant to establishing the effectiveness of interventions. NGA STAR will be used for generating bibliographies and citations, sifting studies, extracting data and for the quality appraisal of the included studies. A GRADE CERQual Microsoft Excel template will be used to record the overall quality of findings from the qualitative evidence. A Microsoft Excel template will also be used to record the findings of questionnaire surveys.
Information sources – databases and dates	As outlined in protocols for key areas 4, 5, 6 and 7.
Identify if an update	This review question is not an update.
Author contacts	Developer: the National Guideline Alliance
Highlight if amendment to previous protocol	For details please see section 4.5 of Developing NICE guidelines: the manual 2014
Search strategy – for 1 database	For details please see appendix B.
Data collection process – forms/duplicate	A standardised evidence table format will be used, and published as appendix D (evidence tables) or H (economic evidence tables).
Data items – define all variables to be collected	For details please see evidence tables in appendix D (evidence tables) or H (economic evidence tables).
Methods for assessing bias at outcome/study level	Standard study checklists were used to critically appraise individual studies. For details please see section 6.2 of Developing NICE guidelines: the manual 2014

Field (based on PRISMA-P)	**Content**
	The confidence in the evidence extracted from the included studies will be evaluated for each theme using GRADE CERQual approach: https://www.cerqual.org/
Criteria for quantitative synthesis (where suitable)	For details please see section 6.4 of Developing NICE guidelines: the manual 2014
Methods for analysis – combining studies and exploring (in)consistency	Segregated (that is convergent) methods for data synthesis (Pearson 2015; Pluye 2014) will be used to interpret the evidence. Included studies will be first categorised according to type of study design, and the data will be analysed as appropriate: for example, • Mean differences (MDs) or standardised mean differences (SMDs) for continuous outcomes, risk ratios (RRs) for dichotomous outcomes, and hazard ratios (HRs) for time to event outcomes, will be used for outcomes relevant to establishing the effectiveness of interventions. Hetereogeneity will be assessed using the I^2 statistic. GRADE will be used to assess the quality of these outcomes. • Thematic analysis will be used to elucidate any themes or patterns revealed across the included qualitative or mixed methods studies relevant to establishing the acceptability of an intervention. GRADE-CERQual will be used to assess the quality of evidence for a theme across studies. Being a mixed methods review, the NGA technical team will present the data from quantitative and qualitative studies together, organised around the protocol interventions (where data are available). The committee will complete the synthesis of these mixed data through their discussions of the evidence. Their interpretation of the relationship between the quantitative and qualitative data is described in the committee discussion of the evidence. References Pearson, A., White, H., Bath-Hextall, F. (2015). A mixed-methods approach to systematic reviews. International Journal of Evidence-based Healthcare, 13: 121-131. Pluye, P., & Hong, Q. N. (2014). Combining the power of stories and the power of numbers: mixed methods research and mixed studies reviews. Annual review of public health, 35: 29-45.
Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual 2014.
Assessment of confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual 2014
Rationale/context – Current management	For details please see the introduction to the evidence review.

Field (based on PRISMA-P)	Content
Describe contributions of authors and guarantor	A multidisciplinary committee developed the guideline. The committee was convened by The National Guideline Alliance and chaired by Mr. Phil Taverner in line with section 3 of Developing NICE guidelines: the manual 2014 Staff from the National Guideline Alliance undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the guideline in collaboration with the committee. For details please see the methods chapter of the guideline.
Sources of funding/support	The National Guideline Alliance is funded by NICE and hosted by The Royal College of Obstetricians and Gynaecologists
Name of sponsor	The National Guideline Alliance is funded by NICE and hosted by The Royal College of Obstetricians and Gynaecologists
Roles of sponsor	NICE funds The National Guideline Alliance to develop guidelines for those working in the NHS, public health, and social care in England
PROSPERO registration number	Not registered

AMSTAR: Assessing the Methodological Quality of Systematic Reviews; CDSR: Cochrane Database of Systematic Reviews; CENTRAL: Cochrane Central Register of Controlled Trials; DARE: Database of Abstracts of Reviews of Effects; GRADE: Grading of Recommendations Assessment, Development and Evaluation; HTA: Health Technology Assessment; MID: minimal important difference; NICE: National Institute for Health and Care Excellence; RCT: Randomised Controlled Trial; RoB: Risk of Bias; SD: Standard Deviation.

Appendix B – Literature search strategies

Literature search strategies for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult cares during: (i) changes to the setting in which caring is performed; (ii) the transition of the person receiving care to adulthood; and (iii) change of carer status or circumstances?

The search for this topic was last run on 7th November 2017.

Database: Embase, Medline, Medline Ahead of Print and In-Process & Other Non-Indexed Citations – OVID [Multifile]

#	Searches
1	caregiver/ use emez or caregivers/ use mesz, prem or caregivers/ use psyh or caregiver burden/ use psyh
2	(carer* or caregiv* or care giv*).ti,ab.
3	1 or 2
4	exp *cognitive therapy/ or (counseling.hw. and exp *counseling/) or *friend/ or *friendship/ or *group dynamics/ or *group process/ or *group therapy/ or *hotline/ or *mindfulness/ or *peer group/ or *problem solving/ or *psychotherapy/ or *reality therapy/ or *relaxation training/ or *self-help/ or *social adaption/ or *social network/ or *social support/ or exp *support group/
5	*advance care planning/ or *bereavement/ or *case management/ or *crisis intervention/ or *friends/ or *group process/ or *group therapy/ or *human relation/ or exp *peer group/ or *social network/ or *support group/ or *terminal care/
6	4 or 5
7	6 use emez
8	exp counseling/ or cognitive behavioral therapy/ or mindfulness/ or patient centered care/ or problem solving/ or psychotherapy*.sh. or exp psychotherapy, group/ or reality therapy/ or relaxation therapy/ or social support/
9	bereavement/ or case management/ or crisis intervention/ or education, nonprofessional/ or friends/ or group processes/ or hotlines/ or interpersonal relations/ or palliative care/ or exp peer group/ or professional family relations/ or exp psychotherapy, group/ or self-help groups/ or exp social networking/ or terminal care/
10	8 or 9
11	10 use mesz, prem
12	case management/ or client centered therapy/ or exp cognitive behavior therapy/ or exp counselling/ or exp group psychotherapy/ or mindfulness/ or exp problem solving/ or psychotherapy/ or reality therapy/ or exp relaxation therapy/ or social support/
13	advocacy/ or bereavement/ or crisis intervention services/ or crisis intervention/ or “death and dying”/ or friendship/ or group dynamics/ or group counseling/ or hot line services/ or interpersonal relationships/ or outreach programs/ or palliative care/ or peer counseling/ or peer evaluation/ or peer relations/ or peers/ or exp peer relations/ or exp social networks/ or self help techniques/ or social networks/ or social group work/ or support groups/ or terminally ill patients/

#	Searches
14	12 or 13
15	14 use psyh
16	*internet/ or *computer/ or *computer network/ or *internet/ or *online system/ or exp *computer assisted therapy/ or *social media/ or *social network/ or exp *telecommunication/
17	16 use emez
18	computers/ or computer assisted instruction/ or computer communication networks/ or exp internet/ or online systems/ or o social media/ or exp social networking/ or therapy, computer assisted/ or telecommunications/ or telemedicine/
19	18 use mesz, prem
20	computer assisted instruction/ or computer assisted therapy/ or computers/ or exp computer mediated communication/ or exp online therapy/ or exp internet/ or exp social media/ or exp social networks/ or telecommunications media/ or telemedicine/
21	20 use psyh
22	or/17,19,21
23	(((psychological* or psychosocial or psychotherapeutic) adj2 (intervention* or program* or support* or therap* or treat*)) or brief intervention* or psychotherap*).ti,ab.
24	(((behaviour* or behavior*) adj2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) adj3 (intervention* or manag* or program* or therap* or treat*)) or cognitiv* behav*).ti,ab.
25	counsel*.ti,ab.
26	(((computer or digital* or distance based or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) adj based) or ((computer or digital* or distance based or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) adj3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) adj (intervention or program* or therap* or psychotherap*)) or elearning or e learning).ti,ab.
27	(case manag* or ((person centred or replacement) adj (care or therap*))).ti,ab.
28	((communit* or social) adj2 support*).ti,ab.
29	((intervention* or therap* or program* or workshop*) adj7 (caregiver* or care giver* or carer*) adj7 (burden or distress* or stress*)).ti,ab.
30	or/7,11,15,22-29
31	(befriend* or be* friend* or buddy or buddies or ((community or lay or paid or support) adj (person or worker*))).ti,ab.
32	((peer* or voluntary or volunteer*) adj3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*)).ti,ab.
33	((peer* or support* or voluntary or volunteer*) adj2 group*).ti,ab.
34	((peer* or support* or voluntary or volunteer*) adj3 (intervention* or program* or rehab* or therap* or service* or skill*)).ti,ab.
35	((peer* adj3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or expert patient* or mutual aid).ti,ab. or (peer* adj3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*)).ti,ab.
36	((bereav* or death or dying or end of life or grief* or ((palliative or terminal) adj care))

#	Searches
	adj3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or anticipatory grief).ti,ab.
37	(((communit* or family or social) adj (network* or support*)) or group conferencing or individualis?ed support).ti,ab.
38	(((carer* or caregiv* or care giv*) adj2 (mentor* or support*)) or (unpaid adj3 support*) or mentoring scheme*).ti,ab.
39	((carer* or caregiv* or care giv*) adj3 (communication or integrat* or relations or relationship*) adj3 (famil* or practitioner* or professional* or worker*)) or (famil* adj3 (intervention* or program*)).ti,ab.
40	(psychoeducat* or psycho educat*).ti,ab.
41	((emotion* adj (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) adj (adapt* or reintegrat* or support*))).ti,ab.
42	((dyadic or loneliness or psychosocial* or psycho social*) adj2 (assist* or intervention* or program* or support* or therap* or treat*)).ti,ab.
43	((emotion* or one to one or transition*) adj support*).ti,ab.
44	(lay adj (led or run)).ti,ab.
45	((crisis or crises or emergenc*) adj3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*)).ti,ab.
46	((coping or resilien* or well being or wellbeing) adj2 (intervention* or program* or therap* or skill* or strateg* or workshop*)).ti,ab.
47	(advocate or advocacy or ((support* adj3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* adj (service* or system)))).ti,ab.
48	((network* or peer*) adj2 (discuss* or exchang* or interact* or meeting*)).ti,ab.
49	(carer* network* or support group*).ti,ab.
50	or/31-49
51	(helpline or help line or ((phone* or telephone*) adj3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) adj2 (assist* or based or driven or led or mediat*))).ti,ab.
52	(helpseek* or ((search* or seek*) adj3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*))).ti,ab.
53	(information adj (needs or provision or support)).ti,ab.
54	(selfhelp or self help or selfmanag* or self manag* or self support or selfsupport).ti,ab.
55	or/51-54
56	*education/ or *health education/ or *education program/ or *first aid/
57	56 use emez
58	caregiver/ed or education/ or first aid/ or exp health education/
59	58 use mesz, prem
60	client education/ or education/ or educational programs/ or health education/
61	60 use psyh
62	(((carer* or caregiv* or care giv*) adj5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) adj3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) adj3 (bandage or cpr or crisis or crises or dressing or

#	Searches
	emergency or ((intimate or personal) adj care) or rescue breath*)) or first aid or personali* train* or resourcefulness train* or (skill* adj2 (build* or coach* or educat* or learn* or train))).ti,ab.
63	(psychoeducat* or psycho educat*).ti,ab,hw.
64	(((medication or pain) adj2 manag*) or pain control program* or ((educat* or train*) adj5 (handling or movement))).ti,ab.
65	or/57,59,61-64
66	exercise*.hw. or exp *physical activity/ or *"physical education"/ or exp *sports/
67	66 use emez
68	exp exercise/ or physical exertion/ or exp "physical education and training"/ or exp sports/
69	68 use mesz, prem
70	exercise/ or exp physical activity/ or "physical education"/ or exp sports/
71	70 use psyh
72	(aerobic train* or exercis* or gym* or jog* or (physical adj (activit* or fit)) or resistance train* or sport* or strength train* or (swim* not rat*) or walk* or weight lift* or (leisure adj2 (activit* or intervention* or program* or therap*)) or leisure based).ti,ab.
73	or/67,69,71-72
74	exp *employment/ or exp *return to work/ or *supported employment/ or *vocational education/ or *vocational rehabilitation/ or *work/ or *work resumption/ or (employment and rehabilitation).hw.
75	74 use emez
76	employment/ or employment, supported/ or rehabilitation, vocational/ or return to work/ or unemployment/ or vocational education/ or work/ or workplace/ or (employment/ and rh.fs.)
77	76 use mesz, prem
78	employment status/ or exp vocational rehabilitation/ or reemployment/ or (employment and rehabilitation).hw. or vocational education/ or work adjustment training/
79	78 use psyh
80	*child welfare/ or *financial management/ or *social care/ or *social security/ or *social welfare/ or “social work/
81	80 use emez
82	“aid to families with dependent children”/ or child welfare/ or financing, government/ or government programs/ or public assistance/ or social security/ or social welfare/ or social work/
83	82 use mesz
84	government programs/ or social security/ or child welfare/ or "welfare services (government)"/ or community welfare services/ or exp social case services/ or social services/ or social security/
85	84 use psyh
86	(((employ* or job* or reemploy* or vocation* or work*) adj3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or carer* lead or flexible working or individuali* support or job centre or (vocat* adj2 employ*) or (work adj2 coach*)).ti,ab.

#	Searches
87	((individual placement adj2 support) or ips model).ti,ab.
88	((permitted or voluntary or rehab*) adj3 work*).ti,ab.
89	((psychosocial or psycho social or social) adj2 rehab*).ti,ab.
90	rehabilitation counsel*.ti,ab.
91	((prevocat* or vocat*) adj3 (advice* or advis* or assist* or casework* or case work* or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*)).ti,ab.
92	(volunteering or (work adj2 placement*)).ti,ab.
93	(((carer* or care giv* or caregiv*) adj3 (card* or employment or passport* or scheme* or work)) or paid employment or social security or social welfare).ti,ab.
94	(return adj to* adj (education or study or training or work*)).ti,ab.
95	(carer* allowance* or caregiv* allowance or flexible support or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging? or money or working rights) adj3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) adj7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) adj7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*))).ti,ab.
96	(signpost* or sign post*).ti,ab.
97	or/75,77,79,81,83,85-96
98	*day care/ or *respite care/
99	98 use emez
100	day care, medical/ or respite care/
101	100 use mesz, prem
102	adult day care/ use psyh or day care centers/ use psyh or respite care/ use psyh
103	(day care or daycare or day therap* or daytherap* or home help or short break or ((carer* or caregiv* or care giv*) adj3 support*)).ti,ab.
104	(((crisis or volunteer) adj support) or holiday* or homehelp* or home help* or housekeep* or house keep* or meal support or personal assistant or respite or ((activity or fund* or short) adj2 break*) or signpost*).ti,ab.
105	or/99,101-104
106	*assistive technology/ or *occupational therapy/ or *telehealth/ or *telemedicine/ or *telemetry/ or *telemonitoring/
107	106 use emez
108	assistive technology/ or occupational therapy/ or self-help devices/ or telemedicine/ or telemetry/ or telemonitoring/
109	108 use mesz, prem
110	assistive technology/ or occupational therapy/ or telemedicine/ or telemetry/
111	110 use psyh
112	((assistive adj2 (platform* or technolog*)) or interactive health communication).ti,ab.
113	(simulated presence or social robot* or telecare or telehealth or telematic* or telemonitor*).ti,ab.
114	(gps track* or location technology).ti,ab.
115	occupational therap*.ti,ab.
116	or/107,109,111-115

#	Searches
117	exp acupuncture/ use emez or exp alternative medicine/ use emez or biofeedback/ or massage/ use emez or meditation/ use emez or acupressure/ use mesz, prem or massage/ use mesz, prem or acupuncture/ use mesz, prem or exp complementary therapies/ use mesz, prem or exp mind body therapies/ use mesz, prem or exp alternative medicine/ use psyh or biofeedback/ use psyh or massage/ use psyh or mind body therapy/ use psyh
118	(chinese medicine or medicine, chinese traditional or (moxibustion or electroacupuncture)).sh,id. or ((alternative or complementary) adj2 (medicine* or therap*)).ti,ab,sh. or (acu point* or acupoint* or acupressur* or acupunctur* or (ching adj2 lo) or cizhen or dianzhen or electroacupunctur* or (jing adj2 luo) or jingluo or massag* or needle therap* or zhenjiu or zhenci).tw.
119	meditation.sh. or meditat*.ti,ab.
120	(acceptance adj2 commitment therap*).ti,ab.
121	dyadic intervention*.ti,ab.
122	(reminiscence adj (group* or therap*)).ti,ab.
123	self disclosure/ use emez,mesz,psyh or ((emotional or self) adj disclosure).ti,ab.
124	art/ or art therapy/ or music/ or music therapy/ or singing/ or painting/ use emez or singing/ use emez, mesz, prem or paintings/ use mesz, prem
125	124 use emez,mesz
126	art/ or art education/ or art therapy/ or "painting (art)"/ or music/ or music education/ or music therapy/ or singing/
127	126 use psyh
128	(art or cafe or cafes or gallery or music or sing or singing).ti,ab.
129	or/117-123,125,127-128
130	30,50,55,65,73,97,105,116,129
131	3 and 130
132	interviews as topic/ or qualitative research/
133	132 use emez
134	interviews as topic/ or anthropology, cultural/ or focus groups/ or exp tape recording/ or personal narrative/ or narration/ or nursing methodology research/ or observation/ or qualitative research/ or sampling studies/ or cluster analysis/ or videodisc recording/
135	134 use mesz, prem
136	cluster analysis/ or "culture (anthropological)" or interviews/ or narratives/ or observation methods/ or qualitative research/ or tape recorders/
137	136 use psyh
138	(interview* or action research or audiorecord* or ((audio or tape or video*) adj5 record*) or colaizzi* or (constant adj (comparative or comparison)) or content analy* or critical social* or (data adj1 saturat*) or discourse analys?s or emic or ethical enquiry or ethno* or etic or experiences or fieldnote* or (field adj (note* or record* or stud* or research)) or (focus adj4 (group* or sampl*)) or giorgi* or glaser or (grounded adj (theor* or study or studies or research)) or heidegger* or hermeneutic* or heuristic or human science or husserl* or ((life or lived) adj experience*) or maximum variation or merleau or narrat* or ((participant* or nonparticipant*) adj3 observ*) or ((philosophical or social) adj research*) or (pilot testing and survey) or purpos* sampl* or qualitative* or ricoeur or semiotics or shadowing or snowball or spiegelberg* or stories or story or storytell* or strauss or structured categor* or tape record* or taperecord* or testimon* or (thematic* adj3

#	Searches
	analys*) or themes or theoretical sampl* or unstructured categor* or van kaam* or van manen or videorecord* or video record* or videotap* or video tap*).ti,ab.
139	(cross case analys* or eppi approach or metaethno* or meta ethno* or metanarrative* or meta narrative* or meta overview or metaoverview or metastud* or meta stud* or metasummar* or meta summar* or qualitative overview* or ((critical interpretative or evidence or meta or mixed methods or multilevel or multi level or narrative or parallel or realist) adj synthes*) or metasynthes*).mp. or (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*)).ti,ab,hw,pt.
140	or/133,135,137-139
141	"*attitude to health"/ or *consumer/ or *consumer attitude/ or *health care quality/ or *patient attitude/ or *patient compliance/ or *patient preference/ or *patient satisfaction/
142	141 use emez
143	*attitude to health/ or comprehensive health care/ or exp consumer participation/ or exp consumer satisfaction/ or "patient acceptance of health care"/ or patient care management/ or patient centered care/ or exp patient compliance/ or patient satisfaction/ or "quality of health care"/
144	143 use mesz, prem
145	exp client attitudes/ or client satisfaction/ or consumer attitudes/ or exp health attitudes/ or exp consumer attitudes/ or patient satisfaction/ or treatment compliance/
146	145 use psyh
147	((carer* or caregiv* or care giv* or famil* or friend* or mother* or father* or son or daughter*) adj3 (account* or anxieties or atisfact* or attitude* or barriers or belief* or buyin or buy in* or choice* or co?operat* or co operat* or expectation* or experienc* or feedback or feeling* or idea* or inform* or involv* or opinion* or participat* or perceive* or (perception* not speech perception) or perspective* or preferen* or prepar* or priorit* or satisf* or view* or voices or worry)).ti,ab.
148	((consumer or patient) adj2 (focus* or centered or centred)).ti,ab.
149	or/142,144,146-148
150	or/140,149
151	clinical trials as topic.sh. or (controlled clinical trial or pragmatic clinical trial or randomized controlled trial).pt. or (placebo or randomi#ed or randomly).ab. or trial.ti.
152	151 use mesz, prem
153	(controlled clinical trial or pragmatic clinical trial or randomized controlled trial).pt. or drug therapy.fs. or (groups or placebo or randomi#ed or randomly or trial).ab.
154	153 use mesz, prem
155	crossover procedure/ or double blind procedure/ or randomized controlled trial/ or single blind procedure/ or (assign* or allocat* or crossover* or cross over* or ((doubl* or singl*) adj blind*) or factorial* or placebo* or random* or volunteer*).ti,ab.
156	155 use emez
157	(assign* or allocat* or crossover* or cross over* or ((doubl* or singl*) adj blind*) or factorial* or placebo* or random* or volunteer*).ti,ab. use psyh
158	or/152,154,156-157
159	meta-analysis/
160	meta-analysis as topic/ or systematic reviews as topic/
161	“systematic review”/
162	meta-analysis/

#	Searches
163	(meta analy* or metanaly* or metaanaly*).ti,ab.
164	((systematic or evidence) adj2 (review* or overview*)).ti,ab.
165	((systematic* or evidence*) adj2 (review* or overview*)).ti,ab.
166	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
167	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
168	(search* adj4 literature).ab.
169	(medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit).ab.
170	cochrane.jw.
171	((pool* or combined) adj2 (data or trials or studies or results)).ab.
172	or/159-160,163,165-171 use mesz, prem
173	(or/161-164,166-171) use emez
174	meta analysis/ use psyh or or/163-171 use psyh
175	(cross case analys* or eppi approach or metaethno* or meta ethno* or metanarrative* or meta narrative* or meta overview or metaoverview or metastud* or meta stud* or metasummar* or meta summar* or qualitative overview* or ((critical interpretative or evidence or meta or mixed methods or multilevel or multi level or narrative or parallel or realist) adj synthes*) or metasynthes*).mp. or (qualitative* and (metaanal* or meta anal* or synthes* or systematic review* or qualitativ*)).ti,ab,hw,pt.
176	or/172-175
177	or/158,176
178	exp case control study/ or cohort analysis/ or cross-sectional study/ or follow up/ or longitudinal study/ or observational study/ or prospective study/ or retrospective study/
179	178 use emez
180	exp case control studies/ or exp cohort studies/ or cross-sectional studies/ or epidemiologic studies/
181	180 use mesz, prem
182	(cohort analysis or followup studies or longitudinal studies or prospective studies or retrospective studies).sh,id. or (followup study or longitudinal study or prospective study or retrospective study).md.
183	182 use psyh
184	((epidemiologic* or observational) adj (study or studies)).ti,ab.
185	(cohort*1 or cross section* or crosssection* or followup* or follow up* or followed or longitudinal* or prospective* or retrospective*).ti,ab.
186	(case adj2 (control or series or stud*)).ti,ab.
187	(nonequivalent control group or posttesting or pretesting or pretest posttest design or pretest posttest control group design or quasi experimental methods or quasi experimental study or time series or time series analysis).sh.
188	(((nonequivalent or non equivalent) adj3 control*) or posttest* or post test* or pre test* or pretest* or quasi experiment* or quasiexperiment* or timeseries or time series).tw.
189	or/179,181,183-188
190	177 or 189

#	Searches
191	190
192	united kingdom/
193	(national health service* or nhs*).ti,ab,in,ad.
194	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
195	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jw,in,ad.
196	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,ad.
197	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,ad.
198	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,ad.
199	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,ad.
200	or/192-199 use emez
201	exp united kingdom/
202	(national health service* or nhs*).ti,ab,in.
203	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
204	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jw,in.

#	Searches
205	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in.
206	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in.
207	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in.
208	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in.
209	or/201-208
210	(exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp great britain/ or europe/)
211	209 not 210
212	211 use mesz, prem
213	(national health service* or nhs*).ti,ab,in,cq.
214	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
215	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,cq.
216	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or

#	Searches
	"hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,cq.
217	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,cq.
218	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,cq.
219	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,cq.
220	or/213-219 use psyh
221	or/200,212,220
222	150 and 221
223	131 and or/177,222

Database: Social Policy and Practice, Health Management Information Consortium - OVID

#	Searches
1	(carer* or caregiv* or care giv*).ti,ab.
2	(((psychological* or psychosocial or psychotherapeutic) adj2 (intervention* or program* or support* or therap* or treat*)) or brief intervention* or psychotherap*).ti,ab.
3	(((behaviour* or behavior*) adj2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) adj3 (intervention* or manag* or program* or therap* or treat*)) or cognitiv* behav*).ti,ab.
4	counsel*.ti,ab.
5	(((computer or digital* or distance based or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) adj based) or ((computer or digital* or distance based or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) adj3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) adj (intervention or program* or therap* or psychotherap*)) or elearning or e learning).ti,ab.
6	(case manag* or ((person centred or replacement) adj (care or therap*))).ti,ab.

#	Searches
7	((communit* or social) adj2 support*).ti,ab.
8	((intervention* or therap* or program* or workshop*) adj7 (caregiver* or care giver* or carer*) adj7 (burden or distress* or stress*)).ti,ab.
9	or/2-8
10	(befriend* or be* friend* or buddy or buddies or ((community or lay or paid or support) adj (person or worker*))).ti,ab.
11	((peer* or voluntary or volunteer*) adj3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*)).ti,ab.
12	((peer* or support* or voluntary or volunteer*) adj2 group*).ti,ab.
13	((peer* or support* or voluntary or volunteer*) adj3 (intervention* or program* or rehab* or therap* or service* or skill*)).ti,ab. or ((peer* adj3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or expert patient* or mutual aid).ti,ab.
14	((bereav* or death or dying or "end of life" or grief* or ((palliative or terminal) near/1 care)) near/3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or "anticipatory grief").ti,ab.
15	(peer* adj3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*)).ti,ab.
16	(((communit* or family or social) adj (network* or support*)) or group conferencing or individualis?ed support).ti,ab.
17	(((carer* or caregiv* or care giv*) adj2 (mentor* or support*)) or (unpaid adj3 support*) or mentoring scheme*).ti,ab.
18	((carer* or caregiv* or care giv*) adj3 (communication or integrat* or relations or relationship*) adj3 (famil* or practitioner* or professional* or worker*)) or (famil* adj3 (intervention* or program*)).ti,ab.
19	(psychoeducat* or psycho educat*).ti,ab.
20	((emotion* adj (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) adj (adapt* or reintegrat* or support*))).ti,ab.
21	((dyadic or loneliness or psychosocial* or psycho social*) adj2 (assist* or intervention* or program* or support* or therap* or treat*)).ti,ab.
22	((emotion* or one to one or transition*) adj support*).ti,ab.
23	(lay adj (led or run)).ti,ab.
24	((crisis or crises or emergenc*) adj3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*)).ti,ab.
25	((coping or resilien* or well being or wellbeing) adj2 (intervention* or program* or therap* or skill* or strateg* or workshop*)).ti,ab.
26	(advocate or advocacy or ((support* adj3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* adj (service* or system)))).ti,ab.
27	((network* or peer*) adj2 (discuss* or exchang* or interact* or meeting*)).ti,ab.
28	(carer* network* or support group*).ti,ab.
29	or/10-28
30	(helpline or help line or ((phone* or telephone*) adj3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) adj2 (assist* or based or driven or led or mediat*))).ti,ab.

