National Institute for Health and Care Excellence

Draft for consultation

Supporting Adult Carers

RQF - Evidence review for providing practical support for adult carers

NICE guideline tbc

Evidence reviews

August 2019

Draft for Consultation

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

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Providing practical support for adult carers

Review question

What practical, social and community support interventions for adult carers are effective, cost-effective, and acceptable to them?

Introduction

The past decade has seen a growing emphasis on the importance for carers and those they support of active participation in a wider range of social and community activities than traditional day and similar services. The Care Act 2014's introduction of Personal Budgets will be driven forward by intentions in the Government's 2019 plans for Universal Personalised Support and a significant increase in Personal Budgets and a greater diversity of community activity and support. Carers UK's annual State of Caring reports underline the importance of personalised, social and community support for carers. However, there are ongoing debates about how best to encourage the wider use of Personal Budgets and Direct Payments and the support and advocacy often necessary to support carers in moving to a different and more personalised care and support system.

Carers UK and other carer organisations have emphasised the risk of isolation and loneliness for carers. 70% of carers responding to the Carers UK annual State of Care survey reported problems with mental health and emotional well-being. Carers can become isolated and peer support through the third sector and volunteers is important in terms of sharing information, offering practical support and advocacy. Carer's breaks are regularly cited as key to carer well-being, with breaks being widely described and varying from sitting services to overnight care. However, there are frequently limited options and an ongoing debate about the commissioning and funding of carer breaks for people with complex needs and the range of options that should be available.

Our evidence also demonstrated the wide range of options and sources of community support which might be available to carers, ranging from dementia cafes and support groups to day centres and home-based volunteer or buddy schemes. The Care Act introduced Personal Budgets for carers, with the possibility of direct payments as well as local authority commissioned care and support. There is currently limited evidence on carers' views of their own Personal Budgets, but the Government's commitment to extending Personal Budgets (and Personal Health Budgets) indicated to the Committee that this was an important development for carers and should be monitored.

Individual support for carers to be active and supported citizens comes within the wider context of initiatives such as the Department of Health and Social Care Innovation Fund to look beyond statutory services and develop carer friendly communities which create a wider range of options for carers and, as Carers UK proposes in its 2018 State of Caring Report, create better integration between health, social care and the voluntary sector and work together to both create 'care friendly' built environments and to encourage carers and those they support to feel fully included in community life.

Summary of protocol

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

Table 1: Summary of the protocol (PICO table)

Population	• Adult carers (18 years of age or older) who provide unpaid care for either ≥1 adults, or ≥1 young people aged 16-17 years with ongoing needs. • Relevant social-/health-care and other practitioners involved in providing care.
Intervention	Any practical support interventions for adult carers, including: • respite care and breaks including: ○ day care ○ in-home respite ○ host-family respite ○ institutional/ overnight respite ○ short breaks ○ respite programmes ○ assistive technologies • replacement care • crisis support • volunteer support • carer support groups • access-specific Carer Passport/cards/schemes • signposting • financial assistance • advocacy/support • communication/integration with health and social care professionals • support for carers of people at end of life and/or people after the person receiving care dies (see RQH).
Comparison	• no intervention • other interventions within the same category.
Outcome	Quantitative outcomes: • Critical outcomes ○ caring-related morbidity ○ impact of caring on carer • Important outcomes ○ social capital ○ carer quality of life ○ carer choice/control/efficacy Qualitative themes: • satisfaction with the intervention • perceived appropriateness of the intervention • perceived acceptability of the intervention • barriers and facilitators.

For full details see the review protocol in appendix A

Evidence

Included studies

This is a mixed-methods review so qualitative and quantitative studies were eligible for inclusion. The objective of this review was to establish whether there are any types of practical support interventions for adult carers that are effective, cost-effective, and acceptable to them.

For the quantitative part of the review, we looked for systematic reviews and randomised control trials (RCTs). For the qualitative part of the review, we looked for studies that collected and analysed data using qualitative methods (including focus groups, interviews, thematic analysis, framework analysis and content analysis). Surveys restricted to reporting descriptive data that were analysed quantitatively were excluded.

Evidence is summarised in a GRADE table for the quantitative studies and GRADE-CERQual tables for qualitative studies. These are provided in appendix F.

Quantitative component of the review

Two RCTs (Ali 2014; and Charlesworth 2008) were included, these studies are summarised in Table 2. One RCT was carried out in Sweden and included 241 young adult carers (Ali 2014). This study aimed to compare the effectiveness of a web-based intervention with a folder-based intervention, to support young adult carers of people experiencing mental illness.

The other RCT was conducted in the UK and included 236 adult carers (Charlesworth 2008). This study aimed to compare the effectiveness and cost-effectiveness of 2 interventions, a social intervention (access to a befriending scheme in addition to usual care) and usual care only, to support adult carers of people living with dementia.

In terms of outcomes, no included RCT reported on carer choice/control/efficacy. Common study limitations were the potential risk of performance bias, with neither RCT blinding included carers to the treatment allocation.

Qualitative component of the review

13 qualitative studies were included (Dali 2012, Greenwood 2012, Greenwood 2013, Harding 2004, Keyes 2016; Larkin 2007, Locock 2010, Mansell 2009, McSwiggan 2017, Moule 2014, Munn-Giddings 2007, Ryan 2008; and Skilbeck 2005)

Table 3 provides a summary of the 13 included qualitative studies. They were published between 2004 (Harding 2004) and 2017 (McSwiggan 2017). All studies included adult carers or adult former carers, with sample sizes ranging from 9 to 151 (Greenwood 2013 and Mansell 2009, respectively) and an overall total of 495 carers in the included studies. Carers were supporting people with a range of conditions (Table 3). All studies were conducted in the UK:

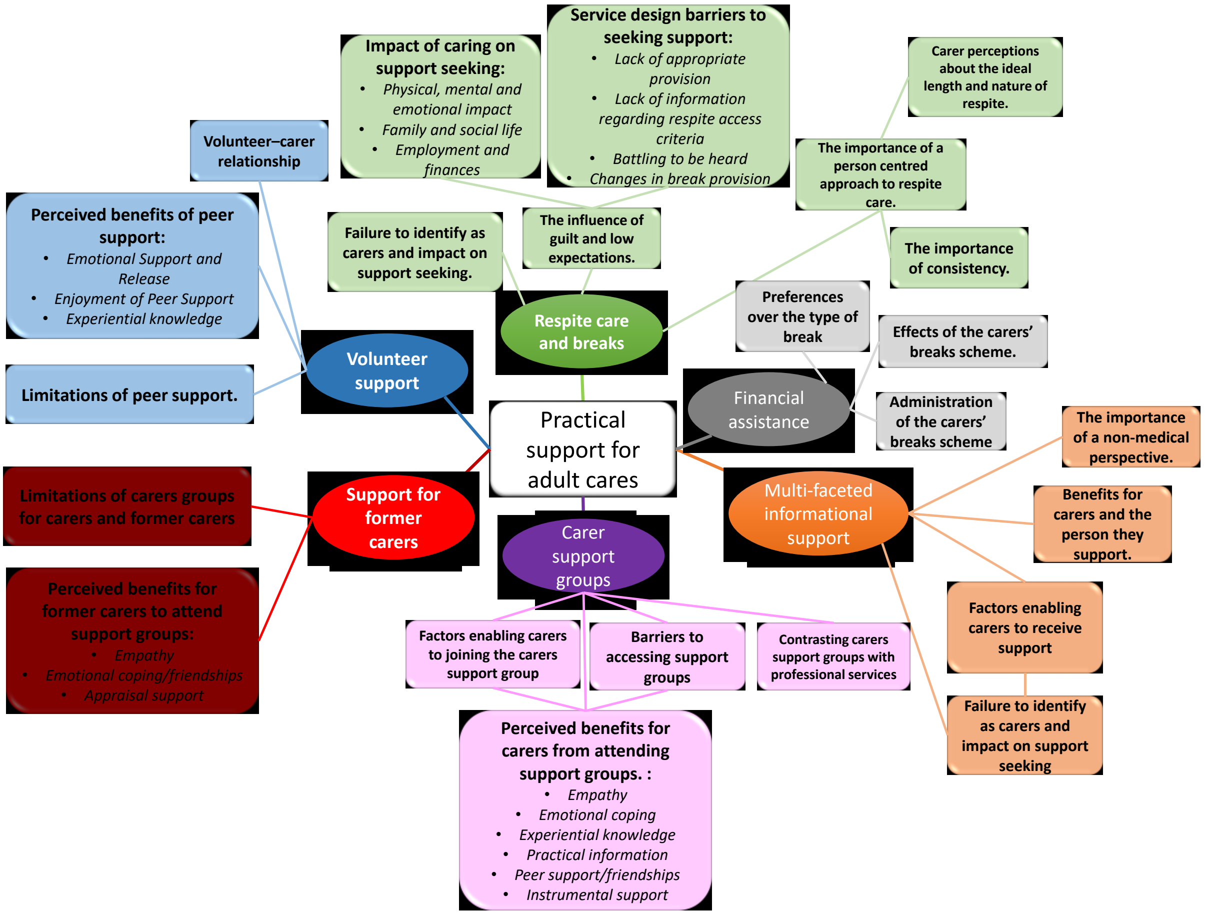
- 10 studies were conducted in England (Greenwood 2012, Greenwood 2013, Harding 2004, Keyes 2016, Larkin 2007, Locock 2010, Moule 2014, Munn-Giddings 2007, Ryan 2008, and Skilbeck 2005)
- 2 studies were conducted in Scotland (Dali 2012, and McSwiggan 2017)
- 1 study was conducted in Wales (Mansell 2009).