#	Searches
31	(helpseek* or ((search* or seek*) adj3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*))).ti,ab.
32	(information adj (needs or provision or support)).ti,ab.
33	(selfhelp or self help or selfmanag* or self manag* or self support or selfsupport).ti,ab.
34	or/30-33
35	(((carer* or caregiv* or care giv*) adj5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) adj3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) adj3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) adj care) or rescue breath*)) or first aid or personali* train* or resourcefulness train* or (skill* adj2 (build* or coach* or educat* or learn* or train))).ti,ab.
36	(psychoeducat* or psycho educat*).ti,ab,hw.
37	(((medication or pain) adj2 manag*) or pain control program* or ((educat* or train*) adj5 (handling or movement))).ti,ab.
38	or/35-37
39	(aerobic train* or exercis* or gym* or jog* or (physical adj (activit* or fit)) or resistance train* or sport* or strength train* or (swim* not rat*) or walk* or weight lift* or (leisure adj2 (activit* or intervention* or program* or therap*)) or leisure based).ti,ab.
40	39
41	(((employ* or job* or reemploy* or vocation* or work*) adj3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or carer* lead or flexible working or individuali* support or job centre or (vocat* adj2 employ*) or (work adj2 coach*)).ti,ab.
42	((individual placement adj2 support) or ips model).ti,ab.
43	((permitted or voluntary or rehab*) adj3 work*).ti,ab.
44	((psychosocial or psycho social or social) adj2 rehab*).ti,ab.
45	rehabilitation counsel*.ti,ab.
46	((prevocat* or vocat*) adj3 (advice* or advis* or assist* or casework* or case work* or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*)).ti,ab.
47	(volunteering or (work adj2 placement*)).ti,ab.
48	(((carer* or care giv* or caregiv*) adj3 (card* or employment or passport* or scheme* or work)) or paid employment or social security or social welfare).ti,ab.
49	(return adj to* adj (education or study or training or work*)).ti,ab.
50	(carer* allowance* or caregiv* allowance or flexible support or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging? or money or working rights) adj3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) adj7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) adj7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*))).ti,ab.
51	(signpost* or sign post*).ti,ab.
52	or/41-51

#	Searches
53	(day care or daycare or day therap* or daytherap* or home help or short break or ((carer* or caregiv* or care giv*) adj3 support*)).ti,ab.
54	(((crisis or volunteer) adj support) or holiday* or homehelp* or home help* or housekeep* or house keep* or meal support or personal assistant or respite or ((activity or fund* or short) adj2 break*) or signpost*).ti,ab.
55	or/53-54
56	((assistive adj2 (platform* or technolog*)) or interactive health communication).ti,ab.
57	(simulated presence or social robot* or telecare or telehealth or telematic* or telemonitor*).ti,ab.
58	(gps track* or location technology).ti,ab.
59	occupational therap*.ti,ab.
60	or/56-59
61	(chinese medicine or medicine, chinese traditional or (moxibustion or electroacupuncture)).sh,id. or ((alternative or complementary) adj2 (medicine* or therap*)).ti,ab,sh. or (acu point* or acupoint* or acupressur* or acupunctur* or (ching adj2 lo) or cizhen or dianzhen or electroacupunctur* or (jing adj2 luo) or jingluo or massag* or needle therap* or zhenjiu or zhenci).tw.
62	meditation.sh. or meditat*.ti,ab.
63	(acceptance adj2 commitment therap*).ti,ab.
64	dyadic intervention*.ti,ab.
65	(reminiscence adj (group* or therap*)).ti,ab.
66	self disclosure/ use emez,mesz,psyh or ((emotional or self) adj disclosure).ti,ab.
67	or/61-66
68	(art or cafe or cafes or gallery or music or sing or singing).ti,ab.
69	68
70	or/9, 29, 34, 38, 40, 52, 55, 60, 67, 69
71	1 and 70

Database: Social Services Abstracts, Sociological Abstracts, International Bibliography for Social Sciences (IBSS), Applied Social Sciences Index and Abstracts (ASSIA) - Proquest

#	Searches
S1	noft (carer* or caregiv* or “care giv*”)
S2	noft (psychotherap*)
S3	noft (((psychological* or psychosocial or psychotherapeutic) near/2 (intervention* or program* or support* or therap* or treat*)) or “brief intervention*” or psychotherap*)
S4	noft (((behaviour* or behavior*) near/2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) near/3 (intervention* or manag* or program* or therap* or treat*)) or “cognitiv* behav*”)
S5	noft (“case manag*” or counsel* or ((“person centred” or replacement) near/1 (care or therap*)))
S6	noft (((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat*

#	Searches
	or video* or web) near/1 based) or ((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) near/3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) near/1 (intervention or program* or therap* or psychotherap*)) or elearning or “e learning”)
S7	noft ((“person centred” or replacement) near/1 (care or therap*))
S8	noft ((communit* or social) near/2 support*)
S9	noft ((intervention* or therap* or program* or workshop*) near/7 (caregiver* or “care giver*” or carer*) near/7 (burden or distress* or stress*))
S10	S2 or S3 or S4 or S5 or S6 or S7 or S8 or S9
S11	noft (befriend* or “be* friend*” or buddy or buddies or ((community or lay or paid or support) near/1 (person or worker*)))
S12	noft ((peer* or voluntary or volunteer*) near/3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*))
S13	noft ((peer* or support* or voluntary or volunteer*) near/2 group*)
S14	noft ((peer* or support* or voluntary or volunteer*) near/3 (intervention* or program* or rehab* or therap* or service* or skill*))
S15	noft (((peer* near/3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or “expert patient*” or “mutual aid”) or (peer* near/3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*)))
S16	noft ((bereav* or death or dying or "end of life" or grief* or ((palliative or terminal) near/1 care)) near/3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or "anticipatory grief")
S17	noft (((communit* or family or social) near/1 (network* or support*)) or “group conferencing” or “individualised support” or “individualized support”)
S18	noft (((carer* or caregiv* or “care giv*”) near/2 (mentor* or support*)) or (unpaid near/3 support*) or “mentoring scheme*”)
S19	noft (((carer* or caregiv* or “care giv*”) near/3 (communication or integrat* or relations or relationship*) near/3 (practitioner* or professional* or worker*)) or (famil* near/3(intervention* or program*)))
S20	noft (psychoeducat* or “psycho educat*”)
S21	noft ((emotion* near/1 (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) near/1 (adapt* or reintegrat* or support*)))
S22	noft ((dyadic or loneliness or psychosocial* or “psycho social*”) near/2 (assist* or intervention* or program* or support* or therap* or treat*))
S23	noft ((emotion* or “one to one” or transition*) near/1 support*)
S24	noft (lay near/1 (led or run))
S25	noft ((crisis or crises or emergenc*) near/3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*))
S26	noft ((coping or resilien* or “well being” or wellbeing) near/2 (intervention* or program* or therap* or skill* or strateg* or workshop*))
S27	noft (advocate or advocacy or ((support* near/3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* near/1 (service* or system))))
S28	noft ((network* or peer*) near/2 (discuss* or exchang* or interact* or meeting*))
S29	noft (carer* network* or “support group*”)

#	Searches
S30	S11 or S12 or S13 or S14 or S15 or S16 or S17 or S18 or S19 or S20 or S21 or S22 or S23 or S24 or S25 or S26 or S27 or S28 or S29
S31	noft (helpline or “help line” or ((phone* or telephone*) near/3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) near/2 (assist* or based or driven or led or mediat*)))
S32	noft (helpseek* or ((search* or seek*) near/3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*)))
S33	noft (information near/1 (needs or provision or support))
S34	noft (selfhelp or “self help” or selfmanag* or “self manag*” or “self support” or selfsupport)
S35	S31 or S32 or S33 or S34
S36	noft (((carer* or caregiv* or “care giv*”) near/5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) near/3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) near/3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) near/1 care) or “rescue breath*”)) or “first aid” or “personali* train*” or” resourcefulness train*” or (skill* near/2 (build* or coach* or educat* or learn* or train)))
S37	noft (psychoeducat* or “psycho educat*”) ti,ab,hw.
S38	noft (((medication or pain) near/2 manag*) or “pain control program*” or ((educat* or train*) near/5 (handling or movement)))
S39	S36 or S37 or S38
S40	noft (“aerobic train*” or exercis* or gym* or jog* or (physical near/1 (activit* or fit)) or “resistance train*” or sport* or “strength train*” or (swim* not rat*) or walk* or weight lift* or (leisure near/2 (activit* or intervention* or program* or therap*)) or “leisure based”)
S41	S40
S42	noft (((employ* or job* or reemploy* or vocation* or work*) near/3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or “carer* lead” or flexible working or “individuali* support” or “job centre” or (vocat* near/2 employ*) or (work near/2 coach*))
S43	noft ((“individual placement” near/2 support) or “ips model”)
S44	noft ((permitted or voluntary or rehab*) near/3 work*)
S45	noft ((psychosocial or “psycho social” or social) near/2 rehab*)
S46	noft (“rehabilitation counsel*”)
S47	noft ((prevocat* or vocat*) near/3 (advice* or advis* or assist* or casework* or “case work*” or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*))
S48	noft (volunteering or (work near/2 placement*))
S49	noft (((carer* or “care giv*” or caregiv*) near/3 (card* or employment or passport* or scheme* or work)) or “paid employment” or “social security” or “social welfare”)
S50	noft (return near/1 to* near/1 (education or study or training or work*))
S51	noft (“carer* allowance*” or “caregiv* allowance” or “flexible support” or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging* or money or “working rights”) near/3 (advice or assist* or

#	Searches
	brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) near/7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) near/7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)))
S52	noft (signpost* or “sign post*”)
S53	S42 or S43 or S44 or S45 or S46 or S47 or S48 or S49 or S50 or S51 or S52
S54	noft (“day care” or daycare or “day therap*” or daytherap* or “home help” or “short break” or ((carer* or caregiv* or care giv*) near/3 support*))
S55	noft (((crisis or volunteer) near/1 support) or holiday* or homehelp* or home help* or housekeep* or house keep* or “meal support” or “personal assistant” or respite or ((activity or fund* or short) near/2 break*) or signpost*)
S56	S54 or S55
S57	noft ((assistive near/2 (platform* or technolog*)) or “interactive health communication”)
S58	noft (“simulated presence” or “social robot*” or telecare or telehealth or telematic* or telemonitor*)
S59	noft (“gps track*” or “location technology”)
S60	noft “occupational therap*”
S61	S57 or S58 or S59 or S60
S62	noft ((alternative or complementary) near/2 (medicine* or therap*)) or “acu point*” or acupoint* or acupressur* or acupunctur* or (ching near/2 lo) or cizhen or dianzhen or electroacupunctur* or (jing near/2 luo) or jingluo or massag* or moxibustion or electroacupuncture or needle therap* or zhenjiu or zhenci)
S63	noft (meditat*)
S64	noft (acceptance near/2 “commitment therap*”)
S65	noft (“dyadic intervention*”)
S66	noft (reminiscence near/1 (group* or therap*))
S67	noft ((emotional or self) near/1 disclosure)
S68	S62 or S63 or S64 or S65 or S66 or S67
S69	noft (art or cafe or cafes or gallery or music or sing or singing)
S70	S69
S71	s10 or s30 or s35 or s39 or s41 or s53 or s56 or s61 or s68 or s70
S72	S1 and S71
S73	noft (interview* or “action research” or audiorecord* or ((audio or tape or video*) near/5 record*) or colaizzi* or (constant near/1 (comparative or comparison)) or content analy* or “critical social*” or (data near/1 saturat*) or “discourse analysis” or “discourse analyses” or emic or “ethical enquiry” or ethno* or etic or experiences or fieldnote* or (field near/1 (note* or record* or stud* or research)) or (focus near/4 (group* or sampl*)) or giorgi* or glaser or (grounded near/1 (theor* or study or studies or research)) or heidegger* or hermeneutic* or heuristic or “human science” or husserl* or ((life or lived) near/1 experience*) or “maximum variation” or merleau or narrat* or ((participant* or nonparticipant*) near/3 observ*) or ((philosophical or social) near/1 research*) or (“pilot testing” and survey) or “purpos* sampl*” or qualitative* or ricoeur or semiotics or shadowing or snowball or spiegelberg* or stories or story or storytell* or strauss or “structured categor*” or “tape record*” or taperecord* or testimon* or (thematic* near/3 analys*) or themes or “theoretical

#	Searches
	sampl*" or "unstructured categor*" or "van kaam*" or "van manen" or videorecord* or "video record*" or videotap* or "video tap*")
S74	noft ("cross case analys*" or "eppi approach" or metaethno* or "meta ethno*" or metanarrative* or "meta narrative*" or "meta overview" or metaoverview or metastud* or "meta stud*" or metasummar* or "meta summar*" or "qualitative overview*" or (("critical interpretative" or evidence or meta or "mixed methods" or multilevel or "multi level" or narrative or parallel or realist) near/1 synthes*) or metasynthes*).mp. or (qualitative* and (metaanal* or "meta anal*" or synthes* or "systematic review*"))
S75	noft ((carer* or caregiv* or "care giv*" or famil* or friend* or mother* or father* or son or daughter*) near/3 (account* or anxieties or atisfact* or attitude* or barriers or belief* or buyin or "buy in*" or choice* or cooperat* or "co operat*" or expectation* or experienc* or feedback or feeling* or idea* or inform* or involv* or opinion* or participat* or perceive* or perspective* or preferen* or prepar* or priorit* or satisf* or view* or voices or worry))
S76	noft ((consumer or patient) near/2 (focus* or centered or centred))
S77	S73 or S74 or S75 or S76
S78	noft (assign* or allocat* or crossover* or cross over* or ((doubl* or singl*) near/1 blind*) or factorial* or placebo* or random* or volunteer*)
S79	S78
S80	noft ("meta analy*" or metanaly* or metaanaly*)
S81	noft ((systematic or evidence) near/2 (review* or overview*))
S82	noft ("cross case analys*" or "eppi approach" or metaethno* or "meta ethno*" or metanarrative* or "meta narrative*" or "meta overview" or metaoverview or metastud* or "meta stud*" or metasummar* or "meta summar*" or "qualitative overview*" or (("critical interpretative" or evidence or meta or "mixed methods" or multilevel or "multi level" or narrative or parallel or realist) near/1 synthes*) or metasynthes*)
S83	S80 or S81 or S82
S84	noft ((epidemiologic* or observational) near/1 (study or studies))
S85	noft (cohort* or "cross section*" or crosssection* or followup* or "follow up*" or followed or longitudinal* or prospective* or retrospective*)
S86	noft (case near/2 (control or series or stud*))
S87	noft (((nonequivalent or non equivalent) near/3 control*) or posttest* or "post test*" or "pre test*" or pretest* or "quasi experiment*" or quasiexperiment* or timeseries or "time series")
S88	S84 or S85 or S86 or S87
S89	S77 or s79 or S83
S90	S72 and S89

Database: CINAHL – EBSCO

1	(mh "caregivers")
2	tx (carer* or caregiv* or "care giv*")
3	#1 or #2
4	(mh "counseling+")
5	(mh "psychotherapy, group+")
6	(mh "cognitive therapy+")
7	(mh "mindfulness")

8 (mh "patient centered care")
9 (mh "problem solving")
10 (mh "reality therapy")
11 (mh "simple relaxation therapy (iowa nic)")
12 (mh "social support (iowa noc)") or (mh "support, psychosocial")
13 tx (psychotherap*)
14 (mh "case management")
15 (mh "crisis intervention")
16 (mh "crisis intervention (iowa nic)")
17 (mh "education, nonprofessional")
18 (mh "social networks")
19 (mh "group processes")
20 (mh "interpersonal relations")
21 (mh "professional-family relations")
22 (mh "support groups")
23 (mh "peer group")
24 (mh "psychotherapy, group")
25 (mh "social networking+")
26 (mh "computers and computerization")
27 (mh "computer assisted instruction")
28 (mh "computer communication networks")
29 (mh "online systems")
30 (mh "social media+")
31 (mh "therapy, computer assisted")
32 (mh "telecommunications")
33 (mh "telemedicine")
34 (mh "internet+")
35 (mh "social networking+")
36 tx (((psychological* or psychosocial or psychotherapeutic) n2 (intervention* or program* or support* or therap* or treat*)) or “brief intervention*” or psychotherap*)
37 tx (((behaviour* or behavior*) n2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) n3 (intervention* or manag* or program* or therap* or treat*)) or “cognitiv* behav*”)
38 tx (“case manag*” or counsel* or ((“person centred” or replacement) n1 (care or therap*)))
39 (((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) n1 based) or ((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) n3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) n1 (intervention or program* or therap* or psychotherap*)) or elearning or “e learning”)
40 tx ((“person centred” or replacement) n1 (care or therap*))
41 tx ((communit* or social) n2 support*)
42 tx ((intervention* or therap* or program* or workshop*) n7 (caregiver* or “care giver*” or carer*) n7 (burden or distress* or stress*))
43 #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42
44 tx (befriend* or “be* friend*” or buddy or buddies or ((community or lay or paid or support) n1 (person or worker*)))

45 tx ((peer* or voluntary or volunteer*) n3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*))
46 tx ((peer* or support* or voluntary or volunteer*) n2 group*)
47 tx ((peer* or support* or voluntary or volunteer*) n3 (intervention* or program* or rehab* or therap* or service* or skill*))
48 tx (((peer* n3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or “expert patient*” or “mutual aid”)
or (peer* n3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*)))
49 tx ((bereav* or death or dying or "end of life" or grief* or ((palliative or terminal) n1 care))
near/3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or "anticipatory grief")
50 tx (((communit* or family or social) n1 (network* or support*)) or “group conferencing” or “individualised support” or “individualized support”)
51 tx (((carer* or caregiv* or “care giv*”) n2 (mentor* or support*)) or (unpaid n3 support*) or “mentoring scheme*”)
52 tx (((carer* or caregiv* or “care giv*”) n3 (communication or integrat* or relations or relationship*) n3 (practitioner* or professional* or worker*)) or (famil* n3(intervention* or program*)))
53 tx (psychoeducat* or “psycho educat*”)
54 tx ((emotion* n1 (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) n1 (adapt* or reintegrat* or support*)))
55 tx ((dyadic or loneliness or psychosocial* or “psycho social*”) n2 (assist* or intervention* or program* or support* or therap* or treat*))
56 tx ((emotion* or “one to one” or transition*) n1 support*)
57 tx (lay n1 (led or run))
58 tx ((crisis or crises or emergenc*) n3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*))
59 tx ((coping or resilien* or “well being” or wellbeing) n2 (intervention* or program* or therap* or skill* or strateg* or workshop*))
60 tx (advocate or advocacy or ((support* n3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* n1 (service* or system))))
61 tx ((network* or peer*) n2 (discuss* or exchang* or interact* or meeting*))
62 tx (carer* network* or “support group*”)
63 #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56 or #57 or #58 or #59 or #60 or #61 or #62
64 tx (helpline or “help line” or ((phone* or telephone*) n3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) n2 (assist* or based or driven or led or mediat*)))
65 tx (helpseek* or ((search* or seek*) n3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*)))
66 tx (information n1 (needs or provision or support))
67 tx (selfhelp or “self help” or selfmanag* or “self manag*” or “self support” or selfsupport)
68 #64 or #65 or #66 or #67
69 (mh "education")
70 (mh "health education")

71 (mh "first aid") or (mh "first aid (iowa nic)")

72 tx (((carer* or caregiv* or “care giv*”) n5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) n3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) n3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) n1 care) or “rescue breath*”)) or “first aid” or “personali* train*” or” resourcefulness train*” or (skill* n2 (build* or coach* or educat* or learn* or train)))

73 tx (psychoeducat* or “psycho educat*”) ti,ab,hw.

74 tx (((medication or pain) n2 manag*) or “pain control program*” or ((educat* or train*) n5 (handling or movement)))

75 #69 or #70 or #71 or #72 or #73 or #74

76 (mh "exertion")

77 (mh "exercise+")

78 (mh "physical education and training+")

79 (mh "sports+")

80 tx (“aerobic train*” or exercis* or gym* or jog* or (physical n1 (activit* or fit)) or “resistance train*” or sport* or “strength train*” or (swim* not rat*) or walk* or weight lift* or (leisure n2 (activit* or intervention* or program* or therap*)) or “leisure based”)

81 #76 or #77 or #78 or #79 or #80

82 (mh "employment")

83 (mh "employment, supported")

84 (mh "rehabilitation, vocational")

85 (mh "job re-entry")

86 (mh "unemployment")

87 (mh "vocational education")

88 (mh "work")

89 (mh "work environment")

90 (MH "Dependent Families")

91 (mh "child welfare")

92 (mh "financing, government")

93 (mh "government programs")

94 (mh "public assistance")

95 (mh "social welfare")

96 (MH "Economic and Social Security")

97 (mh "social work")

98 tx (((employ* or job* or reemploy* or vocation* or work*) n3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or “carer* lead” or flexible working or “individuali* support” or “job centre” or (vocat* n2 employ*) or (work n2 coach*))

99 tx ((“individual placement” n2 support) or “ips model”)

100 tx ((permitted or voluntary or rehab*) n3 work*)

101 tx ((psychosocial or “psycho social” or social) n2 rehab*)

102 tx “rehabilitation counsel*”

103 tx ((prevocat* or vocat*) n3 (advice* or advis* or assist* or casework* or “case work*” or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*))

104 tx (volunteering or (work n2 placement*))

105 tx (((carer* or “care giv*” or caregiv*) n3 (card* or employment or passport* or scheme* or work)) or “paid employment” or “social security” or “social welfare”)
106 tx (return n1 to* n1 (education or study or training or work*))
107 tx (“carer* allowance*” or “caregiv* allowance” or “flexible support” or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging* or money or “working rights”) n3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) n7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) n7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)))
108 tx (signpost* or “sign post*”)
109 #82 or #83 or #84 or #85 or #86 or #87 or #88 or #89 or #90 or #91 or #92 or #93 or #94 or #95 or #96 or #97 or #98 or #99 or #100 or #101 or #102 or #103 or #104 or #105 or #106 or #107 or #108
110 (mh "day care")
111 (mh "respite care") or (mh "respite care (iowa nic)")
112 tx (“day care” or daycare or “day therap*” or daytherap* or “home help” or “short break” or ((carer* or caregiv* or care giv*) n3 support*))
113 tx (((crisis or volunteer) n1 support) or holiday* or homehelp* or home help* or housekeep* or house keep* or “meal support” or “personal assistant” or respite or ((activity or fund* or short) n2 break*) or signpost*)
114 #110 or #111 or #112 or #113
115 (mh "assistive technology")
116 (mh "occupational therapy")
117 (mh "assistive technology devices+")
118 (mh "telemedicine")
119 (mh "telemetry")
120 (mh "telenursing")
121 tx ((assistive n2 (platform* or technolog*)) or “interactive health communication”)
122 tx (“simulated presence” or “social robot*” or telecare or telehealth or telematic* or telemonitor*)
123 tx (“gps track*” or “location technology”)
124 tx “occupational therap*”
125 #115 or #116 or #117 or #118 or #119 or #120 or #121 or #122 or #123 or #124
126 (mh "acupressure")
127 (mh "massage")
128 (mh "acupuncture")
129 (mh "alternative therapies+")
130 (mh "mind body techniques+")
131 (mh "medicine, chinese traditional")
132 (mh "moxibustion")
133 tx ((alternative or complementary) n2 (medicine* or therap*)) or “acu point*” or acupoint* or acupressur* or acupunctur* or (ching n2 lo) or cizhen or dianzhen or electroacupunctur* or (jing n2 luo) or jingluo or massag* or moxibustion or electroacupuncture or needle therap* or zhenjiu or zhenci)
134 (mh "meditation") or (mh "meditation (iowa nic)") or tx (meditate*)
135 tx (acceptance n2 “commitment therap*”)
136 tx “dyadic intervention*”
137 tx (reminiscence n1 (group* or therap*))
138 tx ((emotional or self) n1 disclosure)

139 (mh "self disclosure")
140 (mh "art")
141 (mh "music")
142 (mh "singing")
143 (mh "paint")
144 (mh "art therapy")
145 (mh "singing")
146 tx (art or cafe or cafes or gallery or music or sing or singing)
147 #126 or #127 or #128 or #129 or #130 or #131 or #132 or #133 or #134 or #135 or #136 or #137 or #138 or #139 or #140 or #141 or #142 or #143 or #144 or #145 or #146
148 #3 and (#43 or #63 or #68 or #75 or #81 or #109 or #114 or #125 or #147)
149 (mh "cluster analysis") or (mh "qualitative studies") or (mh "observational methods") or (mh "narratives") or (mh "audiorecording") or (mh "videorecording") or (mh "focus groups") or (mh "anthropology, cultural") or (mh "structured interview") or (mh "unstructured interview") or (mh "semi-structured interview")
150 tx (interview* or “action research” or audiorecord* or ((audio or tape or video*) n5 record*) or colaizzi* or (constant n1 (comparative or comparison)) or “content analy*” or “critical social*” or (data n1 saturat*) or “discourse analysis” or “discourse analyses” or emic or “ethical enquiry” or ethno* or etic or experiences or fieldnote* or (field n1 (note* or record* or stud* or research)) or (focus n4 (group* or sampl*)) or giorgi* or glaser or (grounded n1 (theor* or study or studies or research)) or heidegger* or hermeneutic* or heuristic or “human science” or husserl* or ((life or lived) n1 experience*) or “maximum variation” or merleau or narrat* or ((participant* or nonparticipant*) n1 observ*) or ((philosophical or social) n1 research*) or (“pilot testing” and survey) or “purpos* sampl*” or qualitative* or ricoeur or semiotics or shadowing or snowball or spiegelberg* or stories or story or storytell* or strauss or structured categor* or ”tape record*” or taperecord* or testimon* or (thematic* n1 analys*) or themes or “theoretical sampl*” or “unstructured categor*” or “van kaam*” or “van manen” or videorecord* or “video record*” or videotap* or “video tap*”)
151 tx (“cross case analys*” or “eppi approach” or metaethno* or “meta ethno*” or metanarrative* or “meta narrative*” or “meta overview” or metaoverview or metastud* or “meta stud*” or metasummar* or “meta summar*” or “qualitative overview*” or ((“critical interpretative” or evidence or meta or “mixed methods” or multilevel or “multi level” or narrative or parallel or realist) n1 synthes*) or metasynthes*) or mw (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*)) or tx (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*))
152 (mh "attitude to health") or (mh "consumer participation") or (mh "consumer satisfaction+") or (mh "patient centered care") or (mh "patient compliance") or (mh "quality o health care")
153 tx ((carer* or caregiv* or “care giv*” or famil* or friend* or mother* or father* or son or daughter*) n3 (account* or anxieties or atisfact* or attitude* or barriers or belief* or buyin or “buy in*” or choice* or cooperat* or “co operat*” or expectation* or experienc* or feedback or feeling* or idea* or inform* or involv* or opinion* or participat* or perceive* or (perception* not “speech perception”) or perspective* or preferen* or prepar* or priorit* or satisf* or view* or voices or worry))
154 tx ((consumer or patient) n2 (focus* or centered or centred))
155 #149 or #150 or #151 or #152 or #153 or #154
156 (mh "clinical trials") or (mh "randomized controlled trials") or ab (placebo or randomised or randomized or randomly) or ti (trial)
157 (mh "meta analysis")
158 (mh "systematic review")

159 tx (“meta analy*” or metanaly* or metaanaly*)
160 tx ((systematic* or evidence*) n2 (review* or overview*))
161 tx (“reference list*” or bibliograph* or “hand search*” or “manual search*” or “relevant journals”)
162 tx (“search strategy” or “search criteria” or “systematic search” or “study selection” or “data extraction”)
163 (search* n4 literature)
164 tx (medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit)
165 so cochrane
166 tx ((pool* or combined) n2 (data or trials or studies or results))
167 tx (“cross case analys*” or “eppi approach” or metaethno* or “meta ethno*” or metanarrative* or “meta narrative*” or “meta overview” or metaoverview or metastud* or “meta stud*” or metasummar* or “meta summar*” or “qualitative overview*” or ((“critical interpretative” or evidence or meta or “mixed methods” or multilevel or “multi level” or narrative or parallel or realist) n1 synthes*) or metasynthes*) or mw (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*)) or tx (qualitative* and (metaanal* or meta anal* or synthes* or systematic review*))
168 #157 or #158 or #159 or #160 or #161 or #162 or #163 or #164 or #165 or #166 or #167
169 #155 or #156 or #168
170 #148 and #169

Database: Cochrane Library - Wiley

#	Searches
1	mesh descriptor: [caregivers] this term only
2	(carer* or caregiv* or “care giv*”):ti,ab,kw
3	#1 or #2
4	mesh descriptor: [counseling] explode all trees
5	mesh descriptor: [psychotherapy, group] explode all trees
6	mesh descriptor: [cognitive behavioral therapy] this term only
7	mesh descriptor: [mindfulness] this term only
8	mesh descriptor: [patient centered care] this term only
9	mesh descriptor: [problem solving] this term only
10	mesh descriptor: [reality therapy] this term only
11	mesh descriptor: [relaxation therapy] this term only
12	mesh descriptor: [social support] this term only
13	(psychotherap*):ti,ab,kw
14	(mesh descriptor: [case management] this term only
15	mesh descriptor: [crisis intervention] this term only
16	mesh descriptor: [education, nonprofessional] this term only
17	mesh descriptor: [friends] this term only
18	mesh descriptor: [group processes] this term only
19	mesh descriptor: [hotlines] this term only
20	mesh descriptor: [interpersonal relations] this term only
21	mesh descriptor: [professional family relations] this term only
22	mesh descriptor: [self-help groups] this term only
23	mesh descriptor: [peer group] explode all trees
24	mesh descriptor: [psychotherapy, group] explode all trees
25	mesh descriptor: [social networking] explode all trees
26	mesh descriptor: [computers] this term only
27	mesh descriptor: [computer assisted instruction] this term only
28	mesh descriptor: [computer communication networks] this term only
29	mesh descriptor: [online systems] this term only
30	mesh descriptor: [social media] this term only
31	mesh descriptor: [therapy, computer assisted] this term only
32	mesh descriptor: [telecommunications] this term only
33	mesh descriptor: [telemedicine] this term only
34	mesh descriptor: [internet] explode all trees
35	mesh descriptor: [social networking] explode all trees
36	(((psychological* or psychosocial or psychotherapeutic) near/2 (intervention* or program* or support* or therap* or treat*)) or “brief intervention*” or psychotherap*):ti,ab,kw
37	(((behaviour* or behavior*) near/2 cognitiv*) or cbt or ccbt or ((behavi* or biobehavi* or cognitive*) near/3 (intervention* or manag* or program* or therap* or treat*)) or “cognitiv* behav*”):ti,ab,kw
38	(“case manag*” or counsel* or ((“person centred” or replacement) near/1 (care or therap*))):ti,ab,kw

39	(((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) near/1 based) or ((computer or digital* or “distance based” or dvd or internet or multimedia or online or phone or skill* or technology or telephone or telehealth or telecommunicat* or video* or web) near/3 (coach* or educat* or skill* or support* or training*)) or ((education or teaching) near/1 (intervention or program* or therap* or psychotherap*)) or elearning or “e learning”):ti,ab,kw
40	((“person centred” or replacement) near/1 (care or therap*)):ti,ab,kw
41	((communit* or social) near/2 support*):ti,ab,kw
42	((intervention* or therap* or program* or workshop*) near/7 (caregiver* or “care giver*” or carer*) near/7 (burden or distress* or stress*)):ti,ab,kw
43	#4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42
44	(befriend* or “be* friend*” or buddy or buddies or ((community or lay or paid or support) near/1 (person or worker*))):ti,ab,kw
45	((peer* or voluntary or volunteer*) near/3 (assist* or advice* or advis* or counsel* or educat* or forum* or help* or mentor* or network* or support* or visit*)):ti,ab,kw
46	((peer* or support* or voluntary or volunteer*) near/2 group*):ti,ab,kw
47	((peer* or support* or voluntary or volunteer*) near/3 (intervention* or program* or rehab* or therap* or service* or skill*)):ti,ab,kw
48	(((peer* near/3 (advis* or consultant or educator* or expert* or facilitator* or instructor* or leader* or mentor* or person* or tutor* or worker*)) or “expert patient*” or “mutual aid”) or (peer* near/3 (assist* or counsel* or educat* or program* or rehab* or service* or supervis*))):ti,ab,kw
49	((bereav* or death or dying or "end of life" or grief* or ((palliative or terminal) near/1 care)) near/3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or "anticipatory grief"):ti,ab,kw
50	(((communit* or family or social) near/1 (network* or support*)) or “group conferencing” or “individualised support” or “individualized support”):ti,ab,kw
51	(((carer* or caregiv* or “care giv*”) near/2 (mentor* or support*)) or (unpaid near/3 support*) or “mentoring scheme*”):ti,ab,kw
52	(((carer* or caregiv* or “care giv*”) near/3 (communication or integrat* or relations or relationship*) near/3 (practitioner* or professional* or worker*)) or (famil* near/3(intervention* or program*))):ti,ab,kw
53	(psychoeducat* or “psycho educat*”):ti,ab,kw
54	((emotion* near/1 (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) near/1 (adapt* or reintegrat* or support*))):ti,ab,kw
55	((dyadic or loneliness or psychosocial* or “psycho social*”) near/2 (assist* or intervention* or program* or support* or therap* or treat*)) :ti,ab,kw
56	((emotion* or “one to one” or transition*) near/1 support*):ti,ab,kw
57	(lay near/1 (led or run)):ti,ab,kw
58	((crisis or crises or emergenc*) near/3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support*)):ti,ab,kw
59	((coping or resilien* or “well being” or wellbeing) near/2 (intervention* or program* or therap* or skill* or strateg* or workshop*)):ti,ab,kw

60	(advocate or advocacy or ((support* near/3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* near/1 (service* or system)))):ti,ab,kw
61	((network* or peer*) near/2 (discuss* or exchang* or interact* or meeting*)):ti,ab,kw
62	(carer* network* or “support group*”):ti,ab,kw
63	#44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55 or #56 or #57 or #58 or #59 or #60 or #61 or #62
64	(helpline or “help line” or ((phone* or telephone*) near/3 (help* or instruct* or interact* or interven* or mediat* or program* or rehab* or strateg* or support* or teach* or therap* or train* or treat* or workshop*)) or ((phone or telephone*) near/2 (assist* or based or driven or led or mediat*))):ti,ab,kw
65	(helpseek* or ((search* or seek*) near/3 (care or assistance or counsel* or healthcare or help* or support* or therap* or treat*))):ti,ab,kw
66	(information near/1 (needs or provision or support)):ti,ab,kw
67	(selfhelp or “self help” or selfmanag* or “self manag*” or “self support” or selfsupport) :ti,ab,kw
68	#64 or #65 or #66 or #67
69	mesh descriptor: [education] this term only
70	mesh descriptor: [health education] explode all trees
71	mesh descriptor: [first aid] this term only
72	(((carer* or caregiv* or “care giv*”) near/5 (educat* or intervention* or program* or support* or taught or teach* or train*)) or ((educat* or train* or learn* or taught*) near/3 (intervention* or program*)) or ((educat* or intervention* or program* or support* or taught or teach* or train*) near/3 (bandage or cpr or crisis or crises or dressing or emergency or ((intimate or personal) near/1 care) or “rescue breath*”)) or “first aid” or “personali* train*” or” resourcefulness train*” or (skill* near/2 (build* or coach* or educat* or learn* or train))):ti,ab,kw
73	(psychoeducat* or “psycho educat*”) ti,ab,hw.
74	(((medication or pain) near/2 manag*) or “pain control program*” or ((educat* or train*) near/5 (handling or movement))):ti,ab,kw
75	#69 or #70 or #71 or #72 or #73 or #74
76	mesh descriptor: [physical exertion] this term only
77	mesh descriptor: [exercise] explode all trees
78	mesh descriptor: [physical education and training] explode all trees
79	mesh descriptor: [sports] explode all trees
80	(“aerobic train*” or exercis* or gym* or jog* or (physical near/1 (activit* or fit)) or “resistance train*” or sport* or “strength train*” or (swim* not rat*) or walk* or weight lift* or (leisure near/2 (activit* or intervention* or program* or therap*)) or “leisure based”):ti,ab,kw
81	#76 or #77 or #78 or #79 or #80
82	mesh descriptor: [employment] this term only
83	mesh descriptor: [employment, supported] this term only
84	mesh descriptor: [rehabilitation, vocational] this term only
85	mesh descriptor: [return to work] this term only
86	mesh descriptor: [unemployment] this term only
87	mesh descriptor: [vocational education] this term only
88	mesh descriptor: [work] this term only

89	mesh descriptor: [workplace] this term only
90	mesh descriptor: [aid to families with dependent children] this term only
91	mesh descriptor: [child welfare] this term only
92	mesh descriptor: [financing, government] this term only
93	mesh descriptor: [government programs] this term only
94	mesh descriptor: [public assistance] this term only
95	mesh descriptor: [social security] this term only
96	mesh descriptor: [social welfare] this term only
97	mesh descriptor: [social work] this term only
98	(((employ* or job* or reemploy* or vocation* or work*) near/3 (advice or advis* or approach* or assist* or coach* or counsel* or educat* or experience or flexible or integrat* or interven* or liaison* or placement* or program* or rehab* or reintegrat* or retrain* or scheme* or support* or service* or skill* or strateg* or teach* or therap* or train* or transitional*)) or “carer* lead” or flexible working or “individuali* support” or “job centre” or (vocat* near/2 employ*) or (work near/2 coach*)):ti,ab,kw
99	((“individual placement” near/2 support) or “ips model”) :ti,ab,kw
100	((permitted or voluntary or rehab*) near/3 work*):ti,ab,kw
101	((psychosocial or “psycho social” or social) near/2 rehab*):ti,ab,kw
102	“rehabilitation counsel*”:ti,ab,kw
103	((prevocat* or vocat*) near/3 (advice* or advis* or assist* or casework* or “case work*” or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*)):ti,ab,kw
104	(volunteering or (work near/2 placement*)):ti,ab,kw
105	(((carer* or “care giv*” or caregiv*) near/3 (card* or employment or passport* or scheme* or work)) or “paid employment” or “social security” or “social welfare”) :ti,ab,kw
106	(return near/1 to* near/1 (education or study or training or work*)):ti,ab,kw
107	(“carer* allowance*” or “caregiv* allowance” or “flexible support” or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging* or money or “working rights”) near/3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) near/7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) near/7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*))):ti,ab,kw
108	(signpost* or “sign post*”):ti,ab,kw
109	#82 or #83 or #84 or #85 or #86 or #87 or #88 or #89 or #90 or #91 or #92 or #93 or #94 or #95 or #96 or #97 or #98 or #99 or #100 or #101 or #102 or #103 or #104 or #105 or #106 or #107 or #108
110	mesh descriptor: [day care, medical] this term only
111	mesh descriptor: [respite care] this term only
112	(“day care” or daycare or “day therap*” or daytherap* or “home help” or “short break” or ((carer* or caregiv* or care giv*) near/3 support*)):ti,ab,kw
113	(((crisis or volunteer) near/1 support) or holiday* or homehelp* or home help* or housekeep* or house keep* or “meal support” or “personal assistant” or respite or ((activity or fund* or short) near/2 break*) or signpost*):ti,ab,kw
114	#110 or #111 or #112 or #113

115	mesh descriptor: [assistive technology] this term only
116	mesh descriptor: [occupational therapy] this term only
117	mesh descriptor: [self-help devices] this term only
118	mesh descriptor: [telemedicine] this term only
119	mesh descriptor: [telemetry] this term only
120	mesh descriptor: [telemonitoring] this term only
121	((assistive near/2 (platform* or technolog*)) or “interactive health communication”):ti,ab,kw
122	(“simulated presence” or “social robot*” or telecare or telehealth or telematic* or telemonitor*):ti,ab,kw
123	(“gps track*” or “location technology”):ti,ab,kw
124	“occupational therap*”:ti,ab,kw
125	#115 or #116 or #117 or #118 or #119 or #120 or #121 or #122 or #123 or #124
126	mesh descriptor: [acupressure] this term only
127	mesh descriptor: [massage] this term only
128	mesh descriptor: [acupuncture] this term only
129	mesh descriptor: [complementary therapies] explode all trees
130	mesh descriptor: [mind body therapies] explode all trees
131	mesh descriptor: [medicine, chinese traditional] this term only
132	mesh descriptor: [moxibustion] this term only
133	((alternative or complementary) near/2 (medicine* or therap*)) or “acu point*” or acupoint* or acupressur* or acupunctur* or (ching near/2 lo) or cizhen or dianzhen or electroacupunctur* or (jing near/2 luo) or jingluo or massag* or moxibustion or electroacupuncture or needle therap* or zhenjiu or zhenci) :ti,ab,kw
134	meditation.sh. or meditat*:ti,ab,kw
135	(acceptance near/2 “commitment therap*”):ti,ab,kw
136	“dyadic intervention*”:ti,ab,kw
137	(reminiscence near/1 (group* or therap*)):ti,ab,kw
138	((emotional or self) near/1 disclosure):ti,ab,kw
139	mesh descriptor: [self disclosure] this term only
140	mesh descriptor: [art] this term only
141	mesh descriptor: [music] this term only
142	mesh descriptor: [singing] this term only
143	mesh descriptor: [painting] this term only
144	mesh descriptor: [art therapy] this term only
145	mesh descriptor: [singing therapy] this term only
146	(art or cafe or cafes or gallery or music or sing or singing):ti,ab,kw
147	#126 or #127 or #128 or #129 or #130 or #131 or #132 or #133 or #134 or #135 or #136 or #137 or #138 or #139 or #140 or #141 or #142 or #143 or #144 or #145 or #146
148	#3 and (#43 or #63 or #68 or #75 or #81 or #109 or #114 or #125 or #147)

Non-database searches

In addition to the above databases, searches were undertaken in a range of websites and other relevant sources:

1. Agency for Healthcare Research and Quality
2. Care Quality Commission
3. Carer Research and Knowledge Exchange Network
4. Carers Trust
5. Carers UK
6. Centre for Mental Health
7. Centre for International Research on Care, Labour and Equalities
8. Department of Health
9. Department for Work and Pensions
10. Directors of Adult Social Services
11. Equality and Human Rights Commission
12. Eurocarers
13. Google UK
14. Health and Social Care Information Centre
15. Health in Wales
16. Healthcare Improvement Scotland
17. Healthcare Quality Improvement Partnership
18. Institute for Public Policy Research
19. Joseph Rowntree Foundation
20. Kings Fund
21. National Audit Office
22. New Policy Institute
23. NHS England
24. NHS Improving Quality
25. Office for National Statistics
26. Research in Practice
27. Royal College of General Practitioners
28. Royal College of Nursing
29. Royal College of Physicians
30. Royal College of Psychiatrists
31. SIGN
32. Turning Point
33. Welsh Government

Economic evidence

Database: Embase, Medline, Medline Ahead of Print and In-Process & Other Non-Indexed Citations – OVID [Multifile]

#	Searches
1	caregiver/ use emez or caregivers/ use mesz, prem
2	(carer* or caregiv* or care giv*).ti,ab.
3	1 or 2

#	**Searches**
4	budget/ or exp economic evaluation/ or exp fee/ or funding/ or health economics/ or exp health care cost/
5	4 use emez
6	exp budgets/ or exp "costs and cost analysis"/ or economics, nursing/ or economics, pharmaceutical/ or economics/ or exp economics, hospital/ or exp economics, medical/ or exp "fees and charges"/ or value of life/
7	6 use mesz
8	budget*.ti,ab.
9	cost*.ti.
10	(economic* or pharmaco?economic*).ti.
11	(price* or pricing*).ti,ab.
12	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
13	(financ* or fee or fees).ti,ab.
14	(value adj2 (money or monetary)).ti,ab.
15	or/5,7-14
16	3 and 15

Database: Cochrane Library – Wiley

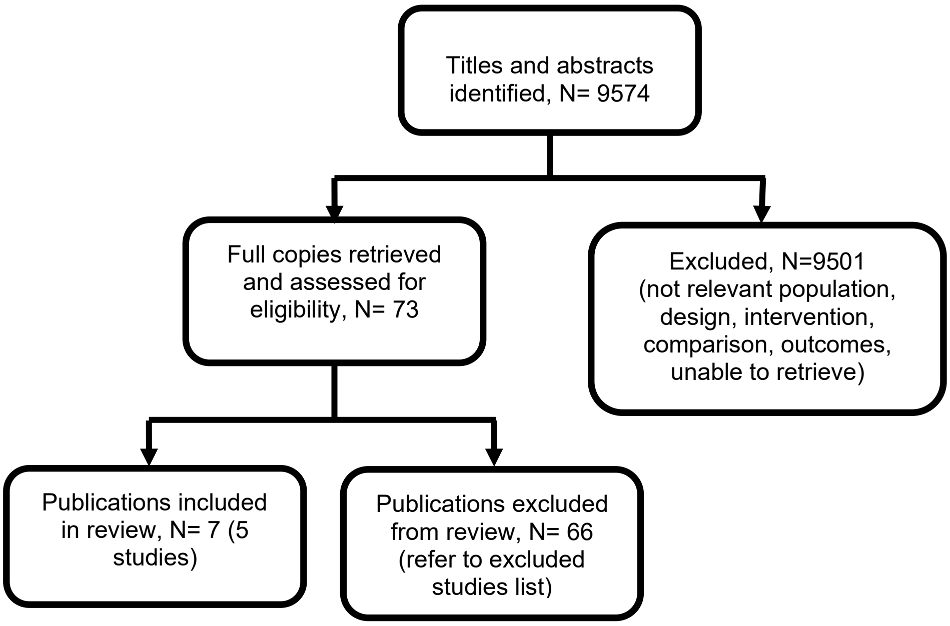
#	Searches
1	mesh descriptor: [caregivers] this term only
2	(carer* or caregiv* or “care giv*”):ti,ab,kw
3	#1 or #2

Appendix C – Evidence study selection

Evidence study selection for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult cares during: (i) changes to the setting in which caring is performed; (ii) the transition of the person receiving care to adulthood; and (iii) change of carer status or circumstances?

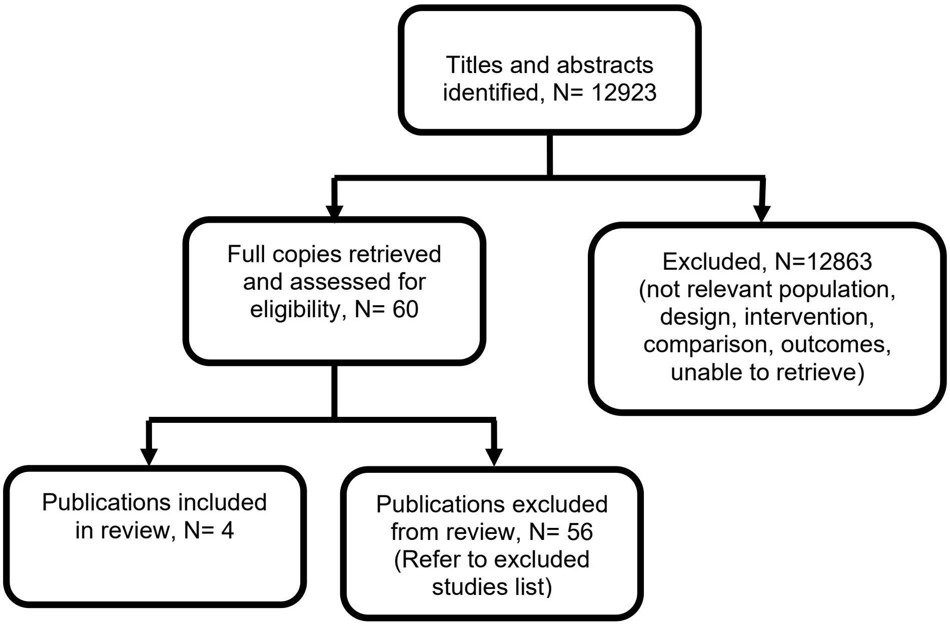
Quantitative component of the review

Figure 2: Flow diagram of article selection for providing practical support for adult carers review



Qualitative component of the review

Figure 3: Flow diagram of article selection for providing practical support for adult carers review



Appendix D – Evidence tables

Evidence tables for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult cares during: (i) changes to the setting in which caring is performed; (ii) the transition of the person receiving care to adulthood; and (iii) change of carer status or circumstances?

Quantitative component of the review

Table 6: Evidence tables for the quantitative studies

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Full citation
Cameron, J. I., Naglie, G., Green, T. L., Gignac, M. A., Bayley, M., Huijbregts, M., Silver, F. L., Czerwonka, A., A feasibility and pilot randomized controlled trial of the "Timing it Right Stroke Family Support Program", Clinical Rehabilitation, 29, 1129-1140, 2015

Ref Id
710297</td>
<td>Sample size
N=31
Self-directed Intervention (n): 10
Stroke support person-directed Intervention (n): 11
Control/ standard care (n): 10

Characteristics
Carer Characteristics
• Age - Mean (SD): Self-directed intervention</td>
<td>Interventions
• Intervention (according to the protocol) - Respite practical support intervention
• Name of intervention (as named in the paper) -Stroke support person directed
• Intervention 2 (according to the</td>
<td>Details
• Randomization methods - Sequentially numbered sealed envelopes containing group allocation to 1 of 3 groups
• Blinding methods - single blind. Research assistants blind to group assignment collected pilot</td>
<td>Results
at 1,3 and 6 months follow-up from stroke
Note: Median and IQR
<table>
<tr><td>Outcomes</td><td colspan="4">Standard care (n=10)</td><td colspan="4">Self-directed intervention (n=10)</td><td colspan="4">Stroke support person-directed intervention (n=11)</td></tr>
<tr><td></td><td>Baseline</td><td>1 month</td><td>3 months</td><td>6 months</td><td>Baseline</td><td>1 month</td><td>3 months</td><td>6 months</td><td>Baseline</td><td>1 month</td><td>3 months</td><td>6 months</td></tr>
<tr><td>Social capital: social support (20 item Medical Outcomes Study Social Support Scale)</td><td>81.1 (70, 94.1)</td><td>71.0 (55.3, 82.8)</td><td>64.5 (50.5, 88.6)</td><td>75.2 (54.8, 98.0)</td><td>75.5 (55.3, 83.1)</td><td>75.8 (72.7, 88.8)</td><td>78.6 (59.2, 93.6)</td><td>68.5 (46.9, 75.9)</td><td>79.1 (53.4, 85.4)</td><td>82.3 (67.1, 90.1)</td><td>76.3 (61.9, 100)</td><td>89.9 (64.9, 95.3)</td></tr>
<tr><td>Caring-related morbidity: Depression (20 item Centre for Epidemiolo</td><td>13 (7.5, 29)</td><td>19.5 (7, 23.8)</td><td>14 (3.8, 19.8)</td><td>8 (5, 23)</td><td>22.5 (20, 29.1)</td><td>18.9 (12, 27)</td><td>13.5 (8.5, 16.4)</td><td>11.6 (8.8, 18.3)</td><td>17.5 (11, 30.3)</td><td>16 (8.5, 24.3)</td><td>11 (2,21)</td><td>12 (7, 23.5)</td></tr>
</table>
</td>
<td>Limitations (assessed using the Cochrane 'Risk of bias' tool for randomized trials)
• Random sequence generation - Unclear. Only describes as sequentially numbered envelopes. Unclear what determined the</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>**Country/ies where the study was carried out**
Canada

Study type
3 group, single blind, mixed methods RCT

Aim of the study
To examine feasibility of conducting a randomised controlled trial of the Timing it Right Stroke Family Support Program (TIRSFSP) and collect pilot data.

Study dates
• Publication date: 2015
• Data collection: Not reported

Source of funding
Supported by Pilot grants from the Canadian</td>
<td>57 (14.9); Stroke support person directed Intervention 57 (19.4); Control 55 (10)
• Gender (% female)- Self-directed intervention (80%) ; Stroke support person directed Intervention (73%); Control 80%
• Relationship to care recipient- Self-directed intervention 80% spouse ; Stroke support person directed Intervention 55% spouse ;</td>
<td>protocol) - Respite practical support intervention
• Name of intervention (as named in the paper) - Self-directed support
• Control (according to the protocol) - No intervention
• Name of control (as named in the paper) - Standard care
Mode of delivery
• Individual
• Face-to-face
• Telephone support
• Guidebook</td>
<td>quantitative data.
• Follow-up measurement - 1, 3, 6 months post stroke
• Sample size statistical power - convenience sample was not chosen to provide sufficient power to detect significant differences between treatment groups and the small sample size precluded conducting adjusted analyses</td>
<td>
<table>
<tr><td>gical Studies Depression Scale [CESD])</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Caring-related morbidity: psychological well-being (10 item Positive Affect Scale)</td><td>35 (27.5 , 38.5)</td><td>33 (20.5, 38)</td><td>37 (27, 41.8)</td><td>36 (34, 41)</td><td>33.5 (27, 43.3)</td><td>34 (33, 44)</td><td>39 (32.8, 42.5)</td><td>37.5 (31.8, 43.8)</td><td>38 (33.5, 44)</td><td>32 (25.5, 37.5)</td><td>43 (33, 49)</td><td>36.5 (30.8, 42.5)</td></tr>
<tr><td>Carer control: mastery (Pearlins 7 item Mastery Scale)</td><td>19 (17.5 , 20)</td><td>18 (17.3, 19)</td><td>18 (16.8, 21)</td><td>17 (17, 19)</td><td>17.5 (17, 19.3)</td><td>19 (16, 20)</td><td>19 (18, 19.8)</td><td>19 (18,21)</td><td>19 (17, 20.5)</td><td>18.5 (17, 20.8)</td><td>19 (18,21)</td><td>20 (17.5, 21.5)</td></tr>
</table>

Additional outcomes described in the methods but were not reported: Carer's stroke knowledge (Stroke Knowledge Test), Carer's participation in valued activities (14 item Caregiving Impact Scale), level of carer's assistance to the stroke survivor (17 item Caregiving Assistance Scale).</td>
<td>randomization process.
• Allocation concealment - Sealed envelopes. Unclear opacity.
• Blinding of participants and personnel - Single blind
• Incomplete outcome data - ITT, but with no description of LOCF. Missing data for the standard care, self-directed intervention and SSP directed intervention groups respectively; at 1 month (20%, 30%, 45%), 3 months</td>
</tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Institutes of Health Research Institute of Aging and the Connaught Fund University of Toronto.	Control 60% spouse - Living with care recipient - Self-directed intervention 70%; Stroke support person directed Intervention 73%; Control 70% Care recipient (condition) - First stroke **Inclusion criteria** - Caregivers for individuals who experienced their first hospitalization for either ischemic or haemorrhagic stroke within the first week post-stroke. Caregivers				(40%, 20%, 27%), and at 6 months (30%, 20%, 18%) - Selective reporting - Yes, 3 outcomes reported in the methods but not in the results section. - Other risk of bias – **Overall RoB** - Very serious **Other information** Intervention links with RQF

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
	had to be able to speak and read English and had to be primarily responsible for providing and/or coordinating community care without financial compensation **Exclusion criteria** - Caregivers were excluded if the person they care for was terminally ill or discharged to complex continuing care, long-term care or assisted living.				
Full citation	**Sample size** N=111	**Interventions**	**Details**	**Results**	**Limitations (assessed**

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Ducharme Francine C, et al.,, "Learning to become a family caregiver" efficacy of an intervention program for caregivers following diagnosis of dementia in a relative, Gerontologist, 51, 484-494, 2011