Most included studies collected data via semi-structured or unstructured interviews, 1 study used questionnaires (Mansell 2009) and 2 studies used focus group techniques (Dali 2012, and Mansell 2009). Data analysis methods included content analysis and thematic analysis, with the latter being the most common method across included studies.

In most of the included qualitative studies, the focus was on the overall experience of carers with respite care and breaks (Dali 2012, Greenwood 2012, Mansell 2009, McSwiggan 2017, and Skilbeck 2005), and carer support groups –including self-help groups or mutual support and peer-support (Locock 2010, Munn-Giddings 2007, Harding 2004, and Keyes 2016), or technical health procedures –nebuliser therapy (Alhaddad 2016) of the care recipient. 1 study focussed on carers' experiences, including the acceptability of and barriers to attending peer support provided by volunteers, namely former carers (Greenwood 2013). 1 study explored the benefits of carer support groups for former carers (Larkin 2007); and finally 1 study explored carers' views about a service offering support to carers in the form of a one-off payment, which they can use for any purpose (Moule 2014).

According to our thematic synthesis, providing practical support for adult carers has been explored in a number of central themes (as shown in Figure 1).

Figure 1: Thematic map



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 are presented in Table 2 and Table 3.

Quantitative component of the review

Table 2: Summary of included quantitative studies

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison (in the review)
Ali 2014	**Setting** Sweden **Study type** Two-groups RCT **Aim of the study**	N=241 **Carer characteristics** • Age – years, Mean (SD):	• I = Web-based support • C = Folder support	• Multi-faceted informational support intervention

Study	Details	Participants	Intervention groups evaluated (as named in the paper)	Comparison (in the review)
	This study aimed to compare the effectiveness of two interventions, a web-based support and a folder support, to support young adult carers of people experiencing mental illness **Study dates** 2010-2011 **Follow-up** 4 and 8 months	○ I = 20.5 (2.6) ○ C = 20.5 (2.5) • Gender (M/F - N) ○ I: 33/87 ○ C: 38/83 **Care recipient characteristics** Condition: Mental illness		
Charlesworth 2008	**Setting** UK **Study type** Two-groups cost-effectiveness RCT **Aim of the study** This study was aimed to compare the effectiveness and cost-effectiveness of two interventions, a social support intervention (access to an employed befriending facilitator in addition to usual care) and usual care only, to support adult carers of people living with dementia **Study dates** 2002-2004 **Follow-up** 6, 15 and 24 months	N=236 **Carer characteristics** • Age – years, Mean (SD): ○ I = 68.4 (11.3) ○ C = 20.5 (2.6) • Gender (M/F - N) ○ I: 40/76 ○ C: 44/76 **Care recipient characteristics** • Condition: Dementia including Alzheimer's Disease	• I = Access to a befriending volunteer (emotional support, informational support or “signposting”) + usual care • C = Usual care only (for example community psychiatric services, day hospitals, day centres, home care or personal care, respite care, and carers’ information or support groups)	• Carer support groups (befriending scheme)

C: Control group; F: Female; I: intervention group; M: Male; N: Number; N/R: 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	Participants	Methods	Themes
Dali 2012 **Aim of the study** This study is stage three of a broader research agenda. The aim of this project was to gather the experiences of unpaid carers in	N=48 adult carers: • 36= focus group • 12= interviews **Carers** • Age (mean age/range – years) = N/R) • Gender (M/F: N)= N/R **Professionals** • N=0	• **Recruitment period:** August to September 2011 • **Data collection & analysis methods:** ○ Data were collected through (face-to-face and telephone) semi-structured interviews and 4 focus group.	Respite care and breaks • Physical, mental and emotional impact • Family and social life • Employment and finances • Failure to identify as carers and impact on support seeking

Study	Participants	Methods	Themes
accessing and using short breaks in their area.	**Care recipients** • (condition) = Range of conditions (for example physical disability, learning disability, long-term condition, old age etc.).	○ No details are reported about the data analysis.	• The influence of guilt and low expectations • Lack of appropriate provision • Lack of information regarding respite access criteria • Battling to be heard • Changes in break provision • The importance of a person centred approach to respite care • Carer perceptions about the ideal length and nature of respite
Greenwood 2012 **Aim of the study** The aims of this qualitative study were to explore carers' experiences of in-home respite, their perceptions of care workers and their perceptions of the impact of respite on themselves and their cared for.	N=12 adult carers **Carers** • Age = range (years): 41 to 90 • Gender (M/F: N)= 3/9 **Professionals** • N=0 **Care recipients** • Condition = Range of conditions (for example dementia, stroke and Parkinson's disease).	• **Recruitment period:** N/R • **Data collection & analysis methods:** ○ Data were collected through (face-to-face) semi-structured interviews. ○ Data were analysed using thematic analysis.	Respite care and breaks • Physical, mental and emotional impact • The influence of guilt and low expectations • Battling to be heard • The importance of a person centred approach to respite care • Carer perceptions about the ideal length and nature of respite
Greenwood 2013 **Aim of the study** The aim of this qualitative study was to explore the experiences of carers, peer volunteers (former carers) and people cared for, with a peer support service.	N=9 adult carers **Carers** • Age = mean - range (years): 64 - 49 to 80 • Gender (M/F: N)= 1/8 **Professionals** • N = 4 peer volunteers (former carers) **Care recipients** • Condition = Dementia	• **Recruitment period:** 2008-2011 • **Data collection & analysis methods:** ○ Data were collected through (face-to-face) semi-structured interviews. ○ The analysis used draws on ethnography framework with the identification of recurrent themes. Analysis followed ''conventional content analysis''.	Volunteer support • Emotional Support and Release • Enjoyment of Peer Support • Experiential knowledge • Limitations of Peer Support • Volunteer–carer relationship
Harding 2004 **Aim of the study** The aims of this mixed-methods study were to	N=24 adult carers **Carers** • Age = range (years): 60 - 26 to 88 • Gender (M/F: N)= N/R	• **Recruitment period:** N/R • **Data collection & analysis methods:** ○ Data were collected from the intervention attendees using semi-	Carer support groups • Factors enabling carers to be joining the carers support group • Empathy • Emotional coping

Study	Participants	Methods	Themes
evaluate a short-term group intervention (Group support + informal teaching) for informal carers of people with a range of conditions attending a home palliative care service.	**Professionals** • N=0 **Care recipients** • Condition = Range of conditions (for example Cancer, HIV, motor neuron disease, Bechet's disease, congestive heart failure, Leigh's syndrome and Parkinson's).	structured interviews, which was administered immediately following the quantitative measures post-intervention. ○ The analysis used a content analysis matrix of principal categories.	• Experiential knowledge • Practical information • Peer support/friendships
Keyes 2016 **Aim of the study** This study is part of a broader research agenda - the Healthbridge study. The aims of this mixed-methods study were to evaluate peer support by and for people living with dementia and carers within initiatives which prioritise peer support as well as peer support that occurred as a result of or alongside services which prioritise advice and information provision.	N=68 adult carers **Carers** • Age (mean age/range –years) = N/R • Gender (M/F: N)=N/R **Professionals** • N = 82 **Care recipients** • (condition) = Dementia	• **Recruitment period:** N/R • **Data collection & analysis methods:** ○ Data were collected through (face-to-face) semi-structured interviews. ○ The analysis used was a five-stage process: 1-coding framework developed; 2-further development of the framework; 3-development of emerging themes; 4-modelling of themes and 5- verification of models based on the entire data set.	Carer support groups • Empathy • Experiential knowledge • Peer support/friendships • Contrasting carers support groups with professional services
Larkin 2007 **Aim of the study** The aims of this qualitative study were to explore the role of face-to-face carers groups in supporting former carers.	N=37 former carers **Carers** • Age = range (years): 30 to 80+ (modal age: 60 to 69 years) • Gender (M/F: N)=11/26 **Professionals** • N=0 **Care recipients** • Condition = Former carer - no condition specific	• **Recruitment period:** N/R • **Data collection & analysis methods:** ○ Data were collected through (face-to-face) semi-structured interviews. ○ The analysis used a grounded theory process.	Carer support groups • Emotional coping • Practical information • Peer support/friendships • Instrumental support • Carer support groups for former carers • Empathy • Emotional coping/friendships and appraisal support • Limitations of carers groups for carers and former carers
Locock 2010	N=22 adult carers	• **Recruitment period:**	Carer support groups

Study	Participants	Methods	Themes
Aim of the study The aims of this qualitative secondary research were to explore attitudes and views to peer support among people with Motor neurone disease and their family carers. It reports findings from a secondary analysis of data from two UK qualitative studies.	**Carers** • Age = More than 18 years old (mean/range -years: N/R) • Gender (M/F: N)=N/R **Professionals** • N=0 **Care recipients** • Condition = Motor neurone disease	Secondary analysis pooling the findings of two UK qualitative studies: Brown 2008: 2005-2006; Locock 2009: 2006-2007 • **Data collection & analysis methods:** o Data were collected by pooling qualitative findings of 2 studies conducted previously by the authors in the UK (Brown 2008; Locock 2009). o In both studies data were collected through semi-structured interviews.	• Barriers to accessing support groups • Emotional coping • Practical information • Peer support/friendships
Mansell 2009 **Aim of the study** The aims of this mixed-methods study were to evaluate carers' perceptions of respite care services offered to them by their local authority. The focus was on carers of people with a learning disability.	N=151 adult carers **Carers** • Age = range (years): 25 to 75 • Gender (M/F: N)=26/135 **Professionals** • N=0 **Care recipient** • Condition = Learning disability	• **Recruitment period:** N/R • **Data collection & analysis methods:** o Data were collected through semi-structured questionnaire including both qualitative and quantitative data, and further qualitative data came from two focus groups. o Data were analysed using thematic analysis.	Respite care and breaks • Lack of information regarding respite access criteria • Battling to be heard • Carer perceptions about the ideal length and nature of respite
McSwiggan 2017 **Aim of the study** The aims of this qualitative study were to explore the carers' perceptions on the scope, quality and fit of information-sharing between carers, older people and respite services.	N=24 adult carers **Carers** • Age = More than 18 years old (mean age/range -years: N/R) • Gender (M/F: N)=N/R **Professionals** • N=0 **Care recipients** • Condition = Older people (for example Cognitive, Dysphasia, Visual and auditory).	• **Recruitment period:** 2013-2014. • **Data collection & analysis methods:** o Data were collected through semi-structured interviews. o The analysis used a framework approach (Gale 2013) and was an iterative process taking place alongside data generation and transcription. Thematic analysis was undertaken by two researchers.	Respite care and breaks • Lack of appropriate provision • Lack of information regarding respite access criteria • Changes in break provision
Moule 2014 **Aim of the study** The aims of this qualitative study	N=40 adult carers **Carers**	• **Recruitment period:** 2012-2013 • **Data collection & analysis methods:**	Financial assistance (for respite care and breaks) • Preferences over the type of break

Study	Participants	Methods	Themes
were to explore carers' views of a service which offers support to carers in the form of a one-off payment - which they can use for anything they choose.	• Age = range (years): 21 to 90 • Gender (M/F: N)=9/31 **Professionals** • N=0 **Care recipients** • Condition = Range of conditions (for example Alzheimer's disease, Lewy Body disease, Down's syndrome, epilepsy, multiple sclerosis, autism and attention deficit hyperactivity disorder (ADHD), impairment results from a stroke and cancer).	○ Data were collected through (telephone) semi-structured interviews. ○ The analysis used a thematic framework using a recognised process to support content analysis (Miles and Huberman, 1994).	• Effects of the carers' breaks scheme] • Administration of the carers' breaks scheme
Munn-Giddings 2007 **Aim of the study** The aims of this qualitative study were to explore carers' views of attending self-help/mutual aid groups.	N=15 adult carers **Carers** • Age = range (years): 50 to 67 • Gender (M/F: N)=6/9 **Professionals** • N=0 **Care recipients** • Condition = Range of conditions (for example Alzheimer's disease, Lewy Body disease, and Dementia).	• **Recruitment period:** N/R • **Data collection & analysis methods:** ○ Data were collected through (face-to-face) semi-structured interviews. ○ Data were analysed using thematic analysis. Thematic analysis was undertaken by two researchers.	Carer support groups • Factors enabling carers to joining the carers support group • Empathy • Emotional coping • Experiential knowledge • Practical information • Peer support/friendships • Contrasting carers support groups with professional services
Ryan 2008 **Aim of the study** The aims of this qualitative study were to explore the views of carers of people with lung cancer (compared with professionals) in relation to the provision of a pro-active social support intervention (Macmillan Carers Project).	N=20 adult carers **Carers** • Age = range (years): 37 to 88 • Gender (M/F: N)=4/16 **Professionals** • N= 21 **Care recipients** • Condition = Lung cancer	• **Recruitment period:** N/R • **Data collection & analysis methods:** ○ Data were collected through (face-to-face) semi-structured interviews. ○ The analysis used the thematic approach.	Multi-faceted informational support • Failure to identify as carers and impact on support seeking • Factors enabling carers to receive support • Benefits for carers and the person they support • The importance of a non-medical perspective
Skilbeck 2005 **Aim of the study**	N=25 adult carers **Carers**	• **Recruitment period:** N/R • **Data collection & analysis methods:**	Respite care and breaks

Study	Participants	Methods	Themes
The aims of this mixed-methods study were to explore experiences and expectations of carers whose relative had been admitted to the local hospice for inpatient respite care.	• Age = mean - range (years): 61 - 38 to 78 • Gender (M/F: N)=N/R **Professionals** • N=0 **Care recipients** • Condition = Range of conditions (for example Cancer and neurological conditions).	○ Data were collected through (face-to-face and telephone) semi-structured interviews. ○ The analysis used a process of constant comparison; this involved detailed reading of the transcripts and independent coding of the data by members of the research team.	• Lack of information regarding respite access criteria • Changes in break provision • The importance of consistency. • The importance of a person centred approach to respite care

F: Female; M: Male; N: Number; N/R: not reported.

See the full evidence tables in appendix D.

Quality assessment of outcomes included in the evidence review

See the evidence profiles in appendix F.

Economic evidence

Included studies

One study was identified with respect to the cost-effectiveness of interventions for providing carers with practical support (Charlesworth 2008). Table 4 provides a brief summary of the included study.

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
• Charlesworth 2008 • Cost utility conducted alongside an RCT • UK.	• Carers of people living with dementia.	• Social support intervention: access to a befriending volunteer (emotional support, informational support or "signposting") plus treatment as usual (TAU) • Treatment as usual.	• Societal • 2005-06 prices	Sensitivity analysis was performed to consider the cost-effectiveness of the intervention within different scenarios: • Varying the perspective • Varying the time-point

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 study (Charlesworth 2008) reported on a UK economic evaluation undertaken alongside a RCT. Participants in the trial were adult family carers of people living with dementia. The study aimed to assess:

1. whether a social support intervention (access to an employed befriending facilitator in addition to usual care) is effective relative to usual care alone
2. incremental cost-effectiveness from direct and indirect costs

The intervention provided access to an employed befriending facilitator, and the offer of contact with a trained volunteer befriender, offering one-to-one emotional support for the duration of the befriending schemes (the expectation was that befriending visits by the trained volunteer befrienders would be held weekly for at least 6 months). The intervention was provided in addition to usual care, which comprised typical social and voluntary services for carers, such as short-term and longer term respite support services, information, support groups, and luncheon clubs.

Costing was undertaken using a societal perspective, which included costs incurred by the statutory sector (NHS and other government funded sources), the voluntary sector and the household sector. All costs were presented in UK pounds sterling at 2005-06 prices. Discounting of costs and QALYs accrued in the short-term (between 12 and 15 months) was not undertaken, while costs incurred and quality adjusted life-years (QALYs) accrued between 15 and 24 months were discounted at 3.5%. Data on resource use incorporated the costs relating to the carer and the person with dementia but in the base case utility analysis, health-related quality of life, as measured by EQ-5D, pertained only to the carer. Both resource use and effectiveness evidence were derived from a prospective single-blinded RCT, with a follow-up of 12, 15 and 24 months (Charlesworth 2008).

No significant difference in QALYs and costs were found between carers receiving the emotional support intervention and those receiving usual care only, at 15 months follow-up in the primary analysis. The mean incremental cost-effectiveness ratio (ICER) of befriending was £105,954 with a 42.2% probability that the intervention would be cost-effective at a cost-effectiveness threshold of £30,000 per QALY. When the analysis was based on the utility of the care dyad (care recipient and carer) the ICER for befriending fell to £26,848 with a 51.4% probability of being cost-effective.

One-way sensitivity analysis was used to examine the impact of varying the costing perspective and the time horizon. These analyses showed that as the time-horizon extended, the cost-effectiveness declined, with costs increasing at a faster rate than the corresponding health gain. A key determinant of cost-effectiveness when different sectoral perspectives were adopted, were the proportion of costs borne by the sector. From a statutory perspective, the access to befriending intervention has a lower probability of being cost-effective than a societal approach. On the other hand, the befriending intervention had a 69.9% probability of being cost-effective compared with usual care at a cost-effectiveness threshold of £30,000 per QALY from the voluntary sector perspective.

The authors concluded that 'access to a befriender facilitator' is neither an effective nor a cost-effective intervention in the support of carers of people living with dementia. However, they do suggest that this may in part be an artefact of restricting the primary analysis to the utility of the carer when a case could be made that the utility of the care dyad is more appropriate.

Economic model

No economic model was undertaken for this review because although this was identified as high 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 'PS' and then a number. PS stands for (providing) practical support for adult carers.

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.

Multi-faceted informational support

Caring-related morbidity and carer quality of life

- **PS1 and 2** Very low quality evidence from 1 RCT from Sweden, including 241 young adult carers of people with mental health issues, could not differentiate levels of perceived HR-QoL (customised measure), stress (Perceived Stress Scale), well-being (Well-Being Index-WHO 5), or perceived health (customised measure) between carers receiving an online multi-faceted informational intervention (web-based support) versus usual care (folder-based support) at 4 and 8 months follow-up. The web-site support intervention provided young adult carers with access to practical information and advice about taking care of themselves, available support services, and information about the disease; and was delivered by professionals and updated on a regular basis.

Impact of caring on carer

- **PS3** Very low to low quality evidence from 1 RCT from Sweden showed that there was conflicting evidence about the effects of multi-faceted informational support on perceived levels of caring situation in young adult carers of people with mental health issues. Low quality evidence from this RCT found improved levels of perceived positive caring situation (cope-index, positive subscale) in carers receiving the intervention (web-based support) versus usual care (folder-based support) at 4 months follow-up. However, very low quality evidence from the same RCT, could not differentiate levels of positive caring situation (cope-index, positive subscale) at 8 months follow up, negative caring situation (cope-index, negative subscale), or could not differentiate levels quality of support provided (cope-index, quality of support subscale) between carers receiving the web-based support versus folder-based support at 4 and 8 months follow-up. The web-site support intervention provided young adult carers with access to practical information and advice about taking care of themselves, available support services, and information about the disease; and was delivered by professionals and updated on a regular basis.