Ref Id
708674

Country/ies where the study was carried out
Canada

Study type
2 group RCT

Aim of the study
To test the efficacy of a psycho educational individual</td>
<td>Intervention (n): 62
Control (n): 49
Characteristics
Carer Characteristics
Age - Mean (SD): intervention =60.37 (13.12); control= 62.75 (13.22)
Gender - intervention: 79% female ; control: 79.6% female
Relationship to care recipient, intervention and control groups respectively - wife 25.8%, 22.4%; husband 9.7%, 10.2%, daughter 45.2%,</td>
<td>Intervention (according to the protocol) - Education/ skill based practical support for carers
Name of Intervention (as named in the paper) - psychoeducational program
Control (according to the protocol) - No intervention
Name of control (as named in the paper) - Usual care
Mode of delivery
Individual</td>
<td>Randomization methods - "random assignment"
Blinding methods - Single blind. To keep the interviewers blind to assignment, caregivers were randomised after the baseline interview. Post test/ follow-up caregivers were instructed by the project coordinator not to reveal their group assignment.
Follow-up outcome measurement - Post test and 3 months later
Sample size statistical</td>
<td>
<table>
<tr><td>Outcomes</td><td colspan="3">Intervention n=62, Mean (SD)</td><td colspan="3">Control n=49, Mean (SD)</td></tr>
<tr><td></td><td>Baseline</td><td>Post test</td><td>3 month F/U</td><td>Baseline</td><td>Post test</td><td>3 month F/U</td></tr>
<tr><td>Carer skills, knowledge/confidence or efficacy about supporting person receiving care : Confidence (15 item Self Efficacy Scale)</td><td>48.20 (9.81)</td><td>54.32 (8.63)</td><td>53.52 (8.91)</td><td>50.33 (9.47)</td><td>50.35 (10.18)</td><td>51.65 (9.63)</td></tr>
<tr><td>Carer skills, knowledge/confidence or efficacy about supporting person receiving care : Preparedness (8 item Preparedness for Caregiving Scale)</td><td>25.13 (6.50)</td><td>30.94 (4.92)</td><td>30.48 (4.70)</td><td>27.08 (7.25)</td><td>27.17 (6.69)</td><td>27.17 (7.12)</td></tr>
<tr><td>Carer skills, knowledge/confidence or efficacy about supporting person receiving care : Self efficacy (Revised Scale for Caregiving Self-Efficacy)</td><td>70.04 (14.62)</td><td>72.34 (13.09)</td><td>70.96 (15.36)</td><td>71.15 (15.01)</td><td>67.92 (17.03)</td><td>67.39 (16.87)</td></tr>
<tr><td>Carer knowledge/ confidence/ efficacy: Knowledge of future needs (Planning for Future Needs scale)</td><td>15 (5.84)</td><td>18.56 (6.00)</td><td>19.63 (5.44)</td><td>15.04 (6.90)</td><td>16.13 (7.02)</td><td>18.31 (7.35)</td></tr>
<tr><td>Carer knowledge/ confidence/ efficacy: Knowledge of services (The Knowledge of Services scale)</td><td>18.87 (7.32)</td><td>26.76 (5.58)</td><td>27.27 (5.18)</td><td>20.04 (8.59)</td><td>22.86 (8.21)</td><td>24.29 (8.03)</td></tr>
<tr><td>Resource and service use: Support received by caregivers (27 item Inventory of Socially Supportive Behaviors)</td><td>1.65 (0.32)</td><td>1.76 (0.37)</td><td>1.69 (0.36)</td><td>1.69 (0.35)</td><td>1.66 (0.37)</td><td>1.71 (0.33)</td></tr>
</table>
Additional outcomes reported: Coping strategies (The Carer's Assessment of Managing Index) which assesses the frequency of utilization of 3 coping strategies; problem solving, reframing and stress management, family conflicts (The Family Caregiver Conflict Scale)
</td>
<td>using the Cochrane ‘Risk of bias’ tool for randomized trials)
Random sequence generation - Unclear. No details of the method of randomisation was given.
Allocation concealment - Unclear.
Blinding of participants and personnel - None.
Blinding of outcome assessment - Single blind. Interviewers were kept blind to assignment. Caregivers were</td>
</tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
program conceived to facilitate transition to the caregiver role following diagnosis of Alzheimer disease in a relative. **Study dates** - Publication date: 2011 - Data collection: Not described **Source of funding** Funded by the Alzheimer Society of Canada in partnership with the Canadian Institutes of Health Research and the Canadian Nurses Foundation.	42.9%, son 8.1%, 8.2%, other 11.3%, 16.3% - Living with care recipient (yes) - intervention 46.8%, control 43.8% Care recipient (condition) - Alzheimers **Inclusion criteria** Participants had to be the caregiver (spouse or offspring) self-defined as the person principally responsible (notion of primary caregiver) for a relative 65 years of age or older diagnosed with Alzheimer	○ Face-to-face Workbook	power - No power calculation described.		instructed not to disclose group assignment on interview. - Incomplete outcome data - attrition rates were 2/62 (3.2%) intervention group and 8/49 (16.3%) in the control group. Main reason for dropping out was lack of time. - Selective reporting - low risk - Other risk of bias - unclear risk: insufficient information to permit judgment on sample size

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td></td>
<td>disease in the past 9 months.

Exclusion criteria
Caregivers receiving psychotherapy or participating in a support group at time of study.</td>
<td></td>
<td></td>
<td></td>
<td>statistical power

Overall RoB - very serious

Other information
Intervention links with RQE</td>
</tr>
<tr>
<td>Full citation
Ducharme, F., Lachance, L., Levesque, L., Zarit, S. H., Kergoat, M. J., Maintaining the potential of a psycho-educational program: efficacy of a booster session after an intervention offered family caregivers at disclosure of a relative's dementia diagnosis, Aging</td>
<td>Sample size
N=103 (from previous RCT – Ducharme 2011)
• Intervention Booster (n): 33
• Intervention non- Booster (n): 34
• Control (n): 36

Characteristics
Carer characteristics:
• Age, gender, relationship to care recipient:</td>
<td>Interventions
• Intervention 1 (according to the protocol): Education/ skill based practical support for carers with additional session
• Intervention 1 (as named in the paper): Booster group</td>
<td>Details
• Randomization methods - took account of kinship tie to the cared for person and sex of caregiver (this was not done/ described for the original randomisation). No further details were given. Note: Only the previous study interventions group was re-</td>
<td>Results
At 6 month follow-up:
<table>
<tr><td>Dependent variable</td><td>Successful outcomes
Number of caregivers (%)</td><td>Unsuccessful outcomes
Number of caregivers (%)</td><td>p</td></tr>
<tr><td colspan="4">Carer knowledge/ confidence or efficacy: Emergence of preparedness (Preparedness for Caregiving Scale-8):</td></tr>
<tr><td>Booster group versus</td><td>17 (55)</td><td>14 (45)</td><td>0.014</td></tr>
<tr><td>Control group</td><td>8(28)</td><td>21 (72)</td><td></td></tr>
<tr><td>Non-booster group (versus control group)</td><td>12 (41)</td><td>17 (59)</td><td>0.144</td></tr>
<tr><td colspan="4">Maintenance of psychological distress (Psychological Distress Index -14):</td></tr>
<tr><td>Booster group versus</td><td>15 (48)</td><td>16 (52)</td><td>0.050</td></tr>
<tr><td>Control group</td><td>8 (28)</td><td>21 (72)</td><td></td></tr>
<tr><td>Non-booster group (versus control group)</td><td>16 (55)</td><td>13 (45)</td><td>0.014</td></tr>
<tr><td colspan="4">Carer knowledge/ confidence or efficacy: Emergence of self-efficacy (Revised Scale for Caregiving Scale):</td></tr>
<tr><td>Booster group versus</td><td>15 (54)</td><td>13 (46)</td><td>0.007</td></tr>
<tr><td>Control group</td><td>6 (22)</td><td>21 (78)</td><td></td></tr>
</table>
</td>
<td>Limitations (assessed using the Cochrane ‘Risk of bias’ tool for randomized trials)
• Random sequence generation - unclear methods. Randomization to the 3 groups was not done at the original baseline. Second</td>
</tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
& Mental Health, 19, 207-216, 2015 **Ref Id** 710473 **Country/ies where the study was carried out** Canada **Study type** 3 group, RCT (Follow on study to Ducharme 2011) **Aim of the study** To evaluate the efficacy of a booster session offered 2 weeks after the 6 month post-program assessment. Sort to answer 2 questions: 1) Does the booster session contribute to maintain the positive effects of	caregivers had a mean age of about 60 years and approximately 80% were women. About 49% of caregivers were daughters • Living with care recipient- not reported • No numerical baseline characteristics of the 3 groups were provided Care recipient (condition) • Alzheimer's disease **Inclusion criteria** • Caregivers were a spouse or an offspring, self-defined as the person	• Intervention 2 (according to the protocol): Education/ skill based practical support for carers with no additional session • Intervention 2: (as named in the paper):Non-booster group • Control (according to the protocol): No intervention • Name of control (as named in the paper): Control group • Mode of delivery ○ Individual	randomised to the booster/non booster session. The 3 groups had not been randomised at the original study's baseline • Blinding methods - "the healthcare professionals kept blind to the intervention. Caregivers were recruited by a designated professional in each memory clinic also kept blind to the intervention." Single blind. Unclear if the outcomes were assessed by a blinded investigator.	Non-booster group (versus control group) | 13 (45) | 16 (55) | 0.042 3 caregivers in the booster group and 2 caregivers in the control group did not complete the self-efficacy scale. For all other outcomes, no significant results were found in either condition, booster or non-booster, regarding the expected maintenance of effects (knowledge of services, planning for future, reframing) or the emergence of effects (social support and family conflicts). Full summary of results published in the paper:	randomisation was done taking into account kinship and caregiver gender. No baseline characteristics at second randomisation given. High risk. • Allocation concealment - unclear • Blinding of participants and personnel - no blinding of participants. Healthcare professionals were said to be blinded. • Blinding of outcome assessment - unclear • Incomplete outcome data

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
the program observed post-program?; 2) As caregivers might need some time to put into practice certain skills proposed in the program, does the booster session foster the emergence of positive effects that did not significantly emerge post-program? **Study dates** • Publication date:2015 • Data collection: Not described **Source of funding** The project was funded by the Alzheimer Society of Canada [grant number 09-02]	principally responsible (notion of primary caregiver) for a relative 65 years of age or over and diagnosed with Alzheimer's disease in the past 9 months **Exclusion criteria** • Caregivers receiving psychotherapy or participating in a support group at time of study	○ Face-to-face ○ Single session ○ Post intervention reinforcement (2 weeks after post-program evaluation)	• Follow-up outcome measurement - 6 months from booster session • Sample size statistical power: Used software. 66 participants required, 22 per group, 80% power, type 1 error 5%		- attrition: 14 dropouts. n=2 in the booster session, n=4 non booster session, n=7 control group. Unclear reasoning in each group. "The reasons for dropping out were similar across the 3 groups: institutionalization and death of a relative (n=8), caregiver acute health problem (n=3), and lack of time (n=3). • Selective outcome reporting - high risk. No mean (SD) reported for

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
					the treatment groups. Dichotomised into a successful and unsuccessful outcome using predictive analysis. The 15-item Self-efficacy Scale was dropped from the analysis on account of its strong correlation with preparedness for caregiving. - Other risk of bias – **Overall RoB -** Very serious
Full citation	**Sample size**	**Interventions**	**Details**	**Results**	**Limitations (assessed**

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>• Forster, A, Dickerson, J, Young, J, Patel, A, Kalra, L, Nixon, J, A cluster randomised controlled trial and economic evaluation of a structured training programme for caregivers of inpatients after stroke: the TRACS trial, Health technology assessment, 17, 1-98, 2013
• Forster, Anne, Dickerson, Josie, Young, John, Patel, Anita, Kalra, Lalit, Nixon, Jane, A structured training programme for caregivers of inpatients after</td>
<td>N=930 registered with 928 giving consent
• Intervention (n): 450
• Control (n): 478

Characteristics
Carer characteristics:
• Age - Mean (SD): intervention =61.1 (14.64) ; control= 60.8 (13.91)
• Gender - intervention (n): 140 male ; control (n): 153 male
• Relationship to care recipient - reported as the patient/care giver relationship.</td>
<td>• Intervention (according to the protocol) - Education/ skill based practical support for carers
• Name of the intervention (as named in the paper) - London Stroke Carers Training Course (LSCTC)
• Control (according to the protocol) - No intervention
• Name of control (as named in the paper) - Usual care
• Mode of delivery</td>
<td>• Randomization methods- The unit of randomisation was the SRU. SRUs were randomised on a 1:1 basis to either the intervention or the control group. The randomisation was stratified by geographical region and quality of care (defined as being on and above, or below, the median on the key 12-indicator score of the 2006 NSSA). Block randomisation was used to ensure that these important covariates</td>
<td>
<table>
<tr><th>Outcomes</th><th colspan="3">Intervention group</th><th colspan="3">Control group</th></tr>
<tr><td></td><td>Baseline (unadjusted), Mean (SD)</td><td>6 months follow-up, Mean (SE)</td><td>12 months follow-up, Mean (SE)</td><td>Baseline (unadjusted), Mean (SD)</td><td>6 months follow-up, Mean (SE)</td><td>12 months follow-up, Mean (SE)</td></tr>
<tr><td>Impact of caring on carer: Caregiver burden (Caregiver Burden Scale)</td><td>NR</td><td>45.5 (0.83),n=325</td><td>44.8 (0.97), n=291</td><td>NR</td><td>45.0 (0.83), n=340</td><td>43.8 (0.96), n=314</td></tr>
<tr><td>Impact of caring on carer: Social restriction (Frenchay Activities Index)</td><td>32.9 (7.99), n=441</td><td>31.4 (0.40), n=321</td><td>31.9 (0.41), n=286</td><td>33.5 (7.40), n=470</td><td>32.2 (0.40), n=333</td><td>32.6 (0.41), n=313</td></tr>
<tr><td>Impact of caring on carer: Quality of Life (EQ-5D)</td><td>0.797 (0.232), n=438</td><td>0.777 (0.0114), n=317</td><td>0.806 (0.0122), n=284</td><td>0.791 (0.245), n=471</td><td>0.790 (0.0114), n=333</td><td>0.787 (0.0119), n=312</td></tr>
<tr><td>Caring-related morbidity: Anxiety (Hospital Anxiety and Depression Scale, anxiety score)</td><td>8.3 (4.87), n=442</td><td>7.0 (0.23), n=318</td><td>6.9 (0.26), n=286</td><td>8.0 (4.74), n=470</td><td>7.5 (0.23), n=334</td><td>7.0 (0.26), n=311</td></tr>
<tr><td>Caring-related morbidity: Depression (Hospital Anxiety and Depression Scale, depression score)</td><td>5.2 (4.25), n=442</td><td>5.2 (0.22), n=318</td><td>5.2 (0.22), n=286</td><td>5.0 (3.89), n=471</td><td>5.5 (0.22), n=334</td><td>5.2 (0.22), n=312</td></tr>
<tr><td>Caring-related morbidity: Caregiver Death (n)</td><td></td><td>2</td><td>4 (between 6-12 mths)</td><td></td><td>1</td><td>3 (between 6-12 months)</td></tr>
</table>
Adjusted analyses (2 level hierarchical model with caregivers nested within stroke units, adjusted for patient level baseline covariates (baseline NEADL, sex, caregiver's education , caregiver baseline HADS score, Edinburgh stroke case mix adjuster) and stroke level covariates (geographical region, key 12 indicator score and number of beds in every centre) are also reported (not extracted).
</td>
<td>**using the Cochrane ‘Risk of bias’ tool for randomized trials)**
• Random sequence generation - low risk
• Allocation concealment - low risk
• Blinding of participants and personnel - low risk
• Blinding of outcome assessment - low risk
• Incomplete outcome data - High attrition rate; intervention 26.9% at 6 months, 34.4% at 12 months and in the control</td>
</tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
stroke (TRACS): a cluster randomised controlled trial and cost-effectiveness analysis, Lancet, 382, 2069-2076, 2013 **Ref Id** 708922 **Country/ies where the study was carried out** United Kingdom **Study type** 2 group, multicentre (36 units, 4 regions) cluster RCT,TRACS trial **Aim of the study** To evaluate whether or not a structured, competency-based training	For the intervention and control groups respectively: partner 69.8%, 65.9%; daughter/son 26.2%, 28.2%; other relative 3.8%, 4.8%; other non relative 0.2%, 1.0% - Living with care recipient - reported as 'are the patient and caregiver intending to live together after discharge" Intervention group yes 83.6%, control group 80.8%. Care recipient (condition) - Stroke	○ Individual ○ Delivered while person being cared for was an inpatient, follow-up session in person or telephone	were balanced between the arms of the trial. - Blinding methods - Participants were blinded to the SRUs allocation, and the multidisciplinary staff in each SRU were not informed of the people/caregivers who had consented to study procedures. Baseline assessments done by independent researchers. To avoid selection bias, recruitment was done by Stroke Research Network researchers		group 28% and 34.3% respectively. Outcome data collected through questionnaires. Telephone interview for primary outcomes. - Selective reporting - All stated primary and secondary outcomes were reported. - Other risk of bias - High attrition rate with insufficient recruitment to meet revised power calculation estimation of 950-1000 dyads.

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
programme for caregivers [the London Stroke Carer Training Course (LSCTC)] improved physical and psychological outcomes for patients and their caregivers after disabling stroke, and to determine if such a training programme is cost-effective. **Study dates** - Publication date: 2011 - Data collection: February 2008-February 2010 **Source of funding** This project was funded by the Medical Research Counsel and is managed by the NIHR (project number 09/800/10) on	**Inclusion criteria** Confirmed primary diagnosis of new stroke, were medically stable, were likely to return home with residual disability, and had a caregiver available, willing and able to provide support after discharge. **Exclusion criteria** Patient and caregiver dyads were excluded if the patient was in need of palliative care, if discharge was planned within 1 week of admission to the SRU, or if the patient or caregiver were		who were independent of the multidisciplinary team. - Follow-up outcome measurement - 6 and 12 months (questionnaire, telephone for primary outcomes) - Sample size statistical power - 36 SRUs, each recruiting 25 patients, would result in 450 patients in each group and provide close to 90% power at 5% significance level to detect the clinically relevant difference of 6 points on the NEADL score.		**Overall RoB -** serious **Other information** Intervention links with RQE

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td>behalf of the MRC–NIHR partnership,</td><td>registered to the trial on a previous admission.</td><td></td><td>A sample size of 900 patients provides more than 85% power at the 5% significance level to detect an effect size of one-third in any of the other outcomes. Power was adversely affected by higher than expected loss to follow-up and unequal cluster sizes, so the sample size was increased to 950-1000 to maintain 90% power.</td><td></td><td></td></tr>
<tr><td>Full citation
• Kalra, L., Evans, A., Perez, I.,</td><td>Sample size
N=300
Intervention (n): 151; Control (n): 149</td><td>Interventions
Intervention (according to the protocol)-Education/</td><td>Details
• Randomization methods - block</td><td>Results
Note: Mean and SD were not reported.
At 3 months follow-up<table><tr><th></th><th>Baseline Intervention</th><th>3 month Follow-up Intervention</th><th>Baseline Control</th><th>3 month Follow- up Control</th></tr></table></td><td>Limitations (assessed using the Cochrane ‘Risk of bias’</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Melbourn, A., Patel, A., Knapp, M., Donaldson, N., Training carers of stroke patients: randomised controlled trial, BMJ, 328, 1099, 2004
• Patel, A., Knapp, M., Evans, A., Perez, I., Kalra, L., Training care givers of stroke patients: economic evaluation, BMJ, 328, 1102, 2004

Ref Id
707353

Country/ies where the study was carried out
United Kingdom

Study type</td>
<td>**Characteristics**
Carer characteristics:
• Age: Median (IQR): Intervention 76 (70-80) years, Control 76 (70-82) years
• Gender: Intervention (n): 86/151, Control (n):74/149
• Relationship to care recipient: main caregiver - spouse, intervention n =98 and control n=97
• Living with care recipient: NR
Care recipient (condition)
• Stroke</td>
<td>skill based practical support for carers
Name of the Intervention (as named in the paper) - Care giver training
Control (according to the protocol)- No intervention
Name of control (as named in the paper) - Conventional care

Mode of delivery
• Unclear if group or individual
• Face-to-face
• Information
• Stroke rehabilitation unit setting,</td>
<td>randomisation; each block included 10 subjects. Computer generated random numbers to prepare the allocation schedule in advance. Allocation codes were held in a central office remote from the study environment. After baseline assessment the responsible assessor telephone the randomisation office with patient identification details only, clerical worker entered this onto a computer</td>
<td>
<table>
<tr><th></th><th>n</th><th>Median</th><th>IQR</th><th>n</th><th>Median</th><th>IQR</th><th>n</th><th>Median</th><th>IQR</th><th>n</th><th>Median</th><th>IQR</th></tr>
<tr><td>Impact of caring on carer: EuroQol visual analogue score</td><td>151</td><td>90</td><td>80-95</td><td>140</td><td>80</td><td>71-90</td><td>149</td><td>85</td><td>80-90</td><td>142</td><td>70</td><td>60-80</td></tr>
<tr><td>Impact of caring on carer: Caregiver burden scale</td><td>NR</td><td>NR</td><td>NR</td><td>151</td><td>43</td><td>36-54</td><td>NR</td><td>NR</td><td>NR</td><td>149</td><td>51</td><td>41-62</td></tr>
</table>

At 12 months follow-up
<table>
<tr><th></th><th colspan="3">Baseline Intervention</th><th colspan="3">12 month Follow-up Intervention</th><th colspan="3">Baseline Control</th><th colspan="3">12 month Follow-up Control</th></tr>
<tr><td></td><td>n</td><td>Median</td><td>IQR</td><td>n</td><td>Median</td><td>IQR</td><td>n</td><td>Median</td><td>IQR</td><td>n</td><td>Median</td><td>IQR</td></tr>
<tr><td>Impact of caring on carer: EuroQol visual analogue score</td><td>151</td><td>90</td><td>80-95</td><td>129</td><td>80</td><td>70-90</td><td>149</td><td>85</td><td>80-90</td><td>135</td><td>70</td><td>60-80</td></tr>
<tr><td>Impact of caring on carer: Caregiver burden scale</td><td>NR</td><td>NR</td><td>NR</td><td>140</td><td>32</td><td>27-41</td><td>NR</td><td>NR</td><td>NR</td><td>143</td><td>41</td><td>36-50</td></tr>
<tr><td>Impact of caring on carer: Frenchay activities index</td><td>151</td><td>27</td><td>24-32</td><td>150</td><td>27</td><td>23-30</td><td>149</td><td>28</td><td>25-32</td><td>148</td><td>26</td><td>24-30</td></tr>
<tr><td>Caring-related</td><td>NR</td><td>NR</td><td>NR</td><td>141</td><td>3</td><td>2-4</td><td>NR</td><td>NR</td><td>NR</td><td>143</td><td>4</td><td>3-6</td></tr>
</table>
</td>
<td>**tool for randomized trials)**
• Random sequence generation- Low risk
• Allocation concealment - low risk
• Blinding of participants and personnel - single, outcome assessor blind. Unclear risk if personnel were blinded.
• Incomplete outcome data - low risk. <10% differential between arms.
• Selective outcome reporting - Frenchay</td>
</tr>
</table>

<table>
<thead>
<tr><th>Study details</th><th>Participants</th><th>Interventions</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
</thead>
<tbody>
<tr>
<td>Single blind, 2 groups RCT

Aim of the study
To evaluate the effectiveness of training care givers in reducing burden of stroke in patients and their care givers.

Study dates
Publication date: 2004
Data collection: N/R

Source of funding
The project was funded by NHS R&D Executive's Primary Secondary Interface Priority Programme (Project No:F-4/1997). No competing interests were declared.</td>
<td>Inclusion criteria
People who’d had a stroke were included if they were:
Independent in daily living activities before the stroke
medically and neurologically stable at the time of baseline assessments
expected to return home with residual disability (defined as the need for supervision or physical assistance for core activities of daily living)
Caregivers were required to have no notable disability</td>
<td>1 follow through session at home</td>
<td>database in strict referral order and was given patient allocation to relay to assessor.
Blinding methods - Single blind. Observer who did not participate in allocation or management of the patients assessed outcome at 3 and 12 months after stroke onset.
Follow-up outcome measurement - 3 and 12 months post stroke.
Sample size statistical power: Inclusion of 300 subjects, 80% power to</td>
<td>
<table>
<tr><td>morbidity: Hospital anxiety score</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Caring-related morbidity: Hospital depression score</td><td>NR</td><td>NR</td><td>NR</td><td>141</td><td>2</td><td>1-3</td><td>NR</td><td>NR</td><td>NR</td><td>143</td><td>3</td><td>2-5</td></tr>
</table>
Additional outcomes reported: death, institutionalisation, modified Rankin scale, Barthel index (all for the patients)
Note: analysis stated to be done by ITT with LOCF used in further analyses. However, the paper describes 'we included in the analyses only completed assessments at each time point. n values in the tables above show those who had follow-up data reported at each time point.
Regression analysis: training care givers had a highly significant effect on caregiver burden score, EuroQol and hospital anxiety and depression score at 12 months which was independent of age, stroke severity, extent of disability and caregiver support. Data not provided.</td>
<td>activities index and hospital anxiety and depression scales were only reported at 12 months. Unclear but in methods it states that outcomes were assessed at 3 and 12 months. Length of stay mention in statistical analysis but not reported. Methods include calculation of means and SD - these were not reported in the results tables, only the median and</td>
</tr>
</tbody>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
	(defined as a Rankin score of 0-2) and be willing and able to provide support after discharge. **Exclusion criteria** None described.		detect 30% reduction in cost at 5% significance level. Could also detect differences of 1 point in Barthel index, 1.5 points in Frenchay activities index, 1.5 points in the hospital anxiety and depression scale, 2.5 point in the EuroQol and 1 point in the caregiver burden scale.		interquartile ranges. - Other risk of bias – none **Overall RoB** - very serious **Other information** 75 patients in each group were said to have received caregiver support consisting of a family worker who provided information on services, link with social agencies, advocacy and emotional support for up to 6 months after discharge. Regression analysis was used to asses the confounding

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
					effect of this and other baseline variables (age, extent of disability).

F: Female; F/U: Followup; IQR: Inter quartile range; ITT: Intention to treat analysis; LOCF: Last observation carried forward; M: Male; N/n: Number/number in subgroup; NR: Not reported; RCT: Randomised controlled trial; RoB: Risk of Bias; RQ: Research Question; SD: Standard deviation; SRU: Stroke rehabilitation unit; TAU: Treatment as usual.