Social capital

- **PS4** No data reporting on this outcome

Carer choice/control/efficacy

- **PS5** No data reporting on this outcome

Qualitative themes

- **PS6 Failure to identify as carers and impact on support seeking.** There is very low quality evidence from 1 study that many adult carers did not identify themselves as actual carers, as they felt they were only the spouses, parents and children fulfilling a natural role for their loved ones. This had implications for whether a carer will seek practical support.
- **PS7 Factors enabling carers to seek support.** There is very low quality evidence from 1 study that many professionals delivering a multi-faceted support intervention [Macmillan Carers Project] felt that carers of people with lung cancer were more likely to seek support

if they were emotionally resilient, pro-active, organised (for example, they had routines, lists and knowledge of where to seek information), in good health, financially secure; and had good family relations and support, supportive employment, confidence to admit difficulty with coping and to ask for help, good communication skills and the ability to network.

- **PS8 Benefits for carers and the person they support.** There is very low quality evidence from on1e study that many adult carers often felt that a multi-faceted support intervention [Macmillan Carers Project] enabled their care recipients to stay at home longer, rather than being admitted to hospital and even to die at home (according to the care recipients' wishes). Some carers felt it was important to talk to someone outside of their family or friends, and the medical or nursing team, this was perceived as one of the main benefits of the intervention.
- **PS9 The importance of a non-medical perspective.** There is very low quality evidence from 1 study that many adult carers felt a non-medical, social work background was appropriate for the professionals delivering a multi-faceted support intervention [Macmillan Carers Project]. In addition, several carers felt that the Macmillan Carers Project workers provided information (about the illness, the investigation and treatment process plus future care options) and acted as a useful point of contact, besides giving emotional and practical support.

Respite care and breaks

Caring-related morbidity and carer quality of life

- **PS10** No data reporting on this outcome

Impact of caring on carer

- **PS11** No data reporting on this outcome

Social capital

- **PS12** No data reporting on this outcome

Carer quality of life

- **PS13** No data reporting on this outcome

Carer choice/control/efficacy

- **PS14** No data reporting on this outcome

Qualitative themes

- **PS15 Impact of caring on support seeking.** There is low to very low quality evidence from 2 studies that many adult carers felt their caring role negatively affected their well-being, their family and social life, and their employment opportunities and finances. Low quality evidence suggests that many adult carers reported feelings of exhaustion and lack of sleep, with some who described experiencing mental health problems including depression. In addition, very low quality evidence suggests that many adult carers reported the impact of caring on their family life and on their social lives, including not being able to pursue personal interests, hobbies or see friends. Finally, many employed carers felt that work was fundamental to their sense of self and also provided a break from their caring role; other carers struggled to juggle a job and caring, and some of them experienced loss of income, loss of opportunities for promotion and in some cases had to give up work. All these factors had potential implications for whether a carer will be aware of or will seek support.
- **PS16 Failure to identify as carers and impact on support seeking.** There is very low quality evidence from 1 study that many adult carers did not identify themselves as actual carers, as they felt they were only fulfilling a natural role. This had implications for whether they will seek respite care and breaks.

- **PS17 The influence of guilt and low expectations.** There is low quality evidence from 2 studies that many adult carers experienced feelings of guilt about using respite care and short breaks; for example, some carers felt taking a break amounted to 'admitting defeat'. This could often inhibit them from seeking a break from caring and/or using the breaks they did take. In addition, many adult carers reported feelings of powerlessness and low expectations of respite support; for example some carers felt that they were lucky to receive any help at all and therefore should neither criticise the professional providing respite nor ask them to do additional tasks.
- **PS18 Service design barriers to seeking support.** There is moderate to low quality evidence from five studies that for carers, the lack of appropriate provision of respite services, the lack of information regarding respite access criteria, struggling to be heard by providers, and the changes in break provision were perceived as barriers to support-seeking. Low quality evidence from 2 studies suggests that some carers perceived respite services as unacceptable because of the poor quality or because they were age-inappropriate. Moderate quality evidence from 4 studies suggests that many carers did not know their entitlements to respite and experienced difficulty finding out information, with most of them wanting more information about the availability of respite services. Some carers also reported that they took responsibility for finding out information for themselves because of a lack of information from GPs and social work services. Moderate quality evidence from 4 studies suggests that many carers expressed difficulty when engaging with statutory social services. Carers felt that respite services and professionals should work with them throughout different temporal phases of their caring journeys in a way that responds to carers' changing needs and the changing needs of the person being supported. A number of carers reported that the planning processes to access respite care and breaks was impersonal, time consuming, overly bureaucratic and stressful. They said that opportunities to visit a service before respite care begins are valuable in terms of reassuring carers and care recipients about what will happen during respite care; and, as new care arrangements are navigated, carers highlighted that regular face-to-face contacts are welcomed as a means of building confidence and trustful relationships. Finally, moderate quality evidence from 3 studies suggests that many carers reported that changes in provision of respite care could impact on the care recipient.
- **PS19 The importance of a person centred approach to respite care.** There is moderate to very low quality evidence from 4 studies that explores the experiences and views of carers in relation to the role of professionals in delivering respite support. Very low quality evidence from 1 study suggests that many carers felt professionals to have an unrealistic understanding of the person's circumstances and how natural life stages were different for carers under these circumstances. In addition, moderate quality evidence from 3 studies suggests that carers felt that professionals had to reflect and be responsive to the needs of the care recipient in order to be effective. Carers felt it was very important to have a personal, trusting relationship with professionals delivering respite support. Trust in these professionals included characteristics such as their reliability and sensitivity to the person's needs. Other carers felt that a good respite professional had to have particular qualities, including good communication, understanding and being adaptable as well as being able to stimulate or motivate the person being supported.
- **PS20 Carer perceptions about the ideal length and nature of respite.** There is very low quality evidence from 2 qualitative studies that many adult carers had mixed views in relation to the type of break offered and the duration of the break. Most carers suggested an overnight stay was required for the 'break' to be considered by them as respite. Many carers reported the need to have sufficient time to feel refreshed by the break and this was necessary for them to feel that they had received something that was of value to them. Other carers felt that any length of break had a positive impact.
- **PS21 The importance of consistency.** There is low quality evidence from 2 studies that many adult carers reported that a benefit of having respite at regular time points was the ability to plan their time. Some carers felt that having an infrequent or irregular break actually had a detrimental effect on their ability to cope with the caring role.

Replacement care

- **PS22** No evidence (neither quantitative nor qualitative) was identified about this intervention category

Crisis support

- **PS23** No evidence (neither quantitative nor qualitative) was identified about this intervention category

Volunteer support

Caring-related morbidity and carer quality of life

- **PS24** No data reporting on this outcome

Impact of caring on carer

- **PS25** No data reporting on this outcome

Social capital

- **PS26** No data reporting on this outcome

Carer quality of life

- **PS27** No data reporting on this outcome

Carer choice/control/efficacy

- **PS28** No data reporting on this outcome

Qualitative themes

- **PS29 Perceived benefits of peer support.** There is low quality evidence from 1 study that many adult carers of people living with dementia reported empathy, social and emotional support, enjoyment and experiential knowledge as the main perceived benefits of peer support. Many carers and volunteers (former carers of people living with dementia) perceived peer support to be beneficial because it helped real they were not alone in their experiences and emotions. Carers attending peer support felt less isolated; former carers also felt better meeting other former carers during training and learning (this helped them to realise that their experiences were not unusual and that they are helpful to others). In addition, both carers and volunteers described emotional support and release gained from receiving and giving peer support; they also described peer support as enjoyable and emphasized the pleasure of social interaction –in particular, the volunteers enjoyed meeting new people which sometimes reduced their own isolation. Lastly, many carers felt that peer support helped them to cope by giving them different perspectives of caring and by allowing them to appreciate the importance of their role.
- **PS30 Limitations of peer support.** There is low quality evidence from 1 study that many adult carers of people living with dementia perceived the peer support offered as insufficient, providing only short-lived benefit. One other limitation of peer support was the diversity of carers' reactions to caring and to peer support, which restricted how much the volunteer could help.
- **PS31 Volunteer–carer relationship.** There is low quality evidence from 1 study that most carers and volunteers reported that a key element of the peer volunteer–carer relationship was the shared experience of supporting someone with dementia. In addition, several carers reported they could talk to volunteers about things that they were unable to talk about elsewhere (including among family).

Carer support groups

Caring-related morbidity, social capital and quality of life

- **PS32** Low quality evidence from 1 RCT from the UK, including 236 young carers of people living with dementias, could not differentiate levels of perceived social support

(MSPSS), perceived HR-QoL (EQ-5D global VAS), depression and anxiety (HADS), perceived loneliness (loneliness scale), or perceived affect (PANAS—positive affect subscale) between carers receiving a befriending scheme versus usual care (including either community psychiatric services, day hospitals, day centres, home care or personal care, respite care, or carers' information or support groups) at 6, 15 and 24 months follow-up. The befriending scheme was coordinated by professional befriender facilitators, and delivered by befriending volunteers who provided carers with emotional support, informational support and signposting.