Qualitative component of the review

Table 7: Evidence tables for the qualitative studies

Study details	Participants	Interventions	Methods	Themes and Findings	Comments
Full citation Cobley, C. S., Fisher, R. J., Chouliara, N., Kerr, M., Walker, M. F., A qualitative study exploring patients' and carers' experiences of Early Supported Discharge services after stroke, Clinical rehabilitation, 27, 750-757, 2013 **Ref Id** 722100 **Country/ies where the study was carried out** UK - England (Nottingham) **Study type** qualitative study (peer-reviewed) **Aim of the study** The aims of this qualitative study were to explore the carers' experiences of 'Early Supported Discharge' services for stroke patients in the UK, and inform future	**Sample size** N=15 **Characteristics** **Carer** • Carer age - years = Mean (SD): 72.8 (14.1) • Carer gender (M/F:n)= 2/13 • Relationship to care recipient= N/R (the majority of carers within the study were female spouses) **Professionals** • N/A **Care recipient** • Care recipient (condition)= stroke **Inclusion criteria**	**Interventions** • Phenomenon of interest (as reported in the study): Carers' experiences of the Supported Discharge - Home rehabilitation • Phenomenon of interest (according to the protocol): RQF - Practical support	**Details** • **Recruitment strategy**: Carers were recruited purposively from 2 stroke units in the Nottinghamshire region. Further details on how carers were recruited are not reported. • **Data collection & analysis**: Data were collected through (face-to-face) semi-structured interviews (duration ranged from 30 to 45 minutes). Interviews were conducted in the patients' usual place of residence within 1 and 6 months of hospital discharge and continued until data saturation was reached. All interviews were audio-taped, and transcribed. Interview	**Findings** Carers' experiences of the Supported Discharge - Home rehabilitation: • 'Time not being a carer' • 'Limited support in dealing with carer strain' • 'Lack of education and training of carers' • 'Inadequate provision and delivery of information'	**Limitations (assessed using the CASP checklist for qualitative studies)** • **Q1: Was there a clear statement of the aims of the research?** - Yes • **Q2: Was a qualitative methodology appropriate?** - Yes • **Q3 Was the research design appropriate to address the aims of the research?** - Yes • **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Yes • **Q5: Were the data collected in a way that addressed the research issue?** - Yes • **Q6: Has the relationship between researcher and participants been adequately considered?** - Yes

Study details	Participants	Interventions	Methods	Themes and Findings	Comments
Early Supported Discharge service development and provision. **Study dates** - **Publication date**: 2013 - **Data collection**: N/R **Source of funding** This is a CLAHRC study funded by the National Institute for Health Research. This article presents independent research commissioned by the National Institute for Health Research (NIHR).	Carers of people with a confirmed diagnosis of stroke: 1) with a Barthel Index ≥ 14/20; 2) within 14 days of stroke onset; 3) transferred independently or with assistance of one; 4) with identified rehabilitation goals; 5) their hospital consultant agreed they were medically stable. Carers of people with stroke who were referred to an Early Supported Discharge service, carers of people with stroke who met the inclusion criteria but did not get referred to an Early Supported Discharge service, were recruited to the study. **Exclusion criteria** N/R (look at the inclusion criteria)		data were analysed using inductive thematic analysis performed in parallel by 2 researchers.		- **Q7: Have ethical issues been taken into consideration?** - Yes - **Q8: Was the data analysis sufficiently rigorous?** - Yes - **Q9: Is there a clear statement of findings?** - Yes - **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** – Yes **Overall methodological concerns** - Minor

Study details	Participants	Interventions	Methods	Themes and Findings	Comments
Full citation Davies Sue, Nolan Mike, 'Making the move': relatives' experiences of the transition to a care home, Health and Social Care in the Community, 12, 517-526, 2004 **Ref Id** 715758 **Country/ies where the study was carried out** UK - England (Sheffield) **Study type** qualitative study (peer-reviewed) **Aim of the study** The aim of this qualitative study was to explore experiences of nursing home placement from the viewpoint of carers of older people, around the time of the transition, in order to enable nurses and other healthcare practitioners to better meet their needs.	**Sample size** N=48 **Characteristics** **Carer** - Carer age = Range, years: 45 - 84 - Carer gender (M/F:n)= 21/27 - Relationship to care recipient= parents (n): 0; spouses (n): 11; daughters-sons (n): 33; sibling (n): 0; other/undisclosed (n): 4 (adult niece, nephew or friend) **Professionals** - N/A **Care recipient** - Care recipient (condition)= people admitted to nursing homes (no condition specific)	**Interventions** - Phenomenon of interest (as reported in the study): Carers' experiences of the transition to a care home - Phenomenon of interest (according to the protocol): RQF - Practical support	**Details** - **Recruitment strategy**: A convenience sample of carers was recruited using a range of strategies: 1. Contact with nursing home managers (N=20); 2. Advertisement in local newspaper (N=6); 3. Contacts made on visits to nursing homes (N=3); 4. Advertisement in carers' newsletter (N=3); 5. Sheffield Transitional Care Forum (N=3); and 6. Local branch of Relatives' Association (N=2). The recruitment happened in the Sheffield area. Further details on how carers were recruited are not reported. - **Data collection & analysis**: Data were collected	**Findings** Carers' experiences of the transition to a care home: - 'No pressure/feeling under pressure' - 'Working together/working apart' - 'Feeling supported/feeling unsupported' - 'Being in the know/working in the dark' - 'Being in control/losing control'	**Limitations (assessed using the CASP checklist for qualitative studies)** - **Q1: Was there a clear statement of the aims of the research?** - Yes - **Q2: Was a qualitative methodology appropriate?** - Yes - **Q3 Was the research design appropriate to address the aims of the research?** - Yes - **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Unclear: a convenience sample of carers was recruited, unclear appropriateness to the aims of the research - **Q5: Were the data collected in a way that addressed the research issue?** - Unclear: Theoretical sufficiency/ saturation of data has not been discussed

Study details	Participants	Interventions	Methods	Themes and Findings	Comments
Study dates • **Publication date**: 2004 • **Data collection**: N/R **Source of funding** N/R	**Inclusion criteria** Carers of people who had experienced admission to a nursing home. No further details have been reported **Exclusion criteria** N/R (look at the inclusion criteria)		through (face-to-face) semi-structured interviews. Interviews were conducted in the patients' usual place of residence, with 1 interview took that place at the participant's place of work and 1 in a cafe. All were tape-recorded and later transcribed. All interviews were audio-taped, and transcribed. Interview data were analysed using inductive constructivist method, and comprised 4 steps (Rodwell 1998): 1. Unitising – locating units of meaning within the text; 2. Categorising – taking all the units of data and sorting them into categories of ideas; 3. Filling in patterns – searching for convergent and divergent opinion and		• **Q6: Has the relationship between researcher and participants been adequately considered?** - Yes • **Q7: Have ethical issues been taken into consideration?** - Yes • **Q8: Was the data analysis sufficiently rigorous?** - Unclear: no sufficient details on data analysis methods are reported • **Q9: Is there a clear statement of findings?** - Yes • **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological concerns** - Moderate

Study details	Participants	Interventions	Methods	Themes and Findings	Comments
			seeking explanations for these discrepancies; and 4. Member checks – feeding back the categorisation to participants. Analysis was performed in parallel by 2 researchers. - No details on data saturation/sufficiency were reported		
Full citation Ryan, Assumpta, McKenna, Hugh, Slevin, Oliver, Family care-giving and decisions about entry to care: a rural perspective, Ageing and Society, 32, 1-18, 2012 **Ref Id** 722477 **Country/ies where the study was carried out** UK - Northern Ireland **Study type** Qualitative study (peer-reviewed)	**Sample size** N=29 **Characteristics** **Carer** - Carer age = Range, years: N/R - Carer gender (M/F:n)= N/R - Relationship to care recipient= parents (n): 0; spouses (n): 3; daughters-sons (n): 22; sibling (n): 0; other/undisclosed	**Interventions** - Phenomenon of interest (as reported in the study): Carers' experiences of the nursing home placement. - Phenomenon of interest (according to the protocol): RQF - Practical support	**Details** - **Recruitment strategy**: Carers were recruited purposively in a number of ways through newspaper advertisements, notices in nursing homes and through direct contact with nursing home managers who agreed to administer information packs about the study to relatives of residents who were placed in the home within the previous 18 months.	**Findings** Carers' experiences of the nursing home placement: - 'No place like home' - 'Carer advocate' - 'Choosing a home: a foregone conclusion' - 'Rurality' - 'Familiarity'	**Limitations (assessed using the CASP checklist for qualitative studies)** - **Q1: Was there a clear statement of the aims of the research?** - Yes - **Q2: Was a qualitative methodology appropriate?** - Yes - **Q3 Was the research design appropriate to address the aims of the research?** - Yes - **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Yes

Study details	Participants	Interventions	Methods	Themes and Findings	Comments
Aim of the study The aims of this qualitative study were to explore the rural family carers' experiences of the nursing home placement of an older person. **Study dates** - **Publication date**: 2012 - **Data collection**: 2003 to 2006 **Source of funding** N/R	(n): 4 (niece, nephew) **Professionals** - None **Care recipient** - Care recipient (condition)= Stroke, dementia and immobility (no condition specific) **Inclusion criteria** N/R **Exclusion criteria** N/R		Purposive sampling was used to initiate data collection and thereafter theoretical sampling was employed. The recruitment happened in a large Health and Social Care Trust in Northern Ireland. Further details on how carers were recruited are not reported. - **Data collection & analysis**: Data were collected through (face-to-face) semi-structured interviews. The interviews were conducted at a time and place convenient for participants and theoretical sampling continued until the emerging concepts and categories reached saturation. All interviews were audio-taped, and transcribed. Interview		- **Q5: Were the data collected in a way that addressed the research issue?** - Yes - **Q6: Has the relationship between researcher and participants been adequately considered?** - Yes - **Q7: Have ethical issues been taken into consideration?** - Yes - **Q8: Was the data analysis sufficiently rigorous?** - Yes - **Q9: Is there a clear statement of findings?** - Yes - **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological concerns** - Minor

Study details	Participants	Interventions	Methods	Themes and Findings	Comments
			data were analysed using a constant comparative analysis following the 'Paradigm model' (Strauss and Corbin 1990-1998). Analysis was performed in parallel by 2 researchers, until data saturation. The constant comparison of emerging data facilitated the verification of findings and minimised the likelihood of personal bias (in this case data emerging inductively were confirmed deductively by further theoretically sampled data, including literature)		
Full citation Salisbury, L., Wilkie, K., Bulley, C., Shiels, J., 'After the stroke': Patients' and carers' experiences of healthcare after stroke in Scotland, Health and Social	**Sample size** N=9 **Characteristics** **Carer** • Carer age = Range, years: 57 - 73	**Interventions** • Phenomenon of interest (as reported in the study): Carers' experiences of healthcare after stroke - Functional	**Details** • **Recruitment strategy**: Carers who had attended an FES outpatient clinic for more than 6 months were recruited purposively (to take	**Findings** Carers' experiences of healthcare after stroke - Functional Electrical Stimulation Clinic:	**Limitations (assessed using the CASP checklist for qualitative studies)** • **Q1: Was there a clear statement of the aims of the research?** - Yes

Study details	Participants	Interventions	Methods	Themes and Findings	Comments
Care in the Community, 18, 424-432, 2010 **Ref Id** 718224 **Country/ies where the study was carried out** UK - Scotland (Edinburgh) **Study type** qualitative study (peer-reviewed) **Aim of the study** The aim of this qualitative study was to explore the carers' perceptions of a Functional Electrical Stimulation (FES) out-patient Clinic. **Study dates** - **Publication date**: 2010 - **Data collection**: April to May 2007 **Source of funding** This study was funded by a pump priming grant from	- Carer gender (M/F:n)= 2/16 - Relationship to care recipient= parents (n): 0; spouses (n): 9; daughters-sons (n): 0; sibling (n): 0; other/undisclosed (n): 0 **Professionals** - N/A **Care recipient** - Care recipient (condition)= stroke **Inclusion criteria** N/R ("…some of the carers approached and included in the study looked after relatives with marked communication difficulties." page 425) **Exclusion criteria** N/R (look at the inclusion criteria)	Electrical Stimulation (FES) Clinic. - Phenomenon of interest (according to the protocol): RQF - Practical support	into account the mobility level at the initial clinic assessment and time since stroke). Further details on how carers were recruited are not reported. - **Data collection & analysis**: Data were collected through (face-to-face) semi-structured interviews. All interviews were audio-taped, and transcribed. Interview data were analysed using the framework of Interpretative Phenomenological Analysis (IPA). To enhance the trustworthiness of data, the research team met to review and discuss the coding of the transcripts. Subsequent agreed codes were applied to	- 'What is wrong?' - 'In the hospital' - 'I'm taking them home' - 'Back at home'	- **Q2: Was a qualitative methodology appropriate?** - Yes - **Q3 Was the research design appropriate to address the aims of the research?** - Yes - **Q4: Was the recruitment strategy appropriate to the aims of the research?** - Yes - **Q5: Were the data collected in a way that addressed the research issue?** - Unclear: Theoretical sufficiency/ saturation of data has not been discussed - **Q6: Has the relationship between researcher and participants been adequately considered?** - Unclear: unclear description about relationship between researcher and carers during data collection and analysis - **Q7: Have ethical issues been taken into consideration?** - Yes

Study details	Participants	Interventions	Methods	Themes and Findings	Comments
the Centre for Integrated Healthcare Research.			all transcripts - No details on data saturation/sufficiency were reported		• **Q8: Was the data analysis sufficiently rigorous?** - Unclear: insufficient details on data analysis methods are reported • **Q9: Is there a clear statement of findings?** - Yes • **Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)** - Yes **Overall methodological concerns** - Minor

F: Female; M: Male; N/n: Number/number in subgroup; N/R: Not reported; RQ: Research Question; SD: Standard deviation;

Appendix E – Forest plots

Forest plots for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult cares during: (i) changes to the setting in which caring is performed; (ii) the transition of the person receiving care to adulthood; and (iii) change of carer status or circumstances?

No meta-analysis was undertaken for this review and so there are no forest plots.

Appendix F – GRADE tables

GRADE tables for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult cares during: (i) changes to the setting in which caring is performed; (ii) the transition of the person receiving care to adulthood; and (iii) change of carer status or circumstances?

Work, education and training [Relating to RQD]

No quantitative evidence was identified about this intervention category

Training to provide practical support [Relating to RQE]

Table 8: Educational/skill based training for supporting adult carers

Quality assessment							Number of people		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Intervention (Educational/ skill based training for adult carers)	Control	Relative (95% CI)	Absolute		
Caring- related morbidity: Hospital anxiety score (HADS) at 12 months (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	141	143	-	Intervention[16]: 3 (2-4) Control[16]: 4 (3-6)	VERY LOW	CRITICAL
Caring- related morbidity: Hospital Anxiety Score (HADS) at 6 months follow-up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	318	334	-	MD 0.5 lower (1.14 lower to 0.14 higher)	LOW	CRITICAL

Quality assessment							Number of people		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Intervention (Educational/ skill based training for adult carers)**	**Control**	**Relative (95% CI)**	**Absolute**		
Caring- related morbidity: Hospital Anxiety Score (HADS) at 12 months follow-up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	286	311	-	MD 0.1 lower (0.82 lower to 0.62 higher)	LOW	CRITICAL
Caring- related morbidity: Hospital Depression Score (HADS) at 6 months follow-up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	318	334	-	MD 0.3 lower (0.91 lower to 0.31 higher)	LOW	CRITICAL
Caring- related morbidity: Hospital Depression score (HADS) at 12 months (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	141	143	-	Intervention[16]: 2 (1-3) Control[16]: 3 (2-5)	VERY LOW	CRITICAL
Caring- related morbidity: Hospital Depression Score (HADS) at 12 months follow-up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	286	312	-	MD 0 higher (0.61 lower to 0.61 higher)	LOW	CRITICAL
Caring-related morbidity: Caregiver Death at 6 months follow-up from baseline												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	2/450	1/478	RR 2.12 (0.19 to 23.35)	2 more per 1000 (from 2 fewer to 47 more)	LOW	CRITICAL
Caring-related morbidity: Caregiver Death at 12 months follow-up from baseline												

Quality assessment							Number of people		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Intervention (Educational/ skill based training for adult carers)	Control	Relative (95% CI)	Absolute		
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	6/450	4/478	RR 1.59 (0.45 to 5.61)	5 more per 1000 (from 5 fewer to 39 more)	LOW	CRITICAL
Impact of caring on carer: EuroQol visual analogue score at 3 months (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	140	142	-	Intervention[16]: 80 (71-90) Control[16]: 70 (60-80)	VERY LOW	CRITICAL
Impact of caring on carer: EuroQol visual analogue score at 6 months follow-up from baseline (Better indicated by higher values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	317	333	-	MD 0.01 lower (0.04 lower to 0.02 higher)	LOW	CRITICAL
Impact of caring on carer: EuroQol visual analogue score at 12 months (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	129	135	-	Intervention[16]: 80 (70-90) Control[16]: 70 (60-80)	VERY LOW	CRITICAL
Impact of caring on carer: EuroQol visual analogue score at 12 months follow-up from baseline, Cluster RCT (Better indicated by higher values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	284	312	-	MD 0.02 higher (0.01 lower to 0.05 higher)	LOW	CRITICAL

Quality assessment							Number of people		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Intervention (Educational/ skill based training for adult carers)**	**Control**	**Relative (95% CI)**	**Absolute**		
Impact of caring on carer: Caregiver burden scale at 3 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	151	149	-	Intervention[16]: 43 (36-54) Control[16]: 51 (41-62)	VERY LOW	CRITICAL
Impact of caring on carer: Caregiver burden scale at 6 months follow-up from baseline (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	325	340	-	MD 0.5 higher (1.8 lower to 2.8 higher)	LOW	CRITICAL
Impact of caring on carer: Caregiver burden scale at 12 months (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	140	143	-	Intervention[16]: 32 (27-41) Control[16]: 41 (36-50)	VERY LOW	CRITICAL
Impact of caring on carer: Caregiver burden scale at 12 months follow-up from baseline, Cluster RCT (Better indicated by lower values)												
1[4]	randomised trials	serious[5]	no serious inconsistency	no serious indirectness	serious[6]	none	291	314	-	MD 1 higher (1.67 lower to 3.67 higher)	LOW	CRITICAL
Carer skills, knowledge/confidence or efficacy about supporting person receiving care : Confidence (15 item Self Efficacy Scale) at 3 months follow-up from end of intervention (Better indicated by higher values)												
1[13]	randomised trials	very serious[14]	no serious inconsistency	no serious indirectness	serious[6]	none	62	49	-	MD 1.87 higher (1.62	VERY LOW	CRITICAL

Quality assessment							Number of people		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Intervention (Educational/ skill based training for adult carers)**	**Control**	**Relative (95% CI)**	**Absolute**		
										lower to 5.36 higher)		
Carer skills, knowledge/confidence or efficacy about supporting person receiving care : Preparedness (8 item Preparedness for Caregiving Scale) at 3 months follow-up from end of intervention (Better indicated by higher values)												
1[13]	randomised trials	very serious[14]	no serious inconsistency	no serious indirectness	no serious imprecision	none	62	49	-	MD 3.31 higher (1 to 5.62 higher)	LOW	CRITICAL
Carer skills, knowledge/confidence or efficacy about supporting person receiving care : Self - Efficacy (Revised Scale for Caregiving Self-Efficacy) at 3 months follow-up from end of intervention (Better indicated by higher values)												
1[13]	randomised trials	very serious[14]	no serious inconsistency	no serious indirectness	serious[6]	none	62	49	-	MD 3.57 higher (2.51 lower to 9.65 higher)	VERY LOW	CRITICAL
Carer skills, knowledge/confidence or efficacy about supporting person receiving care : Knowledge of future needs (Planning for Future Needs Scale) at 3 months follow-up from end of intervention (Better indicated by higher values)												
1[13]	randomised trials	very serious[14]	no serious inconsistency	no serious indirectness	serious[6]	none	62	49	-	MD 1.32 higher (1.14 lower to 3.78 higher)	VERY LOW	CRITICAL
Carer skills, knowledge/confidence or efficacy about supporting person receiving care : Knowledge of services (The Knowledge of Services Scale) at 3 months follow-up from end of intervention (Better indicated by higher values)												
1[13]	randomised trials	very serious[14]	no serious inconsistency	no serious indirectness	no serious imprecision	none	62	49	-	MD 2.98 higher (0.39	LOW	CRITICAL

Quality assessment							Number of people		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Intervention (Educational/ skill based training for adult carers)**	**Control**	**Relative (95% CI)**	**Absolute**		
										to 5.57 higher)		
Carer skills, knowledge/confidence or efficacy about supporting person receiving care : Preparedness (8 item Preparedness for Caregiving Scale) at 6 months follow-up from end of intervention (Booster versus control)												
1[18]	randomised trials	very serious[19]	no serious inconsistency	no serious indirectness	no serious imprecision	serious[20]	17/31	8/29	RR 1.99 (1.02 to 3.89)	273 more per 1000 (from 6 more to 797 more)	LOW	CRITICAL
Carer skills, knowledge/confidence or efficacy about supporting person receiving care : Self - Efficacy (Revised Scale for Caregiving Self-Efficacy) at 6 months follow-up from end of intervention (Booster versus control)												
1[18]	randomised trials	very serious[19]	no serious inconsistency	no serious indirectness	no serious imprecision	serious[20]	15/28	6/27	RR 2.41 (1.10 to 5.29)	313 more per 1000 (from 22 more to 953 more)	LOW	CRITICAL
Caring-related morbidity: Psychological distress (Psychological Distress Index) at 6 months follow-up from end of intervention (Booster versus control)												
1[18]	randomised trials	very serious[19]	no serious inconsistency	no serious indirectness	serious[6]	serious[20]	15/31	8/29	RR 1.75 (0.88 to 3.51)	207 more per 1000 (from 33 fewer to 692 more)	VERY LOW	CRITICAL
Carer skills, knowledge/confidence or efficacy about supporting person receiving care : Preparedness (8 item Preparedness for Caregiving Scale) at 6 months follow-up from end of intervention (Non-Booster versus control)												

Quality assessment							Number of people		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Intervention (Educational/ skill based training for adult carers)**	**Control**	**Relative (95% CI)**	**Absolute**		
1[18]	randomised trials	very serious[19]	no serious inconsistency	no serious indirectness	serious[6]	serious[20]	12/29	8/29	RR 1.50 (0.72 to 3.12)	138 more per 1000 (from 77 fewer to 585 more)	VERY LOW	CRITICAL
Carer skills, knowledge/confidence or efficacy about supporting person receiving care : Self - Efficacy (Revised Scale for Caregiving Self-Efficacy) at 6 months follow-up from end of intervention (Non-Booster versus control)												
1[18]	randomised trials	very serious[19]	no serious inconsistency	no serious indirectness	serious[6]	serious[20]	13/29	6/27	RR 2.02 (0.89 to 4.55)	227 more per 1000 (from 24 fewer to 789 more)	VERY LOW	CRITICAL
Caring-related morbidity: Psychological distress (Psychological Distress Index) at 6 months follow-up from end of intervention (Non-Booster versus control)												
1[18]	randomised trials	very serious[19]	no serious inconsistency	no serious indirectness	no serious imprecision	serious[20]	16/29	8/29	RR 2.00 (1.02 to 3.93)	276 more per 1000 (from 6 more to 808 more)	LOW	CRITICAL

1 Kalra 2004.
2 The quality of the evidence was downgraded by 2 levels level due to selective outcome reporting.
3 The quality of evidence was downgraded by 1 level as it was not possible to judge the precision of the estimates of effect (due to results being presented as medians and interquartile differences)
4 Forster 2013
5 The quality of the evidence was downgraded by 1 level due to insufficient statistical power.
6 Non-significant result (Any statistically significant change was considered to be important for carers - for any outcome where published MIDs were not identified)
7 Leavey 2004
8 The quality of the evidence was downgraded by 1 level for selective outcome reporting (no mean/SD reported) and no carer baseline data.
9 The quality of the evidence was downgraded by 1 - imprecision was not assessable due to results being presented as model outputs

10 Keeping Burke 2013
11 The quality of the evidence was downgraded by 1 level for selective outcome reporting and limited baseline characteristics
12 The quality of the evidence was downgraded by 1 - imprecision was not assessable due to results being presented as primarily p values
13 Ducharme 2011
14 The quality of the evidence was downgraded by 2 levels due to the unclear method of randomisation and allocation concealment, high differential in attrition between the treatment groups and no statistical power calculation described.
15 All the caregiver resources have been grouped under 1 broad heading for the purpose of GRADE due to all resources having the same quality assessment. The data was not quantitatively analysed in the paper: "Resource-use differences were not compared statistically, firstly because the economic evaluation was focused on costs and cost-effectiveness and, secondly, to avoid problems associated with multiple testing." The resource data is therefore reported narratively.
16 Findings were reported only with median and interquartile ranges
17 Rating the overall certainty in evidence in the absence was not feasible (as for the impossibility to judge the precision of the estimates of effect)
18 Ducharme 2015
19 The quality of the evidence was downgraded by 2 levels due to high differential in attrition between the treatment groups and no statistical power calculation described.
20 The quality of the evidence was further downgraded by 1 level due to the unclear randomization of the carers for this outcome: This is a follow-up booster session study to Ducharme 2011. The intervention group were randomised again (not the control) to the booster and non-booster groups.

Practical support [Relating to RQF]

Table 9: Self guided, tailored support for carers of stroke survivors

Quality assessment							Number of people		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Intervention (Carers' needs tailored and self-guided programme)**	**Control (standard care)**	**Relative (95% CI)**	**Absolute**		
Caring-related morbidity: Depression (CESD-20) at 1 month follow-up from stroke (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	sserious imprecision[3]	none	10	10	-	Intervention[4]: 18.9 (12, 27) Control[4]: 19.5 (7, 23.8)	VERY LOW	CRITICAL
Caring-related morbidity: Depression (CESD-20) at 3 month follow-up from stroke (Better indicated by lower values)												

Quality assessment							Number of people		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Intervention (Carers' needs tailored and self-guided programme)**	**Control (standard care)**	**Relative (95% CI)**	**Absolute**		
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	10	10	-	Intervention[4]: 13.5 (8.5, 16.4) Control[4]: 14 (3.8, 19.8)	VERY LOW	CRITICAL
Caring-related morbidity: Depression (CESD-20) at 6 month follow-up from stroke (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	10	10	-	Intervention[4]: 11.6 (8.8, 18.3) Control[4]: 8 (5, 23)	VERY LOW	CRITICAL
Caring-related morbidity: Psychological well-being (Positive Affect Scale) at 1 month follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	10	10	-	Intervention[4]: 34 (33, 44) Control[4]: 33 (20.5, 38)	VERY LOW	CRITICAL
Caring-related morbidity: Psychological well-being (Positive Affect Scale) at 3 months follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	10	10	-	Intervention[4]: 39 (32.8, 42.5) Control[4]: 37 (27, 41.8)	VERY LOW	CRITICAL
Caring-related morbidity: Psychological well-being (Positive Affect Scale) at 6 months follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	10	10	-	Intervention[4]: 37.5 (31.8, 43.8)	VERY LOW	CRITICAL

Quality assessment							Number of people		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Intervention (Carers' needs tailored and self-guided programme)**	**Control (standard care)**	**Relative (95% CI)**	**Absolute**		
										Control[4]: 36 (34,41)		
Social capital: Social support (Medical Outcomes Study Social Support Scale -20 item) at 1 month follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	10	10	-	Intervention[4]: 75.8 (72.7, 88.8) Control[4]: 71.0 (55.3, 82.8)	VERY LOW	IMPORTANT
Social capital: Social support (Medical Outcomes Study Social Support Scale -20 item) at 3 months follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	10	10	-	Intervention[4]: 78.6 (59.2, 93.6) Control[4]: 64.5 (50.5, 88.6)	VERY LOW	IMPORTANT
Social capital: Social support (Medical Outcomes Study Social Support Scale -20 item) at 6 months follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	10	10	-	Intervention[4]: 68.5 (46.9, 75.9) Control[4]: 75.2 (54.8, 98.0)	VERY LOW	IMPORTANT
Carer choice/control/efficacy: Mastery (Pearlins 7 item Mastery Scale) at 1 month follow-up from stroke (Better indicated by higher values)												

Quality assessment							Number of people		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Intervention (Carers' needs tailored and self-guided programme)**	**Control (standard care)**	**Relative (95% CI)**	**Absolute**		
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	10	10	-	Intervention[4]: 19 (16, 20) Control[4]: 18 (17.3, 19)	VERY LOW	IMPORTANT
Carer choice/control/efficacy: Mastery (Pearlins 7 item Mastery Scale) at 3 months follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	10	10	-	Intervention[4]: 19 (18, 19.8) Control[4]: 18 (16.8, 21)	VERY LOW	IMPORTANT
Carer choice/control/efficacy: Mastery (Pearlins 7 item Mastery Scale) at 6 months follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	10	10	-	Intervention[4]: 19 (18,21) Control[4]: 17 (17, 19)	VERY LOW	IMPORTANT

1 Cameron 2015

2 the quality of the evidence is downgraded by 2 levels due to the unclear method of randomisation and allocation concealment, high attrition rate and differential between arms and selective outcome reporting.

3 The quality of evidence was downgraded by 1 level as it was not possible to judge the precision of the estimates of effect (due to results being presented as medians and interquartile differences)

4 Findings were reported only with median and interquartile ranges

Table 10: Stroke support person-focused intervention for supporting adult carers

Quality assessment							Number of people		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Intervention (Stroke support person-focused intervention)	Control (standard care)	Relative (95% CI)	Absolute		
Caring-related morbidity: Depression (CESD-20) at 1 month follow-up from stroke (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 16 (9, 24) Control[4]: 20 (7, 24)	VERY LOW	CRITICAL
Caring-related morbidity: Depression (CESD-20) at 3 month follow-up from stroke (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 11 (2, 21) Control[4]: 14 (4, 20)	VERY LOW	CRITICAL
Caring-related morbidity: Depression (CESD-20) at 6 month follow-up from stroke (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 12 (7, 24) Control[4]: 8 (5, 23)	VERY LOW	CRITICAL
Caring-related morbidity: Psychological well-being (Positive Affect Scale) at 1 month follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 32 (26, 38) Control[4]: 33 (20.5, 38)	VERY LOW	CRITICAL
Caring-related morbidity: Psychological well-being (Positive Affect Scale) at 3 months follow-up from stroke (Better indicated by higher values)												

Quality assessment							Number of people		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Intervention (Stroke support person-focused intervention)**	**Control (standard care)**	**Relative (95% CI)**	**Absolute**		
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 43 (33, 49) Control[4]: 37 (27, 42)	VERY LOW	CRITICAL
Caring-related morbidity: Psychological well-being (Positive Affect Scale) at 6 months follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 37 (31, 43) Control[4]: 36 (34, 41)	VERY LOW	CRITICAL
Social capital: Social support (Medical Outcomes Study Social Support Scale -20 item) at 1 month follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 82 (67, 90) Control[4]: 71 (55, 83)	VERY LOW	IMPORTANT
65												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 76 (62, 100) Control[4]: 65 (51, 89)	VERY LOW	IMPORTANT
Social capital: Social support (Medical Outcomes Study Social Support Scale -20 item) at 6 months follow-up from stroke (Better indicated by higher values)												

Quality assessment							Number of people		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Intervention (Stroke support person-focused intervention)**	**Control (standard care)**	**Relative (95% CI)**	**Absolute**		
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 90 (65, 96) Control[4]: 76 (55, 98)	VERY LOW	IMPORTANT
Carer choice/control/efficacy: Mastery (Pearlins 7 item Mastery Scale) at 1 month follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 19 (17, 21) Control[4]: 18 (18, 19)	VERY LOW	IMPORTANT
Carer choice/control/efficacy: Mastery (Pearlins 7 item Mastery Scale) at 3 months follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 19 (18, 21) Control[4]: 18 (17, 21)	VERY LOW	IMPORTANT
Carer choice/control/efficacy: Mastery (Pearlins 7 item Mastery Scale) at 6 months follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 20 (18, 22) Control[4]: 17 (17,19)	VERY LOW	IMPORTANT

1 Cameron 2015

2 the quality of the evidence is downgraded by 2 levels due to the unclear method of randomisation and allocation concealment, high attrition rate and differential between arms and selective outcome reporting.

3 The quality of evidence was downgraded by 1 level as it was not possible to judge the precision of the estimates of effect (due to results being presented as medians and interquartile differences)

4 Findings were reported only with median and interquartile ranges

Table 11: Carers' needs tailored stroke support self-guided versus person-focused intervention for supporting adult carers

Quality assessment							Number of people		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Intervention (Carers' needs tailored and self-guided programme)**	**Control (Stroke support person-focused intervention)**	**Relative (95% CI)**	**Absolute**		
Caring-related morbidity: Depression (CESD-20) at 1 month follow-up from stroke (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 16 (9, 24) Control[4]: 19 (12, 27)	VERY LOW	CRITICAL
Caring-related morbidity: Depression (CESD-20) at 3 month follow-up from stroke (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 11 (2, 21) Control[4]: 14 (9, 16)	VERY LOW	CRITICAL
Caring-related morbidity: Depression (CESD-20) at 6 month follow-up from stroke (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 12 (7, 24) Control[4]: 12 (9, 18)	VERY LOW	CRITICAL
Caring-related morbidity: Psychological well-being (Positive Affect Scale) at 1 month follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 32 (26,38) Control[4]: 34 (33,34)	VERY LOW	CRITICAL
Caring-related morbidity: Psychological well-being (Positive Affect Scale) at 3 months follow-up from stroke (Better indicated by higher values)												

Quality assessment							Number of people		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Intervention (Carers' needs tailored and self-guided programme)	Control (Stroke support person-focused intervention)	Relative (95% CI)	Absolute		
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 43 (33, 49) Control[4]: 39 (33, 43)	VERY LOW	CRITICAL
Caring-related morbidity: Psychological well-being (Positive Affect Scale) at 6 months follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 37 (31, 43) Control[4]: 38 (32, 44)	VERY LOW	CRITICAL
Social capital: Social support (Medical Outcomes Study Social Support Scale -20 item) at 1 month follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 82 (67, 90) Control[4]: 76 (73, 89)	VERY LOW	IMPORTANT
Social capital: Social support (Medical Outcomes Study Social Support Scale -20 item) at 3 months follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 76 (62, 100) Control[4]: 79 (59, 94)	VERY LOW	IMPORTANT
Social capital: Social support (Medical Outcomes Study Social Support Scale -20 item) at 6 months follow-up from stroke (Better indicated by higher values)												

Quality assessment							Number of people		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Intervention (Carers' needs tailored and self-guided programme)	Control (Stroke support person-focused intervention)	Relative (95% CI)	Absolute		
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 90 (65, 96) Control[4]: 69 (47, 76)	VERY LOW	IMPORTANT
Carer choice/control/efficacy: Mastery (Pearlins 7 item Mastery Scale) at 1 month follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 19 (17, 20.8) Control[4]: 19 (16, 20)	VERY LOW	IMPORTANT
Carer choice/control/efficacy: Mastery (Pearlins 7 item Mastery Scale) at 3 months follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 19 (18,21) Control[4]: 19 (18, 19.8)	VERY LOW	IMPORTANT
Carer choice/control/efficacy: Mastery (Pearlins 7 item Mastery Scale) at 6 months follow-up from stroke (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	11	10	-	Intervention[4]: 20 (17.5, 21.5) Control[4]: 19 (18, 21)	VERY LOW	IMPORTANT

1 Cameron 2015

2 the quality of the evidence is downgraded by 2 levels due to the unclear method of randomisation and allocation concealment, high attrition rate and differential between arms and selective outcome reporting.

3 The quality of evidence was downgraded by 1 level as it was not possible to judge the precision of the estimates of effect (due to results being presented as medians and interquartile differences)

4 Findings were reported only with median and interquartile ranges

Psychological and emotional support (Relating to RQG)

No quantitative evidence was identified about this intervention category

GRADE - CERQual tables for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult cares during: (i) changes to the setting in which caring is performed; (ii) the transition of the person receiving care to adulthood; and (iii) change of carer status or circumstances?

Table 12: Summary of evidence (GRADE-CERQual) Theme 1: Transition to a long-term care facility - carers' support needs

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological Limitations**	**Coherence of findings**	**Applicability of evidence**	**Adequacy of Data**	**Overall Confidence**
Information needs: choosing a nursing home							
1(Ryan 2012)	1: Semi-structured interviews	Many adult carers seeking a nursing home for the older person they were supporting reported that the following factors influenced their choice of a nursing home: familiarity, rurality and the recommendations made by friends. Other carers felt that the decision-making was further influenced by the expressed wishes of the older relative. All carers said that rarely needed to consult any formal channels for advice on the choice of home.	Minor concerns	Minor concerns	Moderate concerns[1]	Serious concerns[4]	VERY LOW
Information needs: planning for the future							
1(Davies-Sue 2004)	1: Semi-structured interviews	Many adult carers of older people recently admitted to a nursing home reported that they had not been provided with much information to help them to plan for the future.	Serious concerns[2]	Minor concerns	Minor concerns	Serious concerns[4]	VERY LOW
Practical support needs: health and social care professionals							

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	**Design**		**Methodological Limitations**	**Coherence of findings**	**Applicability of evidence**	**Adequacy of Data**	**Overall Confidence**
2(Davies-Sue 2004, Ryan 2012)	2: Semi-structured interviews	Many adult carers of older people recently admitted to a nursing home highly valued the support received from health and social care professionals, particularly in the absence of family support – or in the presence of limited family support. Professionals were seen as playing the central role of carer advocate. During the move to the nursing home, many adult carers expressed the need for a more active interaction with staff. In particular nursing home staff frequently failed to draw upon the knowledge and expertise of family caregivers in developing plans of care for residents. In this context, carers were left to their own initiative to improve ways of ensuring that staff got to know the older person.	Moderate concerns[3]	Minor concerns	Minor concerns	Moderate concerns[5]	LOW
Emotional support needs							
2(Davies-Sue 2004, Ryan 2012)	2: Semi-structured interviews	Many adult carers of older people recently admitted to a nursing home felt that the key to a successful transition appeared to be the availability of a confidant, often a social worker, who could support, listen, and	Moderate concerns[3]	Minor concerns	Minor concerns	Moderate concerns[5]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
		offer advice and comfort. Many adult carers reported that professionals showed no interest in their own needs and the absence of any assessment meant that many relatives were left to work through their feelings and emotions at this time without support. The change of care setting itself was a traumatic experience for many adult carers, some of whom described overwhelming feelings of guilt and loss. During the move to a nursing home, they alternated between feelings of reassurance that their relative would now receive appropriate care and despair that they were no longer able to provide this care.					

1 Evidence was downgraded by 1 due to applicability of evidence, as the evidence from the study supporting the review findings is only partially applicable to the review protocol (it includes rural family carers ' experiences of the nursing home placement of older people)
2 Evidence was downgraded by 1 due to unclear methodological limitations: unclear details on how carers were selected/recruited, no details on data collection/analysis methods are reported, besides the unclear description about relationship between researchers and included carers
3 Evidence was downgraded by 1 due to unclear methodological limitations in 1 out the 2 studies that contributed to the findings (unclear details on how carers were selected/recruited, no details on data collection/analysis methods are reported, besides the unclear description about relationship between researchers and included carers)
4 Evidence was downgraded by 2 due to adequacy of data, as only 1 study supported the review's findings (offering poor data)
5 Evidence was downgraded by 1 due to adequacy of data, as only 2 studies supported the review's findings (offering thin data)

Table 13: Summary of evidence (GRADE-CERQual) Theme 2: Transition to a short-term care facility - carers' support needs

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Information needs							
2(Salisbury 2010, Cobley 2013)	2: Semi-structured interviews	Many adult carers of people admitted to acute care after a stroke expressed needs for detailed 'disease-specific' information, for example including stroke diagnosis, current and future treatment and care needs, availability and how to access community resources, and prognosis.	Minor concerns	Minor concerns	Minor concerns	Serious concerns[1]	LOW

1 Evidence was downgraded by 1 due to adequacy of data, as only 2 studies supported the review's findings (offering thin data)

Table 14: Summary of evidence (GRADE-CERQual) Theme 3: Transition to home from a short-term care facility- carers' support needs

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
Information needs							
2(Salisbury 2010, Cobley 2013)	1: Semi-structured interviews	Many adult carers of people with stroke had a negative experience of discharge planning, most of these carers reported being poorly informed regarding the extent of support available after discharge.	Minor concerns	Minor concerns	Minor concerns	Moderate concerns[1]	LOW
Training and education needs							

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
1(Cobley 2013)	1: Semi-structured interviews	Many adult carers of people with stroke expressed the need for education on how to manage care in the home. In most cases, the training of carers in how best to physically support the person with stroke after the discharge from hospital, was described as inadequate. After the person who'd had a stroke's discharge from healthcare services some carers also highlighted difficulties in coping with the person's emotional and psychological needs.	Minor concerns	Minor concerns	Minor concerns	Serious concerns[2]	LOW
Practical and emotional support needs							
1(Cobley 2013)	1: Semi-structured interviews	After the person they care for had been discharged from healthcare services, many adult carers described a reduction in time for leisure and social activities that, in turn, limited their opportunities for much needed social support. Many of these carers, indicated that they felt thrown into the caring role without receiving enough support from the community stroke teams. They stressed	Minor concerns	Minor concerns	Minor concerns	Serious concerns[2]	LOW

Study information		Description of Theme or Finding	CERQUAL Quality Assessment				
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	Overall Confidence
		the need for services to consider and address carers' issues, including practical and emotional support. Most of them reported feelings of exhaustion and felt physically strained.					

1 Evidence was downgraded by 1 due to adequacy of data, as only 2 studies supported the review's findings (offering thin data)

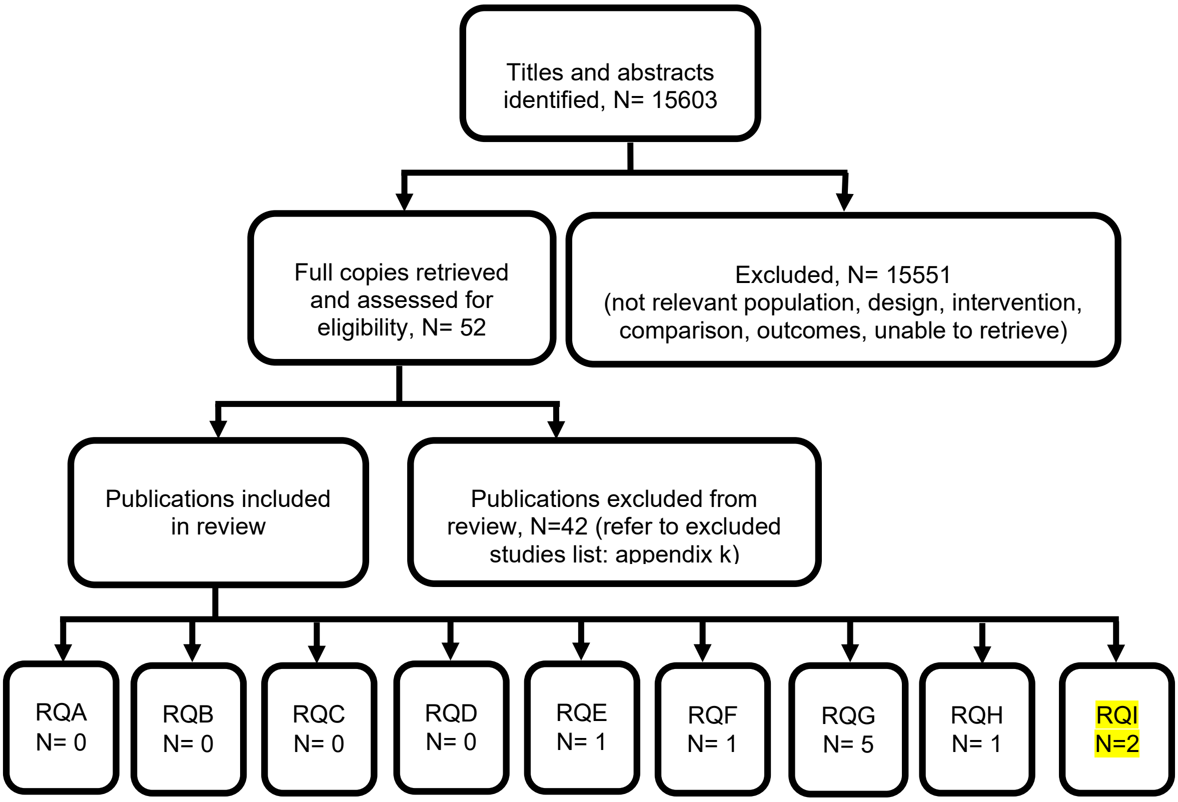
2 Evidence was downgraded by 2 due to adequacy of data, as only 1 study supported the review's findings (offering poor data)

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult carers during (i) changes to the setting in which care is provided, (ii) the transition of the person receiving care to adulthood and (iii) change of carer status or circumstances?

A global economic literature search was undertaken for supporting adult carers. This covered all 9 review questions in this guideline. As shown in Figure 4 below, 2 economic study was identified which was applicable to this review question.

Figure 4: Study selection flow chart



Appendix H – Economic evidence tables

Economic evidence tables for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult cares during: (i) changes to the setting in which caring is performed; (ii) the transition of the person receiving care to adulthood; and (iii) change of carer status or circumstances?

Study Country Study design	Intervention details	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
Study: • Forster 2013 Country: • UK Study design • Cost-effectiveness analysis and cost-utility analysis	Intervention: • Structured, competency-based training programme [the London Stroke Carer Training Course (LSCTC)] Control: • TAU Interventions details: • Participants assessed at baseline, 6 and 12 months • The LSCTC consists of 14 core carer	Study population: • Carers of people with stroke and the person they cared for (dyads) • N=928 ○ Intervention, n=450 ○ Control, n=478 Characteristics [Intervention; Control] • Age (years): Mean (SD): intervention =61.1 (14.64) ; control= 60.8 (13.91) • Sex (M): intervention (n): 140 male ; control (n): 153 male Data sources: • Source of clinical effectiveness data:	Cost description: • Cost categories included: ○ health and social care - nursing/residential care costs; - hospital inpatient, outpatient, day hospital and accident and emergency services care costs; - costs of primary care/community-based health/social care services. ○ Societal - health and social care costs (see above) - informal care costs • Costs Values1:	ICER • 6 month follow-up: ○ Health and social care: Control dominates (£207/–0.004 QALYs) ○ Societal: Control dominates (£99/–0.004 QALYs) • After 1 year: ○ Health and social care: Control dominates (£96/–0.004 QALYs) ○ Societal: £143,500 saving per QALY lost (–£574/–0.004) Sensitivity analysis: • Sensitivity analyses confirmed the	• Perspective: ○ Health and social care ○ Societal • Currency: GBP • Cost year: 2009-2010 • Time horizon: 1 year time horizon as per the RCT endpoint • Discounting: N/A • Applicability: directly applicable • Quality: minor limitations

Study Country Study design	Intervention details	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
	competencies that required training and testing. • These competencies were important knowledge/skills that informal caregivers would need to be able to care effectively for the stroke patient on discharge home • The LSCTC was delivered to carers while the patient was an inpatient in the SRU, with 1 recommended 'follow through' session provided in person or by telephone after hospital discharge. • Training continued until	○ Randomised control trial (N=928)* ○ EQ-5D health profiles, for befriended carers and control group carers, were collected at in order to calculate QALYs. • Source of resource use data: ○ Client Service Receipt Inventory (CSRI)** ○ Randomised control trial (N=928)* • Source of unit costs: ○ Individual-level resource-use quantities were combined with unit costs to calculate a cost per participant ○ National unit costs (for example NHS trust reference cost schedules, Personal Social Services Expenditure and Unit Costs England,	○ Total health and social care - 6 month follow-up: £207 (5 to 408) - 12 months follow-up: -£47 (–241 to 147) - After 1 year: £96 (–186 to 379) ○ Total societal - 6 month follow-up: £99 (–1248 to 1446) - 12 months follow-up: -£644 (–1777 to 489) - After 1 year: £-574 (–3112 to 1964) Outcomes description: • Outcome categories included: ○ QALYs between baseline and 6 months, between 6 months and 12 months and after 1 year • Outcome values1: - 6 month follow-up: -0.00 QALYs(–0.01 to 0.0)	conclusions of the primary analyses	

Study Country Study design	Intervention details	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
	the carer was deemed competent TAU - Usual care (National Clinical Guidelines for stroke)	Unit Costs of Health and Social Care 2010) were used where possible * Forster A, Dickerson J, Young J, Patel A, Kalra L, A structured training programme for caregivers of inpatients after stroke (TRACS): a cluster randomised controlled trial and cost-effectiveness analysis. Lancet 2013;382(9910):2069-76 ** Kalra L, Evans A, Perez I, Melbourn A, Patel A, Knapp M, Training care givers of stroke patients: randomised controlled trial. BMJ 2004;328:1099–101.	- 12 months follow-up: -0.00 QALYs (–0.01 to 0.01) - After 1 year: -0.00 QALYs (–0.02 to 0.02) 1: values are expressed as mean differences between intervention and control group (and 95% CIs)		
Study: - Patel 2004 Country: - UK	Intervention: - Training of carers of people who've had a stroke Control:	Study population: - Carers of people with stroke and they cared for (dyads) - N=300	Cost description: - Cost categories included: ○ initial admission for stroke (including stroke unit, physiotherapist,	ICER - Not performed as the effectiveness results showed there was no statistically significant	- Perspective: ○ Societal - Currency: GBP - Cost year: 2001-2002

Study Country Study design	Intervention details	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
Study design • Cost-effectiveness analysis and cost-utility analysis	• TAU Interventions details: • Participants were assessed at baseline, and 1 year follow-up • Training consisted of: ○ instruction in basic skills of moving and handling ○ facilitation of activities of daily living ○ and simple nursing tasks. • Carers received training over 3 to 5 sessions, each lasting from 30 to 45 minutes, and a follow-up session at home. TAU • Usual care [1 - Information on stroke and its	○ Intervention, n=151 ○ Control, n=149 Characteristics [Intervention; Control] • Age (years): Median (IQR): Intervention 76 (70-80), Control 76 (70-82) • Intervention (n): 86/151, Control (n):74/149 Data sources: • Source of clinical effectiveness data: ○ Randomised control trial (N=300)* ○ EQ-5D health profiles, for befriended carers and control group carers, were collected at in order to calculate QALYs. • Source of resource use data: ○ Randomised control trial (N=300)* • Source of unit costs:	occupational therapist, hospital speech and language therapist); ○ 12 month follow-up, including: - other secondary care services - social services (including social services day care centre); and - community-based care (including respite care). - informal care costs (such as domestic assistance and carers' time) • Costs Values1: ○ initial admission for stroke: -£3176 (-4980 to -1409) ○ 12 month follow-up after the intervention: -£541 (-1479 to 353) [excluding informal care] -£590 (-1634 to 469) [including informal care] - informal care costs: -£49 (-392 to 303)	difference in the reduction of QALYs. Therefore, a cost-minimisation analysis was conducted Sensitivity analysis: • The sensitivity analysis showed that the use of higher costs or longer length of stay increased the total costs in both groups, but did not affect the comparison of the total costs.	• Time horizon: 1 year time horizon as per the RCT endpoint • Discounting: N/A • Applicability: directly applicable • Quality: minor limitations

Study Country Study design	Intervention details	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
	consequences (for example management options); 2 - Involvement in goal setting for rehabilitation and discharge planning; 3 - Encouragement to attend nursing and therapy; and 4 - Advice on community services, benefits, and allowances, including contact information for voluntary support services for carers].	○ Individual-level resource-use quantities were combined with unit costs to calculate a cost per participant ○ National unit costs (including typical NHS sources and local service provider unit costs) were used where possible ○ Cost of informal care were mainly derived from UK minimum wages as a proxy of value for carers' time. * Kalra L, Evans A, Perez I, Melbourn A, Patel A, Knapp M, Training care givers of stroke patients: randomised controlled trial. BMJ 2004;328:1099–101.	○ Total annual costs: -£4091 (–6675 to -1458) Outcomes description: • Outcome categories included: ○ QALYs • Outcome values: After 1 year, the mean QALYs were 0.91 QALYs (+/- 0.11) in the training group and 0.90 QALYs (+/- 0.14) in the control group. 1: values are expressed as mean differences between intervention and control group (and 95% CIs)		

Appendix I – Economic evidence profiles

Economic evidence profiles for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult cares during: (i) changes to the setting in which caring is performed; (ii) the transition of the person receiving care to adulthood; and (iii) change of carer status or circumstances?

Table 15: Economic evidence profiles

Study and country	Limitations	Applicability	Other comments	Incremental costs	Incremental effects	ICER	Uncertainty
Forster 2013 UK	Minor limitations	Partially applicable[1]	Cost Utility analysis	£96	0.00 QALYs	Structured training programme dominated	1-way sensitivity analyses produced the same conclusion as the primary analysis
Patel 2004 UK	Potentially serious limitations [2]	Partially applicable[1]	Cost Utility analysis	-£ 4,091	0.01 QALYs	Training of stroke carers dominant	1-way sensitivity analysis suggested that including the costs on informal care using the replacement care method or increasing the length of stay did not alter the conclusions

Study and country	Limitations	Applicability	Other comments	Incremental costs	Incremental effects	ICER	Uncertainty
							Confidence intervals reported for cost and QALY point estimates

1. *Population is for carers of people with stroke and therefore may not be generalisable to all adult carers*
2. *Costs of the intervention do not appear to have been included in the total costs although the costs of the training are unlikely to offset the observed savings*

Appendix J – Economic analysis

Economic evidence analysis for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult cares during: (i) changes to the setting in which caring is performed; (ii) the transition of the person receiving care to adulthood; and (iii) change of carer status or circumstances?

No economic analysis was conducted for this review question

Appendix K – Excluded studies

List of excluded studies for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult cares during: (i) changes to the setting in which caring is performed; (ii) the transition of the person receiving care to adulthood; and (iii) change of carer status or circumstances?