Impact of caring on carer

- **PS33** No data reporting on this outcome

Carer choice/control/efficacy

- **PS34** No data reporting on this outcome

Qualitative themes

- **PS35 Factors enabling carers to joining support groups.** There is very low quality evidence from 2 studies that for adult carers factors prompting carers to join the carers support group included; feelings of loneliness, perceived diminishing support available via their usual social networks and the need to meet people who were in very similar circumstances.
- **PS36 Barriers for carers to accessing support groups.** There is very low quality evidence from 1 study from the UK that most carers experienced practical access problems, which prevented them from attending face-to-face support groups. For example, some carers [of people with NMD] who were working full-time reported that attending daytime meetings was difficult. In addition, transport services were important in facilitating carers’ [] attendance at the support group, especially for older carers and those who could not drive.
- **PS37 Perceived benefits for carers from attending support groups.** There is moderate to low quality evidence from 5 studies that many adult carers reported the following benefits of attending carer support groups; empathy, emotional coping, experiential knowledge, practical information, peer support or friendship and instrumental support. . Low quality evidence from 3 studies suggests that what many carers felt they gained from being part of the group through meeting people who could empathise and not just sympathise with their experience. In addition, by attending support groups, many carers felt they improved their collective knowledge, which would turn in give them practical and emotional support. Moderate quality evidence from 4 studies indicates that regular group meetings offered a forum in which carers monitored one another’s problems, and assessed whether they were coping (for example, during periods of crisis); other carers reported emotional benefits from sharing less ‘positive’ emotions including sadness, fear, anger and sometimes guilt. The same evidence shows that many carers felt that an important advantage of support groups was sharing advice with each other about accessing local services, claiming benefits, and coping strategies. Finally, moderate quality evidence from 5 studies suggests that many carers felt that an important advantage of support groups was the relationships built between peers, stemming from the comfort of knowing they could contact each other at any time.
- **PS38 Contrasting carers support groups with professional services.** There is low quality evidence from 2 studies that many carers expressed concern at the general lack of appreciation by professional carers of the scope and breadth of their caring responsibilities, and of the importance of their relationship with the person they support (especially in relation to those professionals with whom they did not have long-term contact). For some carers, the support group held significance because they had lost their trust in the ability of services and professionals to meet their needs.

Access-specific Carer Passport/cards/schemes

- **PS39** No evidence (neither quantitative nor qualitative) was identified about this intervention category

Signposting

- **PS40** No evidence (neither quantitative nor qualitative) was identified about this intervention category

Financial assistance

Caring-related morbidity and carer quality of life

- **PS41** No data reporting on this outcome

Impact of caring on carer

- **PS42** No data reporting on this outcome

Social capital

- **PS43** No data reporting on this outcome

Carer quality of life

- **PS44** No data reporting on this outcome

Carer choice/control/efficacy

- **PS45** No data reporting on this outcome

Qualitative themes

- **PS46 Preferences over the type of break.** There is low quality evidence from 1 study that many adult carers receiving an individualised financial support (a one-off payment for funding any form of respite) appreciated having a free choice on the nature of their break. They reported that a range of factors influenced the breaks chosen, including short breaks away (with or without the person being cared for); alternative care for the person with support needs; swimming, gym or exercise classes/membership; and transport for carers to travel with or without the care recipient.
- **PS47 Effects of the carers' breaks scheme.** There is low quality evidence from 1 study that many adult carers receiving an individualised financial support (a one-off payment for funding any form of respite) had mixed views about whether they should or should not receive funding to spend on themselves, with some feeling of "cheating" and not deserving it. Carers associated an improvement in their own well-being and, or ability to care with a positive impact on the care recipient. Finally, for some carers, although the financial support had had positive effects for them, it was perceived as being limited.
- **PS48 Administration of the carers' breaks scheme.** There is low quality evidence from 1 study that many adult carers receiving an individualised financial support (a one-off payment for funding any form of respite) became aware of the Carers' Breaks scheme through a variety of sources, including GP practices, social services, community nurses, the voluntary sector and word of mouth. In addition, they found the assessment for accessing the scheme to be a positive experience, especially when conducted face-to-face.

Advocacy/support

- **PS49** No evidence (neither quantitative nor qualitative) was identified about this intervention category

Communication/integration with health and social care professionals

- **PS50** No evidence (neither quantitative nor qualitative) was identified about this intervention category

Support for former carers

Caring-related morbidity and carer quality of life

- **PS51** No data reporting on this outcome

Impact of caring on carer

- **PS52** No data reporting on this outcome

Social capital

- **PS53** No data reporting on this outcome

Carer quality of life

- **PS54** No data reporting on this outcome

Carer choice/control/efficacy

- **PS55** No data reporting on this outcome

Qualitative themes

- **PS56 Perceived benefits for former carers to attend support groups.** There is low quality evidence from 1 study that many adult former carers felt carer support groups could also meet post-caring needs, for example compensating for their sense of loss after the end of their caring role and helping them feel they 'belong'. Additionally, a number of former carers felt that support groups were a source of friendship that provided social and emotional support and help with decision-making and planning.
- **PS57 Limitations of carers groups for former carers.** There is low quality evidence from 1 study that many adult former carers said the following factors or characteristics relating to other group members could potentially limit the value of carers groups; professional backgrounds, previous caring experiences, feelings about participation in groups and gender.

Economic component of the review

- **PS58** One directly applicable cost-utility analysis from the UK with potentially serious limitations compared the befriending of carers by trained lay workers with usual care in adult carers of people living with dementia. The intervention (befriending of carers by trained workers) was found to be not cost-effective at 15 months follow-up: the incremental cost-effectiveness ratio (ICER) was £105,954 per QALY. Including QALY gains for the person cared for made the befriending intervention borderline cost-effective at a cost-effectiveness threshold of £20,000 to £30,000 per QALY.

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

This evidence review includes both qualitative and quantitative outcomes. Evidence on most of the outcomes considered during protocol development was identified.

When looking at the quantitative data, Impact of caring on carer (including resilience, distress, and burden) and caring-related morbidity (including physical and mental health) were considered to be critical outcomes for this question. Carer choice/control/efficacy, carer quality of life and social capital (that is range of social contact that provides access to social/emotional/practical support) were also considered to be the important outcomes. Quantitative evidence was identified in relation to all critical and important outcomes, except carer choice/control/efficacy.

The committee focussed their discussion mainly on the following qualitative outcomes (or themes), including the predisposing, enabling, and impeding factors for carers to receive support from:

1) respite care and breaks (including impact of caring on carers, identifying as a carer, feelings of guilt in using respite care and breaks, barriers to accessing respite care and breaks, the role of professionals in delivering respite support, the quality of breaks and perceived benefits of respite, and the length or frequency of respite care and breaks);

2) volunteer support (including perceived benefits, drawbacks, challenges, and limitations of peer support, and the volunteer–carer relationship);

3) carer support groups (including barriers and facilitators to accessing support groups, perceived benefits from attending carer support groups, and contrasting carers support groups with professional services); and

4) financial assistance (including financial benefits and administration of receiving support).

The committee also considered two further qualitative outcomes in making recommendations: support for former carers (including perceived benefits and challenges for former carers to attend support groups); and multi-faceted informational interventions for carers (including factors enabling carers to receive the intervention and the care workers to provide it; perceived benefits of the intervention, and the role of professionals in the delivery of the intervention).

The quality of the evidence

In terms of quantitative evidence, 2 randomised controlled trials (RCTs) were included in the review. The quality of evidence ranged from low to very low, and covered only two areas considered during protocol development: multi-faceted informational support, and carer support groups.

Thirteen studies were included in the qualitative component of the review. The quality of evidence for the various themes identified in the qualitative review ranged from moderate to very low, and covered a number of areas (that is carer support groups, financial assistance, multi-faceted informational support, respite care and breaks, support for former carers, and volunteer support.) The committee agreed that the data from the included studies were applicable across all the UK population of adult carers. It was also noted by the committee that the populations of carers in the studies were mixed (in terms of age, gender, and conditions of people being supported), and the data were highly adequate (in terms of richness and quantity of data supporting the findings of the review).

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 coud be used as a basis for recommendations.

Two RCTs provided quantitative evidence about the effectiveness of practical support interventions. One provided very low quality data about a multi-faceted support intervention, demonstrating no improvement in morbidity and quality of life and mixed results on the impact of caring. The other provided low quality data about the effectiveness of a carer befriending scheme, which showed no effect on caring-related morbidity, social capital and quality of life. Given its relatively low overall quality the committee made limited use of the quantitative evidence, focussing more on the strength of the qualitative component. They did however use some findings from the RCT, Ali et al (2014) to supplement recommendations about multi-faceted information support, drafted mainly on the basis of qualitative evidence. This is described below in the ‘benifits and harms’ section.

Benefits and harms

Multi-faceted informational support

The committee drafted recommendations about the content of information for carers. They agreed that the RCT by Ali et al, 2014 provided a basis for citing the different topics about which carers benefit from information.

In discussing the effectiveness evidence from Ali et al (2014) the committee specifically noted that the data demonstrated an initial positive effect on levels of 'perceived positive caring' (at 4 months) although this was not sustained at 8 months. This demonstrated the need for information provision to be continuous, which led them to draft the recommendation that local authorities should keep carers regularly informed about community services and other sources of support.

The evidence about multifaceted informational support led the committee to discuss the importance of a careful assessment of needs. However, they agreed they could not draft recommendations specifically about the conduct of carers' assessments because the evidence for this area will be reviewed under question C.

Carer's breaks

Combined with the evidence about the potential negative effects of caring on support seeking, and the evidence suggested that many carers did not identify themselves as carers (and its implicantion on carer's support seeking), this led the committee to recommend discussing options for having a break with people who were in a caring role and ensuring that people knew that breaks could be tailored to meet their needs, be that around duration or frequency or around the reasons for the break or the type of break they wanted.

Finally, the committee thought the evidence about the importance of consistency in providing carers with respite care and breaks was crucial. This evidence suggested that if respite breaks cannot be relied upon then the benefits they offer are far outweighed by the disruption, upset and stress that causes. For these reasons, the committee agreed to reccomend that respite services should be provided in a consistent and reliable way.

Volunteer support

The evidence about volunteer support was derived entirely from the qualitative evidence. . The 2 studies described at length the benefits of different types of volunteer support (groups, one to one befriending), which included reduced isolation and increased well-being, enjoyment and learning. Since the findings resonated with the committee's experience of volunteer support, they agreed there was a good basis for the recommendations about encouraging uptake through ensuring carers know how to access local support.