Quantitative component of the review

Table 16: Excludies studies from the quantitative component of the review

Study	Reason for Exclusion
Agrawal, K, Suchetha, Ps, Mallikarjunaiah, Hs, A comparative study on quantity of caregiver support for upper limb functional recovery in post stroke, International journal of physiotherapy and research, 3, 77-82, 2013	Study conducted in India
Aguirrezabal, A., Duarte, E., Rueda, N., Cervantes, C., Marco, E., Escalada, F., Effects of information and training provision in satisfaction of patients and carers in stroke rehabilitation, NeuroRehabilitation, 33, 639-647, 2013	Not an RCT study design
Anonymous,, Training carers of stroke patients improves psychosocial measures in both carer and patient, Evidence-Based Healthcare and Public Health, 8, 342-344, 2004	Study excluded as it was a conference abstract only
Bakas, T, Farran, Cj, Austin, Jk, Given, Ba, Johnson, Ea, Williams, Ls, Stroke caregiver outcomes from the Telephone Assessment and Skill-Building Kit (TASK) Topics in Stroke Rehabilitation, 16, 105-121, 2009	Setting to exclude: no UK, Australia, Canada, Europe, Japan, New Zealand, South Africa
Bakker, T. J., Duivenvoorden, H. J., van der Lee, J., Olde Rikkert, M. G., Beekman, A. T., Ribbe, M. W., Benefit of an integrative psychotherapeutic nursing home program to reduce multiple psychiatric symptoms of psychogeriatric patients and caregiver burden after six months of follow-up: a re-analysis of a randomized controlled trial, International Psychogeriatrics, 25, 34-46, 2013	Intervention is multidisciplinary rehabilitation program aimed primarily at person receiving care.
Barca, M., Engedal, K., Haugen, P., Johannessen, A., Thorsen, K., Experiences of adult children of younger persons with dementia: A qualitative study, International Psychogeriatrics, 25, S29-S30, 2013	Study excluded as it was a conference abstract only
Bjorkdahl, A., Nilsson, A. L., Sunnerhagen, K. S., Can rehabilitation in the home setting reduce the burden of care for the next-of-kin of stroke victims?, Journal of Rehabilitation Medicine, 39, 27-32, 2007	Not an intervention of interest: not support interventions for adult carers during changes to the caring role

Study	Reason for Exclusion
Bridges-Webb, C., Giles, B., Speechly, C., Zurynski, Y., Hiramanek, N., Patients with dementia and their carers, Annals of the New York Academy of Sciences, 1114, 130-6, 2007	General survey of carers regarding their health, QoL and use/satisfaction of support
Bryant-Lukosius, D., Carter, N., Reid, K., Donald, F., Martin-Misener, R., Kilpatrick, K., Harbman, P., Kaasalainen, S., Marshall, D., Charbonneau-Smith, R., DiCenso, A., The clinical effectiveness and cost-effectiveness of clinical nurse specialist-led hospital to home transitional care: a systematic review, Journal of Evaluation in Clinical Practice, 21, 763-81, 2015	No study design (review): reviews have been excluded. References have been hand searched for relevant studies
Chenoweth, L, King, Mt, Jeon, Yh, Brodaty, H, Stein-Parbury, J, Norman, R, Haas, M, Luscombe, G, Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial, The lancet. Neurology, 8, 317-325, 2009	Trial examines outcomes in people with dementia
Chien, Wt, Effectiveness of psychoeducation and mutual support group program for family caregivers of chinese people with schizophrenia, Open nursing journal, 2, 28-39, 2008	Study conducted in Hong Kong
Chow Julian Chun-Chung, et al.,, Types and sources of support received by family caregivers of older adults from diverse racial and ethnic groups, Journal of Ethnic and Cultural Diversity in Social Work, 19, 175-194, 2010	Study regarding ethnic/racial differences in use of formal/informal support
Dean, K. M., Hatfield, L. A., Jena, A. B., Cristman, D., Flair, M., Kator, K., Nudd, G., Grabowski, D. C., Preliminary Data on a Care Coordination Program for Home Care Recipients, Journal of the American Geriatrics Society, 64, 1900-1903, 2016	Intervention received by professional carers
Eames, S., Hoffmann, T., Worrall, L., Read, S., Wong, A., Randomised controlled trial of an education and support package for stroke patients and their carers, BMJ Open, 3 (5) (no pagination) 2013	Not an intervention of interest: not support interventions for adult carers during changes to the caring role
Forster, A., Young, J., Chapman, K., Nixon, J., Patel, A., Holloway, I., Mellish, K., Anwar, S., Breen, R., Knapp, M., Murray, J., Farrin, A., Cluster Randomized Controlled Trial: Clinical and Cost-Effectiveness of a System of Longer-Term Stroke Care, Stroke; a journal of cerebral circulation, 46, 2212-2219, 2015	Population to exclude: no focus on adult carers
Forster, A., Young, J., Green, J., Patterson, C., Wanklyn, P., Smith, J., Murray, J., Wild, H., Bogle, S., Lowson, K., Structured re-assessment system at 6 months after a disabling stroke: a randomised	Not an intervention of interest: not support interventions for adult carers during changes to the caring role

Study	Reason for Exclusion
controlled trial with resource use and cost study, Age & AgeingAge Ageing, 38, 2009	
Friedman, Eh, Grant, Js, Re: telephone intervention with family caregivers of stroke survivors after rehabilitation, Stroke; a journal of cerebral circulation, 34, 7-8, 2003	Study excluded as it was a letter only
Gaugler, J. E., Understanding and Supporting Persons with Memory Loss and Their Families Across the Spectrum of Dementia, Journal of Applied Gerontology, 36, 779-781, 2017	Study excluded as it was a Introduction to special issue of journal only
Gaugler, J. E., Reese, M., Sauld, J., A Pilot Evaluation of Psychosocial Support for Family Caregivers of Relatives with Dementia in Long-Term Care: The Residential Care Transition Module, Research in gerontological nursing, 8, 161-172, 2015	Setting to exclude: no UK, Australia, Canada, Europe, Japan, New Zealand, South Africa
Gaugler, J. E., Roth, D. L., Haley, W. E., Mittelman, M. S., Modeling trajectories and transitions: results from the New York University caregiver intervention, Nursing Research, 60, S28-37, 2011	Setting to exclude: no UK, Australia, Canada, Europe, Japan, New Zealand, South Africa
Gaugler, Je, Kane, Rl, Newcomer, R, Resilience and transitions from dementia caregiving, Journals of gerontology. Series B, Psychological sciences and social sciences, 62, P38-44, 2007	Study excluded as it was not a relevant study design
Gaugler, Je, Mittelman, Ms, Hepburn, K, Newcomer, R, Identifying at-risk dementia caregivers following institutionalization: the nursing home admission-burden and nursing home admission-depression prognostic tools, Journal of Applied Gerontology, 33, 624-646, 2014	Study excluded as it was not a relevant study design
Gaugler, Je, Roth, Dl, Haley, We, Mittelman, Ms, Can counseling and support reduce burden and depressive symptoms in caregivers of people with Alzheimer's disease during the transition to institutionalization? Results from the New York University caregiver intervention study, Journal of the American Geriatrics Society, 56, 421-428, 2008	Setting to exclude: no UK, Australia, Canada, Europe, Japan, New Zealand, South Africa
Geldmacher, D. S., Maintaining patients with Alzheimer's disease in the home environment, Advanced Studies in Medicine, 4, 308-313, 2004	Study excluded as it was a general (non-systematic) review
Grant, Js, Glandon, Gl, Elliot, Tr, Newman, Giger J, Weaver, M, Problems and associated feelings experienced by family caregivers of stroke survivors the second and third month postdischarge, Topics in Stroke Rehabilitation, 13, 66-74, 2006	Setting to exclude: no UK, Australia, Canada, Europe, Japan, New Zealand, South Africa
Hamilton, G, Gallagher, M, Pierson, K, Lowes, S, Lin, Py, Ortega, R, Palliative care for dementia: a randomized controlled study of a replicable and	Study excluded as it was conference abstract only

Study	Reason for Exclusion
financially viable model for organizations providing caregiver support, Journal of Pain and Symptom Management, 401-401, 2017	
Hanks, Ra, Rapport, Lj, Wertheimer, J, Koviak, C, Randomized controlled trial of peer mentoring for individuals with traumatic brain injury and their significant others, Archives of Physical Medicine and Rehabilitation, 93, 1297-1304, 2012	Not an intervention of interest: not support interventions for adult carers during changes to the caring role
Harmon, C., Warner, C., RESOURCEFULNESS AND SUPPORT IN STRESS, REWARDS AND MENTAL HEALTH OF GRANDMOTHER CAREGIVERS, The Gerontologist, 48, 236, 2008	Study excluded as it was conference abstract only
Hendrix, C., Ray, C., Informal caregiver training on home care and cancer symptom management prior to hospital discharge: a feasibility study, Oncology Nursing Forum, 33, 793-8, 2006	Not an intervention of interest: not support interventions for adult carers during changes to the caring role
Hendrix, Cc, Bailey, De, Steinhauser, Ke, Olsen, Mk, Stechuchak, Km, Lowman, Sg, Schwartz, Aj, Riedel, Rf, Keefe, Fj, Porter, Ls, Tulsky, Ja, Effects of enhanced caregiver training program on cancer caregiver's self-efficacy, preparedness, and psychological well-being, Supportive Care in Cancer, 24, 327-336, 2016	Not an intervention of interest: not support interventions for adult carers during changes to the caring role
Hendrix, Cristina C., Landerman, Richard, Abernethy, Amy P., Effects of an individualized caregiver training intervention on self-efficacy of cancer caregivers, Western Journal of Nursing Research, 35, 590-610, 2013	Not an intervention of interest: not support interventions for adult carers during changes to the caring role
Hung, Lc, Liu, Cc, Hung, Hc, Kuo, Hw, Effects of a nursing intervention program on disabled patients and their caregivers, Archives of Gerontology and Geriatrics, 36, 259, 2003	Study conducted in Taiwan
Kalra, L, Evans, A, Perez, I, Melourn, A, Patel, A, Knapp, M, Donaldson, N, A randomised controlled trial of caregiver training in stroke patients, Stroke; a journal of cerebral circulation, 35, 239, 2004	No study design (conference abstract)
Keeping-Burke L, Purden M, Frasure-Smith N, Cossette S, McCarthy F, Bridging the transition from hospital to home: effects of the VITAL telehealth program on recovery for CABG surgery patients and their caregivers. Res Nurs Health 2013;36(6):540-53	Study excluded as there was not sufficient data reporting.
King, Rb, Hartke, Rj, Houle, T, Lee, J, Herring, G, Alexander-Peterson, Bs, Raad, J, A problem-solving early intervention for stroke caregivers: one year follow-up, Rehabilitation nursing, 37, 231-243, 2012	Study excluded as it was not an RCT study design
Korn, L., Logsdon, R., Polissar, N., Gomez-Beloz, A., Waters, T., Ryser, R., A RANDOMIZED TRIAL OF A COMPLEMENTARY/ALTERNATIVE MEDICINE	Study excluded as it was conference abstract only

Study	Reason for Exclusion
APPROACH FOR STRESS REDUCTION IN AMERICAN INDIAN FAMILY CAREGIVERS, The Gerontologist, 48, 81, 2008	
Landeiro, Maria Jose Lumini, Peres, Heloisa Helena Ciqueto, Martins, Teresa Vieira, Evaluation of the educational technology "Caring for dependent people" by family caregivers in changes and transfers of patients and tube feeding, Revista Latino-Americana de Enfermagem Vol 24 2016, ArtID e2774, 24, 2016	Study excluded as it was not an RCT study design
Larson, J, Franzén-Dahlin, A, Billing, E, Arbin, M, Murray, V, Wredling, R, The impact of a nurse-led support and education programme for spouses of stroke patients: a randomized controlled trial, Journal of Clinical Nursing, 14, 995-1003, 2005	This RCT was published before 2014 (psychosocial and emotional support)
Leavey G, Gulamhussein S, Papadopoulos C, Johnson-Sabine E, Blizard B, A randomized controlled trial of a brief intervention for families of patients with a first episode of psychosis. Psychol Med 2004;34(3):423-31	No outcome of interest (satisfaction with the intervention)
Lee, D. C., McDermott, F., Hoffmann, T., Haines, T. P., 'They will tell me if there is a problem': limited discussion between health professionals, older adults and their caregivers on falls prevention during and after hospitalization, Health Education Research, 28, 1051-1066, 2013	Population to exclude: no primary focus on adult carers
Li, H, Melnyk, Bm, McCann, R, Chatcheydang, J, Koulougliotti, C, Nichols, Lw, Lee, Md, Ghassemi, A, Creating avenues for relative empowerment (CARE): a pilot test of an intervention to improve outcomes of hospitalized elders and family caregivers, Research in Nursing & Health, 26, 284-299, 2003	Setting to exclude: no UK, Australia, Canada, Europe, Japan, New Zealand, South Africa
Li, H, Powers, Ba, Melnyk, Bm, McCann, R, Koulougliotti, C, Anson, E, Smith, Ja, Xia, Y, Glose, S, Tu, X, Randomized controlled trial of CARE: an intervention to improve outcomes of hospitalized elders and family caregivers, Research in Nursing & Health, 35, 533-549, 2012	Setting to exclude: no UK, Australia, Canada, Europe, Japan, New Zealand, South Africa
Lincoln, Nb, Francis, Vm, Lilley, Sa, Sharma, Jc, Summerfield, M, Evaluation of a stroke family support organiser: a randomized controlled trial, Stroke; a journal of cerebral circulation, 34, 116-121, 2003	This RCT was published before 2014 (practical support)
Lund, L., Ross, L., Petersen, M. A., Groenvold, M., Cancer caregiving tasks and consequences and their associations with caregiver status and the caregiver's relationship to the patient: a survey, BMC Cancer, 14, 2014	Study excluded as it was a general survey study

Study	Reason for Exclusion
Magill, N., Rhind, C., Hibbs, R., Goddard, E., Macdonald, P., Arcelus, J., Morgan, J., Beecham, J., Schmidt, U., Landau, S., Treasure, J., Two-year Follow-up of a Pragmatic Randomised Controlled Trial Examining the Effect of Adding a Carer's Skill Training Intervention in Inpatients with Anorexia Nervosa, European Eating Disorders Review, 24, 122-30, 2016	Not an intervention of interest: not support interventions for adult carers during changes to the caring role
Mant, J, Winner, S, Roche, J, Wade, Dt, Family support for stroke: one year follow up of a randomised controlled trial, Journal of neurology, neurosurgery, and psychiatry, 76, 1006-1008, 2005	This RCT was published before 2014 (practical suport)
Marsden, D., Quinn, R., Pond, N., Golledge, R., Neilson, C., White, J., McElduff, P., Pollack, M., A multidisciplinary group programme in rural settings for community-dwelling chronic stroke survivors and their carers: a pilot randomized controlled trial, Clinical Rehabilitation, 24, 328-41, 2010	Not an intervention of interest: not support interventions for adult carers during changes to the caring role
Martin-Martin, Lydia M., Valenza-Demet, Gerald, Ariza-Vega, Patrocinio, Valenza, Carmen, Castellote-Caballero, Yolanda, Jimenez-Moleon, Jose Juan, Effectiveness of an occupational therapy intervention in reducing emotional distress in informal caregivers of hip fracture patients: A randomized controlled trial, Clinical Rehabilitation, 28, 772-783, 2014	Not an intervention of interest: not support interventions for adult carers during changes to the caring role
McCullagh, E., Brigstocke, G., Donaldson, N., Kalra, L., Determinants of caregiving burden and quality of life in caregivers of stroke patients, Stroke, 36, 2181-6, 2005	Study excluded as it was not an RCT study design
McDonald, J., Swami, N., Hannon, B., Lo, C., Pope, A., Oza, A., Leighl, N., Krzyzanowska, M. K., Rodin, G., Le, L. W., Zimmermann, C., Impact of early palliative care on caregivers of patients with advanced cancer: cluster randomised trial, Annals of Oncology, 28, 163-168, 2017	Although carer received various kinds of support (social, emotional, training) attendance at palliative care not compulsory for them. Intervention primarily for care recipient.
Ostwald, S. K., Godwin, K. M., Cron, S. G., Kelley, C. P., Hersch, G., Davis, S., Home-based psychoeducational and mailed information programs for stroke-caregiving dyads post-discharge: a randomized trial, Disability & Rehabilitation, 36, 55-62, 2014	Setting to exclude: no UK, Australia, Canada, Europe, Japan, New Zealand, South Africa
Perrin, Pb, Johnston, A, Vogel, B, Heesacker, M, Vega-Trujillo, M, Anderson, J, Rittman, M, A culturally sensitive Transition Assistance Program for stroke caregivers: examining caregiver mental health and stroke rehabilitation, Journal of rehabilitation research and development, 47, 605-617, 2010	Setting to exclude: no UK, Australia, Canada, Europe, Japan, New Zealand, South Africa
Pfeiffer, K, Beische, D, Hautzinger, M, Berry, Jw, Wengert, J, Hoffrichter, R, Becker, C, Schayck, R,	Not an intervention of interest: not support interventions for

Study	Reason for Exclusion
Elliott, Tr, Telephone-based problem-solving intervention for family caregivers of stroke survivors: a randomized controlled trial, Journal of Consulting and Clinical Psychology, 82, 628-643, 2014	adult carers during changes to the caring role
Pierce, Ll, Steiner, Vl, Khuder, Sa, Govoni, Al, Horn, Lj, The effect of a Web-based stroke intervention on carers' well-being and survivors' use of healthcare services, Disability and rehabilitation, 31, 1676-1684, 2009	Setting to exclude: no UK, Australia, Canada, Europe, Japan, New Zealand, South Africa
Powell, J. M., Fraser, R., Brockway, J. A., Temkin, N., Bell, K. R., A telehealth approach to caregiver self-management following traumatic brain injury: A randomized controlled trial, Journal of Head Trauma Rehabilitation, 31, 180-190, 2016	Setting to exclude: no UK, Australia, Canada, Europe, Japan, New Zealand, South Africa
Powell, J. M., Wise, E. K., Brockway, J. A., Fraser, R., Temkin, N., Bell, K. R., Characteristics and concerns of caregivers of adults with traumatic brain injury, Journal of Head Trauma Rehabilitation, 32, E33-E41, 2017	Setting to exclude: no UK, Australia, Canada, Europe, Japan, New Zealand, South Africa
Raivio, Minna, Eloniemi-Sulkava, Ulla, Laakkonen, Marja-Liisa, Saarenheimo, Marja, Pietila, Minna, Tilvis, Reijo, Pitkala, Kaisu, How do officially organized services meet the needs of elderly caregivers and their spouses with Alzheimer's disease?, American Journal of Alzheimer's Disease and Other Dementias, 22, 360-368, 2007	Study excluded as it was a general survey about use of services and satisfaction with them
Schulz, Richard, Rosen, Jules, Klinger, Julie, Musa, Donald, Castle, Nicholas G., Kane, April L., Lustig, Amy, Effects of a psychosocial intervention on caregivers of recently placed nursing home residents: A randomized controlled trial, Clinical Gerontologist: The Journal of Aging and Mental Health, 37, 347-367, 2014	Setting to exclude: no UK, Australia, Canada, Europe, Japan, New Zealand, South Africa
Smith, G. C., Egbert, N., Dellman-Jenkins, M., Nanna, K., Palmieri, P. A., Reducing depression in stroke survivors and their informal caregivers: a randomized clinical trial of a Web-based intervention, Rehabilitation Psychology, 57, 196-206, 2012	Setting to exclude: no UK, Australia, Canada, Europe, Japan, New Zealand, South Africa
Smith, J., Forster, A., Young, J., A randomized trial to evaluate an education programme for patients and carers after stroke, Clinical Rehabilitation, 18, 726-36, 2004	Not the concept or phenomenon of interest: not support interventions for adult carers during changes to the caring role
Smith, Je, Forster, A, Young, Jb, A randomised trial to evaluate improved routine communication to patients and carers after stroke, Cerebrovascular diseases (basel, switzerland) 16, 70, 2003	No study design (conference abstract)

Study	Reason for Exclusion
Sun, V, Raz, Dj, Ruel, N, Chang, W, Erhunmwunsee, L, Reckamp, K, Tiep, B, Ferrell, B, McCorkle, R, Kim, Jy, A Multimedia Self-management Intervention to Prepare Cancer Patients and Family Caregivers for Lung Surgery and Postoperative Recovery, Clinical lung cancer. (no pagination) 2017, Date of Publication: November 10, 2017	Setting to exclude: no UK, Australia, Canada, Europe, Japan, New Zealand, South Africa
Treasure, Janet, Sepulveda, Ana R., MacDonald, Pam, Whitaker, Wendy, Lopez, Carolina, Zabala, Maria, Kyriacou, Olivia, Todd, Gill, Interpersonal maintaining factors in eating disorder: Skill sharing interventions for carers, International Journal of Child and Adolescent Health, 1, 331-338, 2008	Study excluded as the article only describes an intervention
Treasure, Janet, Todd, Gill, Interpersonal maintaining factors in eating disorder: Skill sharing interventions for carers, 125-137, 2016	Study excluded as the article only describes an intervention
Turner, A., Hambridge, J., Alston, M., Sweetapple, A., White, J., Hackett, M., Pollack, M., Group cognitive behaviour therapy for emotional distress in stroke patients and their carers: Impact on quality of life, participation and autonomy and carer burden, International Journal of Stroke, Conference, 2012	Study excluded as it was not a study design (conference abstract)
Visser-Meily, A., van Heugten, C., Post, M., Schepers, V., Lindeman, E., Intervention studies for caregivers of stroke survivors: a critical review, Patient Education & Counseling, 56, 257-67, 2005	Only includes 2 studies published in or after 2003 (Lincoln 2003; Teng 2003) both of which were included in original search.

Qualitative component of the review

Table 17: Excludies studies from the qualitative component of the review

Study	Reason for Exclusion
Adams Kathryn Betts, The transition to caregiving: the experience of family members embarking on the dementia caregiving career, Journal of Gerontological Social Work, 47, 3-29, 2006	Setting to exclude: no UK evidence
Allicock, M., Haynes-Maslow, L., Johnson, L. S., Carpenter, W. R., Vines, A. I., Belle, D. G., Phillips, R., Cherry, M. W., Peer Connect for African American breast cancer survivors and caregivers: a train-the-trainer approach for peer support, Translational Behavioral Medicine, 7, 495-505, 2017	Not the concept/ phenomenon of interest: not support interventions for adult carers during changes to the caring role
Altschuler, A., Liljestrand, P., Grant, M., Hornbrook, M. C., Krouse, R. S., McMullen, C. K., Caregiving and mutuality among long-term colorectal cancer survivors with ostomies: qualitative study, Supportive Care in Cancer, 1-9, 2017	Not the concept/ phenomenon of interest: not support interventions for adult carers during changes to the caring role

Study	Reason for Exclusion
Aoun, Samar M., Breen, Lauren J., Oliver, David, Henderson, Robert D., Edis, Robert, O'Connor, Margaret, Howting, Denise, Harris, Rodney, Birks, Carol, Family carers' experiences of receiving the news of a diagnosis of Motor Neurone Disease: A national survey, Journal of the Neurological Sciences, 372, 144-151, 2017	Study excluded as not a qualitative study design
Association Of Directors Of Adult Social, Services, Carers as partners in hospital discharge: improving carer recognition, support and outcomes within timely and supported discharge processes: a review, 39p., 2010	Study excluded as not a qualitative study design
Bertrand, R., Fredman, L., Barrett, A., Coleman, S., PREDICTING INDIVIDUAL TRAJECTORIES OF CHANGE OVER TIME IN PERCEIVED STRESS AMONG CAREGIVERS, The Gerontologist, 44, 369, 2004	Study excluded as full text is an abstract only
Bleijlevens, M. H., Stolt, M., Stephan, A., Zabalegui, A., Saks, K., Sutcliffe, C., Lethin, C., Soto, M. E., Zwakhalen, S. M., Changes in caregiver burden and health-related quality of life of informal caregivers of older people with Dementia: evidence from the European RightTimePlaceCare prospective cohort study, Journal of advanced nursing, 71, 1378-1391, 2015	Study excluded as not a qualitative study design
Blum, Kay, Sherman, Deborah W., Understanding the Experience of Caregivers: A Focus on Transitions, Seminars in Oncology Nursing, 26, 243-258, 2010	Study excluded as not a qualitative study design
Borthwick Rachel, Newbronner Liz, Stuttard Lucy, 'Out of Hospital': a scoping study of services for carers of people being discharged from hospital, Health and Social Care in the Community, 17, 335-349, 2009	Not the relevant study design (review): reviews have been excluded. References have been hand searched for relevant studies
Bragstad Line Kildal, et al.,, Informal caregivers' participation when older adults in Norway are discharged from the hospital, Health and Social Care in the Community, 22, 155-168, 2014	Study excluded as not a qualitative study design
Byrne, Kerry, Spousal caregivers' experiences during their husbands'/wives' transition from a geriatric rehabilitation unit to home, Dissertation Abstracts International: Section B: The Sciences and Engineering, 69, 6745, 2009	Study excluded as full text is a dissertation
Byrne, Kerry, Orange, Joseph B., Ward-Griffin, Catherine, Care Transition Experiences of Spousal Caregivers: From a Geriatric Rehabilitation Unit to Home, Qualitative health research, 21, 1371, 2011	Setting to exclude: no UK evidence
Cameron, Jill I., Naglie, Gary, Silver, Frank L., Gignac, Monique A., Stroke family caregivers' support needs	Setting to exclude: no UK evidence

Study	Reason for Exclusion
change across the care continuum: a qualitative study using the timing it right framework, Disability and rehabilitation, 35, 315-324, 2013	
Chamberlain, K., Reid, N., Warner, J., Shelton, D., Dawe, S., A qualitative evaluation of caregivers' experiences, understanding and outcomes following diagnosis of FASD, Research in Developmental Disabilities, 63, 99-106, 2017	Population to exclude: no adult carers of adults or young people (16)
Chapman Bev, Koskelainen Maria, Survey addresses improving support for family carers, Journal of Dementia Care, 36-37, 2003	Not the concept/ phenomenon of interest: not support interventions for adult carers during changes to the caring role
Coleman, E. A., Roman, S. P., Family caregivers' experiences during transitions out of hospital, Journal for healthcare quality : official publication of the National Association for Healthcare Quality, 37, 12-21, 2015	Setting to exclude: no UK evidence
Cornwell, Petrea, Dicks, Bronwyn, Fleming, Jennifer, Haines, Terry P., Olson, Sarah, Care and support needs of patients and carers early post-discharge following treatment for non-malignant brain tumour: establishing a new reality, Supportive Care in Cancer, 20, 2595-610, 2012	Setting to exclude: no UK evidence
Csikai Ellen L, Martin Shadi S, Bereaved hospice caregivers' views of the transition to hospice, Social Work in Health Care, 49, 387-400, 2010	Setting to exclude: no UK evidence
Czerwonka, Anna I., Herridge, Margaret S., Chan, Linda, Chu, Leslie Michele, Matte, Andrea, Cameron, Jill I., Changing support needs of survivors of complex critical illness and their family caregivers across the care continuum: A qualitative pilot study of Towards RECOVER, Journal of Critical Care, 30, 242-249, 2015	Setting to exclude: no UK evidence
Davies, F., Edwards, A., Brain, K., Edwards, M., Jones, R., Wallbank, R., Robertson, N. P., Wood, F., 'You are just left to get on with it': qualitative study of patient and carer experiences of the transition to secondary progressive multiple sclerosis, BMJ Open, 5, e007674, 2015	Not the concept/ phenomenon of interest: not support interventions for adult carers during changes to the caring role
DiGiacomo, Michelle, Lewis, Joanne, Nolan, Marie T., Phillips, Jane, Davidson, Patricia M., Transitioning From Caregiving to Widowhood, Journal of Pain and Symptom Management, 46, 817-825, 2013	Setting to exclude: no UK evidence
Dossa, A., Bokhour, B., Hoenig, H., Care transitions from the hospital to home for patients with mobility impairments: patient and family caregiver experiences, Rehabilitation Nursing Journal, 37, 277-85, 2012	Not UK evidence

Study	Reason for Exclusion
Egdell, Valerie, Who cares?, Ageing and Society, 33, 2013	Does not include qualitative data on specific strategies for supporting carers during transitions, rather this paper has a general focus
Egdell, Valerie, Who cares? Managing obligation and responsibility across the changing landscapes of informal dementia care, Ageing & Society, 33, 888-907, 2013	Not the concept phenomenon of interest: not support interventions for adult carers during changes to the caring role
Epiphaniou, E., Hamilton, D., Bridger, S., Robinson, V., Rob, G., Beynon, T., Higginson, I., Harding, R., Adjusting to the caregiving role: the importance of coping and support, International journal of palliative nursing, 18, 541-5, 2012	Not the concept phenomenon of interest: not support interventions for adult carers during changes to the caring role
First, Jennifer M. A. M. S. W., Cheak-Zamora, Nancy C. PhD, Teti, Michelle DrPH, A qualitative study of stress and coping when transitioning to adulthood with autism spectrum disorder, Journal of Family Social Work, 19, 220-236, 2016	Setting to exclude: no UK evidence
Ford, Bryan Keith, Ingersoll-Dayton, Berit, Burgio, Kathryn, Care transition experiences of older veterans and their caregivers, Health & Social Work, 41, 129-138, 2016	Setting to exclude: no UK evidence
Foust, Janice B., Vuckovic, Nancy, Henriquez, Ernesto, Hospital to Home Health Care Transition: Patient, Caregiver, and Clinician Perspectives, Western Journal of Nursing Research, 34, 194, 2012	Setting to exclude: no UK evidence
Frank, A., Transition: provision of assistive technology can enhance independence and reduce carer strain, Clinical Medicine, 7, 198; author reply 198, 2007	Study excluded as not a qualitative study design
Giosa, Justine L., Stolee, Paul, Dupuis, Sherry L., Mock, Steven E., Santi, Selena M., An Examination of Family Caregiver Experiences during Care Transitions of Older Adults, Canadian Journal on Aging, 33, 137-53, 2014	Setting to exclude: no UK evidence
Girgis, A., Abernethy, A. P., Currow, D. C., Caring at the end of life: do cancer caregivers differ from other caregivers?, BMJ supportive & palliative care, 5, 513-517, 2015	Setting to exclude: no UK evidence
Gladstone, James W., Dupuis, Sherry L., Wexler, Evelyn, Changes in Family Involvement Following a Relative's Move to a Long-Term Care Facility, Canadian Journal on Aging, 25, 93-106, 2006	Setting to exclude: no UK evidence
Kristof, Lorand M. D. Msc, Fortinsky, Richard H. PhD, Kellett, Kathy PhD, Porter, Martha B. A., Robison, Julie PhD, Experiences of Informal Caregivers of Older Adults Transitioned From Nursing Homes to the Community Through the Money Follows the Person	Setting to exclude: no UK evidence

Study	Reason for Exclusion
Demonstration, Journal of Aging & Social Policy, 29, 20-34, 2017	
Mc, Conkey Roy, Transitions and young people with autism spectrum disorders, 46p., bibliog., 2010	This report was aimed to find out the supports which the young people with autism spectrum disorders and their families receive from health and social services and the supports they feel they require now and once their son or daughter leaves school. This report was excluded because 1) of the study population: age of carers not reported whilst 284 young adults with ASD (49% of the sample) are aged under 14 years and 298 are 14 years and over (further details are not reported).
Millligan Christine, Caring for older people in New Zealand: informal carers' experiences of the transition of care from the home to residential care, 84p., bibliog., 2004	Setting to exclude: no UK evidence
Morgan Hazel, Davies Jill, Prepared for the future?: information to prepare families when a young person with a learning disability is leaving school or college, 33p., 2009	Population to exclude: no adult carers of adults or young people (16)
O'Brien, Mary R., Preston, Harriet, Family carer perspectives of acute hospital care following a diagnosis of motor neuron disease: a qualitative secondary analysis, BMJ supportive & palliative care, 5, 503, 2015	Not the concept/ phenomenon of interest: not support interventions for adult carers during changes to the caring role
Olasoji, Michael, Maude, Phil, McCauley, Kay, A journey of discovery: Experiences of carers of people with mental illness seeking diagnosis and treatment for their relative, Issues in Mental Health Nursing, 37, 219-228, 2016	Setting to exclude: no UK evidence
Patel, M., Chawla, R., Krynicki, C. R., Rankin, P., Upthegrove, R., Health beliefs and carer burden in first episode psychosis, BMC Psychiatry, 14, 171, 2014	Study excluded as not a qualitative study design
Plank, A., Mazzoni, V., Cavada, L., Becoming a caregiver: new family carers' experience during the transition from hospital to home, Journal of clinical nursing, 21, 2072-82, 2012	Setting to exclude: no UK evidence
Popejoy, Lori L. PhD Aprn B. C. Gcns, Complexity of Family Caregiving and Discharge Planning, Journal of Family Nursing, 17, 61, 2011	Setting to exclude: no UK evidence