Support for former carers

Based on qualitative evidence, the committee discussed that former carers attending support groups were likely to perceive feelings of improved social, emotional and practical support. Therefore they recommended that is important extending support services for former carers, including through peer support groups.

Advocacy

There were neither quantitative nor qualitative data about the benefits or harms of advocacy services. The committee nevertheless drafted recommendations, based on their expertise and knowledge and via consensus as a means of highlighting the legal requirements placed on local authorities in the Care Act, 2014.

Access specific schemes

There were neither quantitative nor qualitative data about the effectiveness or acceptability of carer passport schemes as a means of providing access to practical support for carers so the committee did not make any recommendations relating to this intervention. Carer passport schemes are intended to improve identification, recognition and support of carers. Their implementation is currently being introduced in five key settings –enabling hospitals, workplace, community organisations, education setting and mental health trusts to identify and support carers within their organisations – and the committee agreed it would be a good use of research funding to establish the effectiveness of the schemes and to understand people's views and lived experiences about them to inform potential continued implementation.

Signposting

The committee also noted the lack of evidence about social prescribing which they agreed reflected a gap in knowledge about signposting more generally; in their minds the former being a more structured, directive type of the latter. The committee were aware of emerging evidence about the effectiveness of social prescribing more generally, but they agreed to recommend research about its effectiveness and acceptability specifically as a means of supporting carers.

Cost-effectiveness and resource use

The committee agreed there could be some resource implications from their recommendations with respect to advice and information provision but they noted that they largely embodied current practice and would help maximise the benefit from these interventions at a relatively low cost.

No quantitative or cost-effectiveness evidence was found for carer breaks and the committee made a qualitative assessment of cost-effectiveness. There was a consensus among the committee that the provision of carer breaks plays a role in reducing spending "downstream" by preventing crises and the breakdown of caring arrangements. In that context the committee considered that carer breaks can promote the well-being of both the carer and the recipient of care. Therefore, the committee considered that some level of carer breaks was likely to be cost-effective and that this is also consistent with the Care Act (2014), where carer breaks are used as an example of a tertiary prevention service than can facilitate carers in continuing to have "a life of their own". Whilst, provision of carer break services is variable the committee did not consider that their recommendations represented a change in practice.

Included economic evidence did not demonstrate the cost-effectiveness of carer support groups and therefore no specific recommendations were made by the committee with respect to the provision of such groups.

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Appendices

Appendix A – Review protocols

Review protocol for review question: What practical, social and community support interventions for adult carers are effective, cost-effective, and acceptable to them?

Table 5: Review protocol

Field (based on PRISMA-P)	**Content**
Review question	What practical, social and community support interventions for adult carers are effective, cost-effective, and acceptable to them?
Type of review question	Systematic mixed studies review
Objective of the review	The objective of this review is to establish whether there are any types of practical support interventions for adult carers that are effective, cost-effective, and acceptable to them.
Eligibility criteria – population/disease/condition/issue/domain	• Adult carers (18 years of age or older) who provide unpaid care for either ≥1 adults, or ≥1 young people aged 16-17 years with ongoing needs. • Health-/social-care and other practitioners involved in their care.
Eligibility criteria – intervention(s)/exposure(s)/prognostic factor(s)	Any practical support interventions for adult carers, including: • Respite care and breaks including: ○ Day care ○ In-home respite ○ Host-family respite ○ Institutional/ overnight respite ○ Short breaks (for example holidays, funded breaks, activities-based) ○ Respite programmes ○ Assistive technologies (for example telecare/presence/simulated presence) • Replacement care (for example Meal support, personal assistant) • Crisis support (including support provided in accordance with care plan, as well as situations not covered by this, for example Carer Emergency Support card)

Field (based on PRISMA-P)	**Content**
	- Volunteer support (for example housework) - Carer support groups (for example sessions and networks, peer support or mentoring scheme; befriending; telephone support) - Access-specific Carer Passport/cards/schemes (that is those that provide access benefits – for example to local facilities - to carers; note that the term 'Carer Passport' is also used in clinical settings to indicate document that records carer is known to services and is entitled to access services) - Signposting - Financial assistance (for example Carer's Allowance) - Advocacy/support (regardless of who provides it) - Communication/integration with health and social care professionals (interpersonal relations, for example, with lead or named professionals) - Support for carers of people at end of life and/or people after the person receiving care dies (for example former carers/ex-carers) Themes from the qualitative evidence regarding views and experiences of adult carers, and related professionals, may include: - Satisfaction with the intervention - Perceived appropriateness of the intervention - Perceived acceptability of the intervention - Barriers and facilitators 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 – comparator(s)/control or reference (gold) standard	For studies assessing the effectiveness of an intervention: - No intervention - Different types of intervention within each category (for example day care versus in-home respite)
Outcomes and prioritisation	Outcomes relevant to determining the effectiveness of interventions are: CRITICAL OUTCOMES:

Field (based on PRISMA-P)	**Content**
	• Caring-related morbidity (including physical and mental health [anxiety, depression, stress/emotional wellbeing only]) (MID: statistically significant difference) • Impact of caring on carer (for example resilience, distress, burden; ability to work/study or remain a carer) (minimally important difference [MID]: statistically significant difference) IMPORTANT OUTCOMES: • Social capital (that is range of social contact that provides access to social/emotional/practical support: Measures include Social Support Index and Social Support Survey Instrument) (MID: statistically significant difference) • Carer quality of life (MID: statistically significant difference) • Carer choice/control/efficacy (Note that quality of life measures, such as Adult Carer Quality of Life Questionnaire [AC-QoL], personal Wellbeing Index-Adult [PWI-A] Warwick-Edinburgh Mental Well-being Scale [WEMWBS] includes questions about this) (MID: statistically significant difference) *For the relevant outcomes above, only validated scales will be included.* Results of the qualitative evidence synthesis will be determined by thematic analysis and the use, if appropriate, of thematic maps. The final results of the review will be determined by the mixed studies qualitative synthesis of all studies.
Eligibility criteria – study design	No restrictions on study designs will be made. That is, quantitative, qualitative, and mixed-methods studies will all be considered. Studies will be categorised according to their relevance to answer a specific aspect of the question - for example RCTs or observational studies to assess the effectiveness of the intervention; qualitative research for assessing the acceptability of an intervention – in line with the typology of evidence for social interventions developed by Muir Gray (1996) and in consultation with the GC. References Muir Gray, JM. (1996). Evidence-based healthcare. London, UK: Churchill Livingstone.
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, and South Africa will be included for the quantitative component of the review. Studies from other countries will not be included because substantial differences in their carer populations and/or social-/health-care systems.

Field (based on PRISMA-P)	Content
	• Only UK studies will be included for the qualitative component of the review • Full-text English-language articles published in or after 2003 • Full-text reports of complex/multi-component interventions will be assessed for relevance to this review question *Exclusion criteria* • Conference abstracts will be excluded as they typically do not provide sufficient information to evaluate risk of bias/quality of study. • Non-English language articles 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, certain study designs may be prioritised (for example RCTs for the quantitative component) or a more recent publication dates 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	Stratified/subgroup analysis • Category of intervention • Adult carers providing support or who have provided support for people at the end of life (presented as part of review question 8) • Changes to the caring role, defined as: (i) changes to the setting in which caring is performed, (ii) transition of the person receiving care to adulthood, or (iii) change of carer status or circumstances (presented as part of review question 9) Further stratification/subgroup analysis (for example socioeconomic factors), if needed, will be directed by the GC and be contingent on the themes or patterns that are revealed by the initial synthesis of the quantitative and qualitative evidence
Selection process – duplicate screening/selection/analysis	Duplicate screening will be performed using STAR - minimum sample size is 10% of the total for <1000 titles and abstracts, and 5% of the total for ≥1000 titles and abstracts. All discrepancies are discussed and resolved between 2 screeners. Any disputes will be resolved in discussion with the Senior Systematic Reviewer. Data extraction will be supervised by a senior reviewer. Draft excluded studies and evidence tables will be discussed with the Topic Advisor, prior to circulation to the Topic Group for their comments. Resolution of disputes will be by discussion between the senior reviewer, Topic Advisor and Chair.

Field (based on PRISMA-P)	**Content**
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 software will be used for generating bibliographies and citations, study sifting, data extraction and recording quality assessment of 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	Sources to be searched: • ASSIA, CDSR, DARE, Embase, IBSS, Medline, Medline In-Process, PsycINFO, Sociological Abstracts, Social Services Abstracts, Social Policy and Practice Filters: • Systematic review • RCT • Qualitative study • NICE UK geographic • Standard animal/non-English language exclusion Limits: • Date from 2003
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
Search strategy – for one database	For details please see appendix F of the guideline
Data collection process – forms/duplicate	A standardised evidence table format will be used, and published as appendix G (evidence tables) or H (economic evidence tables) of the guideline.
Data items – define all variables to be collected	For details please see evidence tables in appendix G (evidence tables) or H (economic evidence tables) of the guideline.
Methods for assessing bias at outcome/study level	The following checklists will be used to assess risk of bias/quality of individual studies: • ROBIS for systematic reviews/meta-analyses of interventions studies • Cochrane RoB tool v1 for (individual or cluster) RCTs

Field (based on PRISMA-P)	Content
	• Cochrane ROBINS-I for non-randomised (clinical) controlled trials, cohort studies, and historical controlled studies • CASP Case Control Checklist for case control studies • The appropriate EPOC RoB Tool will be used for (i) complex interventions involving randomised and/or non-randomised interventions, (ii) controlled before-and-after studies, (iii) interrupted time series studies, and • JBI Checklist for cross-sectional studies • IHE Checklist for case series (that is non-controlled longitudinal studies) • Boynton & Greenhalgh checklist for cross-sectional surveys and survey questionnaire studies • Newcastle-Ottawa Scale for studies examining associations between variables (this does not include variables relevant to clinical diagnosis and prognosis). • CASP Qualitative Checklist for individual qualitative studies
Criteria for quantitative synthesis (where suitable)	For details please see section 6.4 of Developing NICE guidelines: the manual
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 standard 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. Heterogeneity 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.