Study	Reason for Exclusion
Ramsay, P., Huby, G., Merriweather, J., Salisbury, L., Rattray, J., Griffith, D., Walsh, T., Boyd, J. A., Mackenzie, S. J., Krishan, A., Lewis, S. C., Murray, G. D., Forbes, J. F., Smith, J., Hull, A. M., Wallis, C., Stewart, J., Bateman, A., Wilson, E., Gillies, M., Kean, S., Hope, D., Dawson, H., McCulloch, C., Antonelli, J., Boardman, L., Dow, L., Williams, W., McCann, A., Alexander, S., Patient and carer experience of hospital-based rehabilitation from intensive care to hospital discharge: Mixed methods process evaluation of the RECOVER randomised clinical trial, BMJ Open, 6 (8) (no pagination) 2016	No qualitative data on carers experiences
Roberto, Karen A., Jarrott, Shannon E., Family Caregivers of Older Adults: A Life Span Perspective, Family Relations, 57, 100-111, 2008	Study excluded as not a qualitative study design
Simon Chantal, Kumar Satinder, Kendrick Tony, Cohort study of informal carers of first-time stroke survivors: Profile of health and social changes in the first year of caregiving, Social Science and Medicine, 69, 404-410, 2009	Study excluded as not a qualitative study design
Tanskanen, S., Morant, N., Hinton, M., Lloyd-Evans, B., Crosby, M., Killaspy, H., Raine, R., Pilling, S., Johnson, S., Service user and carer experiences of seeking help for a first episode of psychosis: a UK qualitative study, BMC Psychiatry, 11, 157, 2011	Not the concept/ phenomenon of interest: not support interventions for adult carers during changes to the caring role
Teel, Cynthia S., Carson, Paula, Family experiences in the journey through dementia diagnosis and care, Journal of Family Nursing, 9, 38-58, 2003	Setting to exclude: no UK evidence
Toles, Mark, Young, Heather M., Ouslander, Joseph, Improving Care Transitions in Nursing Homes, Generations, 36, 78-85, 2012	Study excluded as not a qualitative study design
Turner, B., Fleming, J., Cornwell, P., Worrall, L., Ownsworth, T., Haines, T., Kendall, M., Chenoweth, L., A qualitative study of the transition from hospital to home for individuals with acquired brain injury and their family caregivers, Brain Injury, 21, 1119-30, 2007	Setting to exclude: no UK evidence
Waldboth, Veronika, Patch, Christine, Mahrer-Imhof, Romy, Metcalfe, Alison, Living a normal life in an extraordinary way: A systematic review investigating experiences of families of young people's transition into adulthood when affected by a genetic and chronic childhood condition, International journal of nursing studies, 62, 44, 2016	Not the relevant study design (review): reviews have been excluded. References have been hand searched for relevant studies
Waldrop, Deborah PhD M. S. W., Meeker, Mary Ann D. N. S. R. N., Kutner, Jean S. M. D. Msph, The Developmental Transition From Living With to Dying	Setting to exclude: no UK evidence

Study	Reason for Exclusion
From Cancer: Hospice Decision Making, Journal of Psychosocial Oncology, 33, 576, 2015	
Wells, R., Dywan, J., Dumas, J., Life satisfaction and distress in family caregivers as related to specific behavioural changes after traumatic brain injury, Brain Injury, 19, 1105-15, 2005	Setting to exclude: no UK evidence
White, Carole L., Mayo, Nancy, Hanley, James A., Wood-Dauphinee, Sharon, Evolution of the caregiving experience in the initial 2 years following stroke, Research in Nursing & Health, 26, 177-189, 2003	Study excluded as not a qualitative study design
Wiles, J., Informal caregivers' experiences of formal support in a changing context, Health & social care in the community, 11, 189-207, 2003	Setting to exclude: no UK evidence
Williams, Chris, Thorpe, Rosamund, Harris, Nonie, Dickinson, Hilary, Barrett, Chris, Rorison, Francine, Going home from hospital: The postdischarge experience of patients and carers in rural and remote Queensland, Australian Journal of Rural Health, 14, 9-13, 2006	Setting to exclude: no UK evidence
Wong, Jen D., Shobo, Yetunde, Types of family caregiving and daily experiences in midlife and late adulthood, Research on Aging, 39, 2017	Setting to exclude: no UK evidence
Young Carers International Research, Evaluation,, Young adult carers in the UK: experiences, needs and services for carers aged 16-24, Benefits, 17, 75-77, 2009	Not the concept/ phenomenon of interest: not support interventions for adult carers during changes to the caring role

Economic component of the review

A global economic literature search was undertaken for supporting adult carers. This covered all 9 review questions in this guideline. The table below is a list of excluded studies across the entire guideline and studies listed were not necessarily identified for this review question.

Table 18: Excludies studies from the economic component of the review

Study	Reason for Exclusion
Arksey Hilary, et al.,, Review of respite services and short-term breaks for carers for people living with dementia: report for the National Co-ordinating Centre for NHS Service Delivery and Organisation	Study design: This report is a review, and reviews are excluded. References could not be hand-searched as there was no reference list included in the report.
Arts, E. E., Landewe-Cleuren, S. A., Schaper, N. C., Vrijhoef, H. J., The cost-effectiveness of substituting physicians with diabetes nurse specialists: a randomized controlled trial with 2-year follow-up, Journal of advanced nursing, 68, 1224-34, 2012	Population of interest: the study focus is primarily on patients.

Study	Reason for Exclusion
Forster, A., Young, J., Chapman, K., Nixon, J., Patel, A., Holloway, I., Mellish, K., Anwar, S., Breen, R., Knapp, M., Murray, J., Farrin, A., Cluster Randomized Controlled Trial: Clinical and Cost-Effectiveness of a System of Longer-Term Stroke Care, Stroke; a journal of cerebral circulation, 46, 2212-2219, 2015	Population of interest: the study focus is primarily on patients.
Forster, A., Young, J., Green, J., Patterson, C., Wanklyn, P., Smith, J., Murray, J., Wild, H., Bogle, S., Lowson, K., Structured re-assessment system at 6 months after a disabling stroke: a randomised controlled trial with resource use and cost study, Age & AgeingAge Ageing, 38, 2009	This cost analysis is focused primarily on patients.
Gardiner, Clare, Brereton, Louise, Frey, Rosemary, Wilkinson-Meyers, Laura, Gott, Merryn, Approaches to capturing the financial cost of family care-giving within a palliative care context: A systematic review, Health & Social Care in the Community, 24, 519-531, 2016	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Gitlin LN, Hodgson N, Jutkowitz E, Pizzi L. The cost-effectiveness of a nonpharmacologic intervention for individuals with dementia and family caregivers: the tailored activity program. Am J Geriatr Psychiatry 2010;18(6):510-9.	Economic evaluation conducted in the USA.
Gomes, B., Calanzani, N., Curiale, V., McCrone, P., Higginson, I. J., Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers, Cochrane Database of Systematic Reviews, 2016 (3) (no pagination), 2013	Study design - this review of HE studies has been excluded for this guideline - but its references have been checked for any relevant HE study.
Gomes, Barbara, Calanzani, Natalia, Higginson, Irene J., Benefits and costs of home palliative care compared with usual care for patients with advanced illness and their family caregivers, JAMA: Journal of the American Medical Association, 311, 1060-1061, 2014	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Heslin, M., Forster, A., Healey, A., Patel, A., A systematic review of the economic evidence for interventions for family carers of stroke patients, Clinical Rehabilitation, 30, 119-33, 2016	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE study.
Hoefman, R. J., van Exel, J., Brouwer, W. B., Measuring Care-Related Quality of Life of Caregivers for Use in Economic Evaluations: CarerQol Tariffs for Australia, Germany, Sweden, UK, and US, PharmacoEconomics, 35, 469-478, 2017	No intervention of interest.
Huter, K., Kocot, E., Kissimova-Skarbek, K., Dubas-Jakobczyk, K., Rothgang, H., Economic evaluation of health promotion for older people-methodological problems and challenges, BMC Health Services Research, 16 Suppl 5, 328, 2016	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Jones Carys, Edwards Rhiannon Tudor, Hounsome Barry, A systematic review of the cost-effectiveness of	Study design - this review of HE studies has been excluded

Study	Reason for Exclusion
interventions for supporting informal caregivers of people living with dementia residing in the community, International Psychogeriatrics, 24, 6-18, 2012	for this guideline - but its references have been hand-searched for any relevant HE studies.
Jones, C., Edwards, R. T., Hounsome, B., Health economics research into supporting carers of people living with dementia: A systematic review of outcome measures, Health and Quality of Life Outcomes, 10 (no pagination), 2012	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Jutkowitz, E., Gitlin, L. N., Pizzi, L. T., Evaluating willingness-to-pay thresholds for dementia caregiving interventions: application to the tailored activity program, Value in Health, 13, 720-5, 2010	Economic evaluation conducted in the USA.
Kenealy, T. W., Parsons, M. J., Rouse, A. P., Doughty, R. N., Sheridan, N. F., Hindmarsh, J. K., Masson, S. C., Rea, H. H., Telecare for diabetes, CHF or COPD: effect on quality of life, hospital use and costs. A randomised controlled trial and qualitative evaluation, PLoS ONE [Electronic Resource], 10, e0116188, 2015	Population of interest: the study focus is primarily on patients.
Kenrik Duru, O., Ettner, S. L., Vassar, S. D., Chodosh, J., Vickrey, B. G., Cost evaluation of a coordinated care management intervention for dementia, American Journal of Managed Care, 15, 521-528, 2009	Population of interest: the study focus is primarily on patients.
Knapp, M., King, D., Romeo, R., Schehl, B., Barber, J., Griffin, M., Rapaport, P., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Sampson, E. L., Cooper, C., Livingston, G., Cost effectiveness of a manual based coping strategy programme in promoting the mental health of family carers of people living with dementia (the START (STrAtegies for RelaTives) study): a pragmatic randomised controlled trial (Structured abstract), Bmj, 347, f6342, 2013	Study finding updated by a more recent HE study (Livingston 2014).
Lauret, G. J., Gijsbers, H. J., Hendriks, E. J., Bartelink, M. L., de Bie, R. A., Teijink, J. A., The ClaudicatioNet concept: design of a national integrated care network providing active and healthy aging for patients with intermittent claudication, Vascular Health & Risk Management, 8, 495-503, 2012	Research protocol.
Li, C., Zeliadt, S. B., Hall, I. J., Smith, J. L., Ekwueme, D. U., Moinpour, C. M., Penson, D. F., Thompson, I. M., Keane, T. E., Ramsey, S. D., Burden among partner caregivers of patients diagnosed with localized prostate cancer within 1 year after diagnosis: an economic perspective, Supportive Care in Cancer, 21, 3461-9, 2013	Not the intervention of interest: This study estimates lost productivity and informal caregiving and associated costs among partner caregivers of localized prostate cancer patients within 1 year after diagnosis.
Lopez-Villegas, A., Catalan-Matamoros, D., Robles-Musso, E., Peiro, S., Workload, time and costs of the informal carers in patients with tele-monitoring of pacemakers: the PONIENTE study, Clinical Research in Cardiology, 105, 307-313, 2016	Not the intervention of interest: aim of this study was to assess the burden borne by and the costs to informal carers of patients with remotely monitored pacemakers.

Study	Reason for Exclusion
Magnusson, L., Hanson, E., Supporting frail older people and their family carers at home using information and communication technology: cost analysis, Journal of advanced nursing, 51, 645-57, 2005	This cost analysis uses a case study methodology involving 5 families, cost and resource usage are not reported separately for carers and patients.
Mason, A., Weatherly, H., Spilsbury, K., Arksey, H., Golder, S., Adamson, J., Drummond, M., Glendinning, C., A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers, Health Technology Assessment (Winchester, England), 11, 1-157, iii, 2007	Study design - this review of HE studies has been excluded for this guideline (but its references have been hand-searched for any relevant HE studies.
Mason, Anne, Weatherly, Helen, Spilsbury, Karen, Golder, Su, Arksey, Hilary, Adamson, Joy, Drummond, Michael, The Effectiveness and Cost-Effectiveness of Respite for Caregivers of Frail Older People, Journal of the American Geriatrics Society, 55, 290-299, 2007	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Menn P, Holle R, Kunz S, Donath C, Lauterberg J, Dementia care in the general practice setting: a cluster randomized trial on the effectiveness and cost impact of three management strategies. Value Health. 2012 Sep-Oct;15(6):851-9	Population of interest: no primary focus on carers.
Morgan, R. O., Bass, D. M., Judge, K. S., Liu, C. F., Wilson, N., Snow, A. L., Pirraglia, P., Garcia-Maldonado, M., Raia, P., Fouladi, N. N., Kunik, M. E., A break-even analysis for dementia care collaboration: Partners in Dementia Care, Journal of General Internal Medicine, 30, 804-9, 2015	Population of interest: the study focus is primarily on patients.
Nichols LO, Chang C, Lummus A, Burns R, Martindale-Adams J, The cost-effectiveness of a behavior intervention with caregivers of patients with Alzheimer's disease. J Am Geriatr Soc. 2008 Mar;56(3):413-20	This economic evaluation was conducted in the USA.
Nichols LO, Martindale-Adams J, Zhu CW, Kaplan EK, Zuber JK, Impact of the REACH II and REACH VA Dementia Caregiver Interventions on Healthcare Costs. J Am Geriatr Soc. 2017 May;65(5):931-936	This economic evaluation was conducted in the USA.
Orgeta, V., Leung, P., Yates, L., Kang, S., Hoare, Z., Henderson, C., Whitaker, C., Burns, A., Knapp, M., Leroi, I., Moniz-Cook, E. D., Pearson, S., Simpson, S., Spector, A., Roberts, S., Russell, I. T., de Waal, H., Woods, R. T., Orrell, M., Individual cognitive stimulation therapy for dementia: a clinical effectiveness and cost-effectiveness pragmatic, multicentre, randomised controlled trial, Health Technology Assessment (Winchester, England), 19, 1-108, 2015	Population of interest: the study focus is primarily on patients.
Patel, A., Forster, A., Young, J., Nixon, J., Chapman, K., Knapp, M., Mellish, K., Holloway, I., Farrin, A., Cluster randomised trial evaluation of a patient and carer centred system of longer-term stroke care (the LoTS care trial): Economic evaluation, Cerebrovascular Diseases, 35, 584, 2013	Conference abstract.

Study	Reason for Exclusion
Pickard, Linda, The effectiveness and cost-effectiveness of support and services to informal carers of older people: a review of the literature prepared for the Audit Commission, 2004	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Quinn, C., Anderson, D., Toms, G., Whitaker, R., Edwards, R. T., Jones, C., Clare, L., Self-management in early-stage dementia: a pilot randomised controlled trial of the efficacy and cost-effectiveness of a self-management group intervention (the SMART study), Trials [Electronic Resource], 15, 74, 2014	Research protocol.
Romeo, R., Knapp, M., Banerjee, S., Morris, J., Baldwin, R., Tarrier, N., Pendleton, N., Horan, M., Burns, A., Treatment and prevention of depression after surgery for hip fracture in older people: cost-effectiveness analysis, Journal of Affective Disorders, 128, 211-9, 2011	Population of interest: no adult carers.
Sandberg, M., Jakobsson, U., Midlov, P., Kristensson, J., Cost-utility analysis of case management for frail older people: effects of a randomised controlled trial, Health Economics Review, 5 (1) (no pagination), 2015	Population of interest: no adult carers.
Schepers, J., Annemans, L., Simoens, S., Hurdles that impede economic evaluations of welfare interventions, Expert Review of Pharmacoeconomics & Outcomes Research, 15, 635-42, 2015	Study design - this review of HE studies has been excluded - but its references have been hand-searched for any relevant HE studies.
Søgaard R, Sørensen J, Waldorff FB, Eckermann A, Buss DV, Early psychosocial intervention in Alzheimer's disease: cost utility evaluation alongside the Danish Alzheimer's Intervention Study (DAISY). BMJ Open. 2014 Jan 15;4(1):e004105	Population of interest: no primary focus on carers.
Sogaard, R., Sorensen, J., Waldorff, F. B., Eckermann, A., Buss, D. V., Waldemar, G., Private costs almost equal health care costs when intervening in mild Alzheimer's: a cohort study alongside the DAISY trial, BMC Health Services Research, 9, 215, 2009	Study findings updated by a more recent HE study (Søgaard 2014)
Teng, J., Mayo, N. E., Latimer, E., Hanley, J., Wood-Dauphinee, S., Cote, R., Scott, S., Costs and caregiver consequences of early supported discharge for stroke patients, Stroke, 34, 528-36, 2003	Population of interest: the study focus is primarily on patients.
Toseland RW, Smith TL. The impact of a caregiver health education program on health care costs. Research on Social Work Practice 2006;16(1):9–19.	This economic evaluation was conducted in the USA.
Vicente, C., Sabapathy, S., Formica, L., Maturi, B., Piwko, C., Cost-utility analysis of tocilizumab in the treatment of active systemic juvenile idiopathic arthritis, Value in Health, 16 (3), A225, 2013	Not the intervention of interest: The objective of this HE study is to determine the cost-effectiveness of tocilizumab with or without methotrexate compared to placebo with methotrexate for the treatment of juvenile idiopathic arthritis.

Study	Reason for Exclusion
Wilson, E., Thalanany, M., Shepstone, L., Charlesworth, G., Poland, F., Harvey, I., Price, D., Reynolds, S., Mugford, M., Befriending carers of people living with dementia: a cost utility analysis, International Journal of Geriatric Psychiatry, 24, 610-23, 2009	Duplication (Charlesworth 2008).
Wittenberg, E., Prosser, L. A., Disutility of illness for caregivers and families: A systematic review of the literature, Pharmacoeconomics, 31, 489-500, 2013	Study design - this review of HE studies has been excluded - but its references have been hand-searched for any relevant HE studies.
Wray, L. O., Shulan, M. D., Toseland, R. W., Freeman, K. E., Vasquez, B. E., Gao, J., The effect of telephone support groups on costs of care for veterans with dementia, Gerontologist, 50, 623-31, 2010	Population of interest: no adult carers.

Appendix L – Research recommendations

Research recommendations for review question: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult cares during: (i) changes to the setting in which caring is performed; (ii) the transition of the person receiving care to adulthood; and (iii) change of carer status or circumstances?

No research recommendations were made for this review question.

Appendix M – Quotes extracted from the included papers, which support the qualitative review findings

Quotes extracted from included papers for review: What is the effectiveness, cost-effectiveness, and acceptability of interventions for supporting adult cares during: (i) changes to the setting in which caring is performed; (ii) the transition of the person receiving care to adulthood; and (iii) change of carer status or circumstances?

Davies-Sue 2004

- ‘No pressure/feeling under pressure'

“After a while, I think my mother must have had problems or shown herself in a bad light, or they misunderstood her, and they asked me to remove her. It was within the fortnight, I felt that it wasn’t a lot of time.” (Adult carer of a person admitted to a nursing home - no condition specific)

- ‘Working together/working apart'

“*And as I was telling you about his clothes – ‘Oh, we’ve got a lady that’ll do this’ – this sort of attitude. I’ve been and told them everything that they want to know, and I will buy his clothes. I object strongly to that lady telling me, you know, to that extent. If they had said to me, ‘Well, we’ve got a lady, Mrs P, that sees to the needs of clothing, and if you like, then she will go and do the shopping for you’ – now that’s a different kettle of fish. But to turn round and say, ‘And we’ve got someone to see to the clothes,’ it’s a different attitude all together and I object to it strongly, I really do*.” (Adult carer of a person admitted to a nursing home - no condition specific)

- ‘Feeling supported/feeling unsupported'

“The matron and the other lady we know greeted us – that was quite nice. Mum was taken to her room … she was quite upset and I did nothing but cry. Just the thought of having to leave her there. One of the sisters tried to comfort me, she was very good.” (Adult carer of a person admitted to a nursing home - no condition specific)

“*They were lovely. And so that made me feel better. Because it is an emotional experience. Because I’ve been responsible for him for the last 6 years, and to suddenly let go and hand him over to somebody else, and think, oh, you know, ‘I hope it’s going to be all right.’ I did feel quite emotional about it. And I shed quite a few tears over it. But you know, they’ve all been so lovely. And that’s helped. I feel now some of the staff are more like a friend.*” (Adult carer of a person admitted to a nursing home - no condition specific)

“*Yes, well, I think there’s a lot, maybe, either at the hospital or at the home, that someone could have said, you know – ‘How are you feeling about this? How is it affecting you? Are you coming to terms with it?’ Where I just got on and did it, you know, I didn’t have time really to think.*” (Adult carer of a person admitted to a nursing home - no condition specific)

"*There was a questionnaire and they said, 'How much do you want to be involved? You know, would you want to know if you were away, if anything happened to your Mum?' I said, 'Oh I would!' They also asked me about my own feelings about my Mum moving in, was I OK about it.*" (Adult carer of a person admitted to a nursing home - no condition specific)

"*If I could turn the clock back, I think that I might have gone down a different avenue. And I would have insisted that I get more help in the community to perhaps keep her at home for a few more months. I could perhaps have said that she might even be with me now. Then perhaps I could have let go when she really got bad. But I can't turn the clock back. So I've got to accept what it is at this moment in time*." (Adult carer of a person admitted to a nursing home - no condition specific)

- 'Being in the know/working in the dark'

"Well, I used to have. There you used to be, it just depends who's on. They'd say, 'Would you like a dinner Jim?' and I'd say, 'Yes please.' But they never asked me for ages, about 12 months since I had one. " (Adult carer of a person admitted to a nursing home - no condition specific)

- 'Being in control/losing control'

"*They're together, they are looked after, they're warm and they're fed, and there's somebody there 24 hours a day if they need medical care. Acknowledging the fact that we're here and we've got a family and we've got our lives to live, they're not here. You couldn't want for anything more than that. Now, because you've got that situation – and even now we're still experimenting with patterns of visiting and trying to do the things we have to do like running the house, like decorating, we have difficulty in fitting in the things we have to do – and I'm not talking about going out, I'm talking about the things we have to do. We're struggling with our own lives and work, and they are actually being looked after, and to actually go somewhere and start beating your fists on somebody's desk and starting it all up again …*" (Adult carer of a person admitted to a nursing home - no condition specific)

Salisbury 2010

- 'In the hospital'

"*It took about 10 days before she was in the stroke unit. And I phoned Chest, Heart and Stroke [Medical Charity] on the day after she had the stroke and she'd actually said the hospital was quite bad for that and people weren't getting treated by the stroke unit, and that made me very bitter because I felt Florence's stroke got so much worse during that period because she couldn't get the proper treatment*." (Adult carer of a person with stroke)

"*My daughter says you've been here [Accident and Emergency] too long its time you were moved. And she said you're the one to say it*." (Adult carer of a person with stroke)

- 'I'm taking them home'

"*One of the staff nurses said to me think about my husband's long term care, you'll never be able to take him home, and that really, it really, really upset me. I says my husband's long term care is in his own home with* me." (Adult carer of a person with stroke)

"*Before he came out of hospital they wanted to put him in a home because I wouldn't be there to manage but I said no he's not going into a home*." (Adult carer of a person with stroke)

- 'Back at home'

"*We've actually - through Chest, Heart and Stroke [Medical Charity] - started to go to the gym."* (Adult carer of a person with stroke)

Ryan 2012

- 'No place like home'

"*She wanted to be at home. She would never have had wanted to be in any of those places. I remember trying asking her once and she wouldn't give an answer. People just don't want to think of these things*." (Adult carer of a person admitted to a nursing home - no condition specific)

- 'Carer advocate'

"He got a bit ill and the doctor came up. He said to me Kate it's going to get until worse. He said it had to come to an end. I said I would be alright. He said to me that I wasn't too well. It was getting to me but I wasn't giving in to them. He said that it was going to kill me. The social workers and the doctor encouraged me all the time what to do. I didn't think I would take a heart attack out of it." (Adult carer of a person admitted to a nursing home - no condition specific)

"*My doctor said to me that the rest of the family would be blamed for that because they walked away from it. I remember one time going to the doctor and asked for a tonic. I said I felt my patience and my nerves were totally shredded and she questioned me about it and said that it was totally unacceptable and that I couldn't go on. She didn't say it in so many words but I think she was saying that I would be heading for a nervous breakdown*." (Adult carer of a person admitted to a nursing home - no condition specific)

- 'Choosing a home: a foregone conclusion'

"*I came down to see Jolene who is the Manager and she took me round the whole place. Before I got to that stage it already had been recommended by several people*." (Adult carer of a person admitted to a nursing home - no condition specific)

"*My sister and I had actually chatted about that and mum had said one time to my sister that if she went to a nursing home she would like to go to the 'Elms'. In that respect it left it a little a bit easier for us in that we knew that if she was going to a nursing home that is where she had said*." (Adult carer of a person admitted to a nursing home - no condition specific)

- ‘Choosing a home: Rurality'

“*A lot of people love the country and they see the silage being made up and the cows down the field. The girls bring them out for a walk in their wheelchairs or whatever when the weather is warmer*.” (Adult carer of a person admitted to a nursing home - no condition specific)

- ‘Choosing a home: Familiarity'

“*When my mother was admitted and I looked round and I seen five people she would have known as residents who were in that home. I knew one of the nurses that I worked with previously in the hospital … it was a big help*.” (Adult carer of a person admitted to a nursing home - no condition specific)

Cobley 2013

- ‘Time not being a carer'

“*I could get on with the little jobs that wanted doing or I could just put my feet up and have a rest, so it made life a darn sight easier for me*.” (Adult carer of a person with stroke - receiving Early Supported Discharge services)

- ‘Limited support in dealing with carer strain'

“*Well I’m tired; I’ve lost such a lot of weight, it’s very demanding”* (Adult carer of a person with stroke - receiving Early Supported Discharge services)

“... *more active me, I’ve had to be a lot more active than I used to be because he used to do well half of what I used to do”* (Adult carer of a person with stroke - receiving Early Supported Discharge services)

“*Since he’s come home I’ve not really gone out very much. Normally I would just go out and do whatever, but I haven’t been able to do that since he’s come home from hospital”* (Adult carer of a person with stroke - receiving Early Supported Discharge services)

“*I’m very disappointed that they didn’t offer to help me, because obviously he would have had to go into a home or somewhere if I wasn’t doing it. So I mean I’m saving them a lot of money and time.”* (Adult carer of a person with stroke - receiving Early Supported Discharge services)

- ‘Lack of education and training of carers'

”*I don’t think they told me anything, I was just left out in the cold ... I didn’t have a clue what was going on ...’ (interview 6; carer). They also felt neglected: ‘these health professionals forget about the carer who is looking after the sick patient.”* (Adult carer of a person with stroke - receiving Early Supported Discharge services)

“*I wasn’t physically shown the best way to support him ... it was all trial and error’ .”* (Adult carer of a person with stroke - receiving Early Supported Discharge services)

“*His depression ... I just don’t know what to do. I can’t cope because I don’t know what to do to stop it. When he is continuously crying, it can be really wearing* *because you're helpless."* (Adult carer of a person with stroke - receiving Early Supported Discharge services)

'Inadequate provision and delivery of information'

"*It would have been nice to have somebody sit down with me and say this is what's happened, this is why it's happened, this is what you can expect. Okay, so it is there in the leaflets but you just kind of flick through the leaflets."* (Adult carer of a person with stroke - receiving Early Supported Discharge services)