Field (based on PRISMA-P)	**Content**
	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. If sufficient relevant RCT evidence is available, publication bias will be explored using RevMan5 software to examine funnel plots.
Assessment of confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual. For assessing confidence in the qualitative evidence prior to the mixed-methods qualitative synthesis of evidence, GRADE-CERQual will be used. A mixed-methods qualitative synthesis will be used to summarise and interpret the evidence.
Rationale/context – Current management	For details please see the introduction to the evidence review in the guideline.
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. 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 in PROSPERO

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 practical, social and community support interventions for adult carers are effective, cost-effective, and acceptable to them?

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/
14	12 or 13
15	14 use psyh

#	Searches
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)) adj3 (advice* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or anticipatory grief).ti,ab.

#	Searches
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 emergency or ((intimate or personal) adj care) or rescue breath*)) or first aid or

#	Searches
	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.

#	Searches
116	or/107,109,111-115
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

#	Searches
	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 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/

#	Searches
160	meta-analysis as topic/ or systematic reviews as topic/
161	“systematic review”/
162	meta-analysis/
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.

#	Searches
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
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.

#	Searches
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.
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.

#	Searches
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 "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.

#	Searches
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.
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*

#	Searches
	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.
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.

#	Searches
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
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* 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*))

#	Searches
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*”)
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*)

#	Searches
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 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

#	Searches
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 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")

#	Searches
S88	S84 or S85 or S86 or S87
S89	S77 or s79 or S83
S90	S72 and S89

Database: CINAHL – Proquest

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

Economics

Database: 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
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

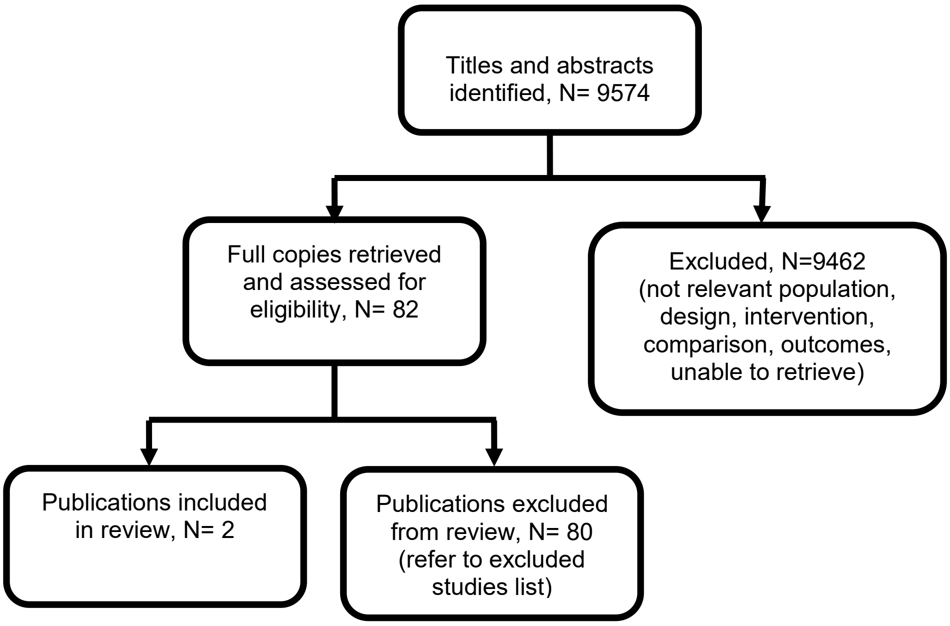
#	Searches
1	mesh descriptor: [caregivers] this term only
2	(carer* or caregiv* or “care giv*”):ti,ab,kw
3	#1 or #2

Appendix C – Evidence study selection

Study selection for review question: What practical, social and community support interventions for adult carers are effective, cost-effective, and acceptable to them?

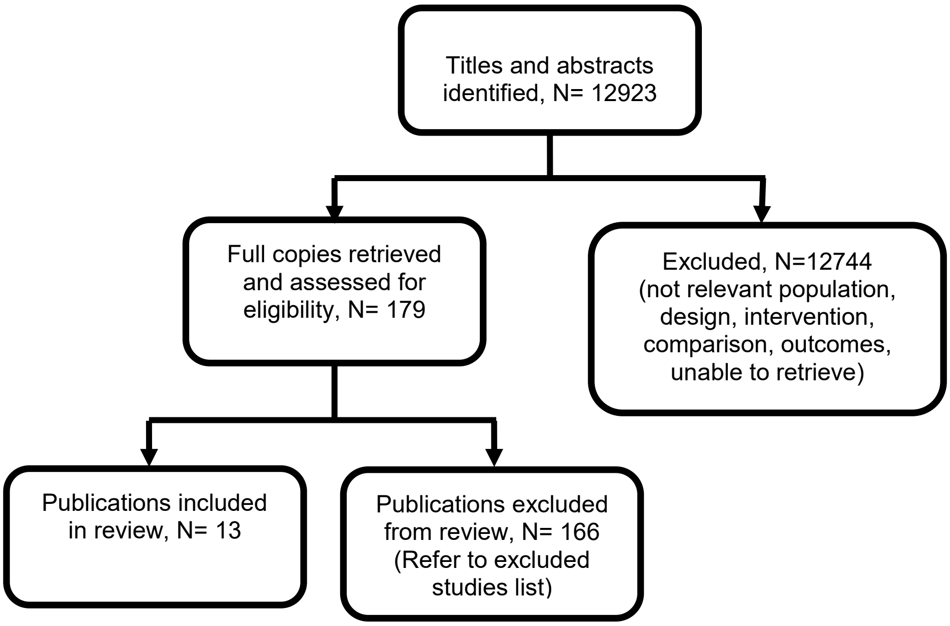
Quantitative component of the review

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 practical, social and community support interventions for adult carers are effective, cost-effective, and acceptable to them?

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
Ali, L, Krevers, B, Sjöström, N, Skärsäter, I, Effectiveness of web-based versus folder support interventions for young informal carers of persons with mental illness: a randomized controlled trial, Patient Education and Counseling, 94, 362-371, 2014

Ref Id
710151</td>
<td>Sample size
N=241
I = 120;
C = 121
Characteristics
Carers
Carer age (years) Mean -- SD :
I = 20.5 -- 2.6;
C = 20.5 -- 2.5
Carer (gender-M/F)
I (n): 33/87
C (n): 38/83
Relationship to (n): N/R
Living with (yes/no - n): N/R: (supposedly all</td>
<td>Interventions
Name of intervention [1] group (as reported in the paper): Web-based support
Name of intervention [2] group (as reported in the paper): N/A
Name of control group (as reported in the paper): Folder support</td>
<td>Details
Geographical setting: Nation-wide
Setting where intervention is provided: Online
Recruitment procedures: The study sample was identified using the Swedish national population register in 2009. Carers were contacted through a private recruitment company and surveyed about the inclusion criteria.
Sample size statistical power: Achieved for 4</td>
<td>Results
4 months follow-up
<table><tr><th>Outcomes - Mean (SD)</th><th>Intervention – web support (n=120)*</th><th>Control – folder support(n=121)*</th></tr><tr><td>Impact of caring on carer: caring situation (Cope-negative)</td><td>11.3 (3.3)</td><td>10.8 (3.4)</td></tr></table></td>
<td>Limitations (assessed using the Cochrane ‘Risk of bias’ tool for randomized trials)
Random sequence generation: Low risk
Allocation concealment: Unclear risk (Not described in sufficient detail)
Blinding of participants/personnel: Unclear risk (Not described in sufficient detail, potential performance bias)
Blinding of outcome assessment: Unclear risk (Not described in sufficient detail,</td>
</tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments

Country/ies where the study was carried out
Sweden
Study type
Two-groups RCT
Aim of the study
This study aimed to compare the effectiveness of two interventions, a web-based support and a folder support, for young adult carers of people experiencing mental illness.
Study dates
N/R
Source of funding
The Swedish Institute for Health Science
	carers were living with the care recipient)
	- Duration of caring (years) Mean -- SD :
	  ○ I = 43.6 -- 45.2 ;
	  ○ C = 45.8 -- 51.2
	Care recipient
	- condition: Mental illness
	Providers
	- sample (n): N/A
	Inclusion criteria
	1. 16–25 years old
	2. supporting a person with mental illness
	3. and being able to understand and communicate in Swedish.
	Young adult carers are defined as a young person who provides, or intends to provide, care, assistance, or support to a person who is disabled or
			months follow-up (not for 8 months follow-up)
			- Randomization methods: The allocation sequence was performed by a statistician and the randomization was performed with block randomization stratified for the carers relationship to the supported person (family/friend/unknown).
			- Blinding: No details
			- Follow-up outcome measurement from baseline: 4 and 8 months
				Impact of caring on carer: caring situation (Cope-positive) — 12.1 (2.5) — 11.3 (2.7)
				Impact of caring on carer: caring situation (Cope-quality of support) — 8.91 (3.0) — 9.08 (2.8)
				Carer quality of life: Self rated QoL — 30/76 — 28/75
					potential detention bias)
					- Incomplete outcome data: High risk (Attrition bias because amount of incomplete outcome data: high dropout rate at 8 month follow-up, in the 8 month analysis the number of participants did not reach the power calculation - assessments were 77.5% in the web group and 71.9% of the control group)
					- Selective reporting: Low risk
					- Other bias: High risk (baseline imbalances between groups: There were significant differences in stress and negative impact, with the intervention group showing lower values at baseline than the control group).

<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>suffers from a long-term illness, mental health problem or other conditions for which the disabled person needs care and support. The young carer carries out tasks over an extended period of time with a level of responsibility appropriate to a mature adult or a professional.
Exclusion criteria
N/R (Please look at the inclusion criteria)</td>
<td></td>
<td></td>
<td>
<table>
<tr><td>(Very Good)</td><td></td><td></td></tr>
<tr><td>Carer quality of life: Self rated QoL (Good)</td><td>30/76</td><td>28/75</td></tr>
<tr><td>Caring-related morbidity: stress (Perceived Stress Scale)</td><td>25.5 (7.2)</td><td>26.8 (7.6)</td></tr>
<tr><td>Caring-related morbidity: well-being (well-being index-WHO-5)</td><td>55.1 (19.5)</td><td>56.1 (20.7)</td></tr>
</table>
</td>
<td>Overall risk of bias: very serious

Other information
• Main provider of the intervention: On-line professional led
• Mode of intervention delivery: On-line (web-site with asynchronous information) + face-to-face (on-line forum real-time)
• Is the intervention tailored to carer needs (individualised)?: unclear</td>
</tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
				Caring-related morbidity: Self rated health (Very Good) | 13/70 | 19/69 Caring-related morbidity: Self rated health (Good) | 43/70 | 36/69 *Intention to treat population • 8 months follow-up	

Outcomes - Mean (SD)	Intervention – web support (n=120)*	Control – folder support(n =121)*
Impact of caring on carer: caring situation	11.5 (3.7)	11.3 (3.1)

<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></td><td></td><td></td><td>
<table>
<tr><td>(Cope - negative)</td><td></td><td></td></tr>
<tr><td>Impact of caring on carer: caring situation (Cope - positive)</td><td>12.1 (2.5)</td><td>11.6 (2.5)</td></tr>
<tr><td>Impact of caring on carer: caring situation (Cope - quality of support)</td><td>8.92 (2.6)</td><td>8.9 (2.5)</td></tr>
</table>
</td><td></td></tr>
</table>

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
				<table><tr><td>Carer quality of life: Self rated QoL (Very Good)</td><td>21/82</td><td>31/80</td></tr><tr><td>Carer quality of life: Self rated QoL (Good)</td><td>30/82</td><td>31/80</td></tr><tr><td>Caring-related morbidity: stress (Perceived Stress Scale)</td><td>25.1 (9.6)</td><td>25.3 (8.9)</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></td><td></td><td></td><td></td><td>
<table>
<tr><td>Caring-related morbidity: well-being (well-being index-WHO-5)</td><td>59.4 (19.4)</td><td>60.3 (20.4)</td></tr>
<tr><td>Caring-related morbidity: Self rated health (Very Good)</td><td>23/75</td><td>25/75</td></tr>
<tr><td>Caring-related morbidity:</td><td>32/75</td><td>33/75</td></tr>
</table>
</td><td></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></td><td></td><td></td><td></td><td><table><tr><td>Self rated health (Good)</td><td></td><td></td></tr></table>* Intention to treat population</td><td></td></tr>
<tr><td>Full citation
Charlesworth, G., Shepstone, L., Wilson, E., Thalanany, M., Mugford, M., Poland, F., Does befriending by trained lay workers improve psychological well-being and quality of life for carers of people living with dementia, and at what cost? A randomised controlled trial, Health Technology Assessment (Winchester,</td>
<td>Sample size
N=236
- I = 116;
- C = 120

Characteristics
Carers
- Carer age (years) Mean -- SD :
o I = 68.4 -- 11.3
o C = 20.5 -- 2.6
- Carer (gender-M/F)
o I (n): 40/76;
o C (n): 44/76
- Relationship to (n):
o parents (n): 0
o spouses (n): 159
o daughters-sons (n): 66
o sibling (n): 0
o other/undisclosed (n): 8</td>
<td>Interventions
- Name of intervention [1] group (as reported in the paper): access to a befriending volunteer (emotional support, informational support or “signposting”) + usual care
- Name of intervention [2] group (as reported in the paper): N/A
- Name of control group (as reported in the paper): (for example community psychiatric services, day hospitals, day centres, home care or personal care, respite care, and carers’ information or support groups)</td>
<td>Details
- Geographical setting: The sample was identified in the UK, in the East Anglian counties of Norfolk and Suffolk, and in the London Borough of Havering, with recruitment between April 2002 and July 2004
- Setting where intervention is provided: In-home/community
- Recruitment procedures: Mix of recruitment strategies: 1) Mail outs of publicity posters and leaflets; 2) Media publicity; 3) Voluntary-sector mail outs; 3) Presentations to</td>
<td>Results
- 6 months follow-up
<table>
<tr><td>Outcomes</td><td>N =*</td><td>Mean (SD)</td><td>N =*</td><td>Mean (SD)</td></tr>
<tr><td>Social support: Perceived support (MSPSS)</td><td>102</td><td>45.0 (9.02)</td><td>113</td><td>45.3 (9.16)</td></tr>
<tr><td>Carer quality of life (EQ-5D global VAS)</td><td>101</td><td>75.7 (17.0)</td><td>112</td><td>72.9 (17.7)</td></tr>
<tr><td>Caring-related morbidity: mood - depression (HADS</td><td>104</td><td>6.03 (3.63)</td><td>113</td><td>5.84 (3.96)</td></tr>
</table></td>
<td>Limitations (assessed using the Cochrane ‘Risk of bias’ tool for randomized trials)
- Random sequence generation: Low risk
- Allocation concealment: Low risk
- Blinding of participants/personnel : High risk (participants and personnel not blinded, potential performance bias)
- Blinding of outcome assessment: Low risk (assessors blinded to group assignment)
- Incomplete outcome data: Low risk (low attrition rate, similar dropout rate for</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>England), 12, iii, v-ix, 1-78, 2008

Ref Id
706691

Country/ies where the study was carried out
UK
Study type
Two-groups cost-effectiveness RCT

Aim of the study
This study was aimed to compare the effectiveness and cost-effectiveness of two interventions, a social support intervention (access to an employed befriending facilitator in addition to usual care) and usual care only, to support adult</td>
<td>• Living with (yes/no - n): 203/33
• Duration of caring (years) Mean -- SD :
  ○ I = 3.9 -- 7.7 ;
  ○ C = 3.7 -- 3.5
Care recipient
• condition: Dementias
Providers
• sample (n): N/A

Inclusion criteria
• Adult carers aged 18 years or older
• Carers supporting a person with a primary progressive dementia;
• and carers should either be cohabiting with the care recipient, or spending an average of 20 hours or more per week on care-related tasks such as supervision and assistance in</td>
<td></td>
<td>potential participants and to gatekeepers
• Sample size statistical power: Achieved
• Randomization methods: this was a cluster-randomized study where the general practices (GPs) are the clusters and thus the units of randomization. GPs were randomly assigned to the three study arms by permuted blocked randomization, which was stratified by study region and type of practice (single versus group). The randomization was carried out by the statistics and data center by using an allocation ratio of 1:1:1;
• Blinding: The study is unblinded with respect to the GPs, the patients, and their caregivers. Outcome assessors were blinded.</td>
<td>
<table>
<tr><td>depression scale)</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Caring-related morbidity: mood - anxiety (HADS anxiety scale)</td><td>104</td><td>6.35 (4.46)</td><td>113</td><td>6.96 (4.37)</td></tr>
<tr><td>Caring-related morbidity: mood – loneliness (loneliness scale)</td><td>104</td><td>2.06 (2.04)</td><td>106</td><td>2.21(2.21)</td></tr>
<tr><td>Caring-related morbidity: mood – affect (PANAS—positive affect)</td><td>103</td><td>30.1 (8.13)</td><td>112</td><td>31.5 (8.31)</td></tr>
</table>
*Intention to treat population
• 15 months follow-up</td>
<td>similar reasons across groups)
• Selective reporting: Low risk
• Other bias: Low risk

Overall risk of bias: serious

Other information
• Main provider of the intervention: Professional led (be-friender facilitator)
• Mode of intervention delivery: face-to-face
• Is the intervention tailored to carer needs (individualised)? Yes</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>carers of people living with dementia

Study dates
2002-2004

Source of funding
The project was project (ISRCTN 08130075) was funded by the Health Technology Assessment (HTA) Programme (project 99/34/07). Befriender expenses were funded by Norfolk and Suffolk Social Services, the King’s Lynn and West Norfolk Branch of the Alzheimer’s Society and an AdHoc grant from the Department of Health to North</td>
<td>activities of daily living

Exclusion criteria
• Carers with significant congenital or acquired cognitive impairment
• Carers with terminal illness
• Carers of people in permanent residential, nursing or long-stay hospital accommodation</td>
<td></td>
<td>• Follow-up outcome measurement from baseline: 6, 15 and 24 months</td>
<td>
<table>
<tr><th>Outcomes</th><th>N =*</th><th>Mean (SD)</th><th>N =*</th><th>Mean (SD)</th></tr>
<tr><td>Social support: Perceived support (MSPSS)</td><td>95</td><td>44.0 (10.19)</td><td>106</td><td>44.6 (9.88)</td></tr>
<tr><td>Carer quality of life (EQ-5D global VAS)</td><td>95</td><td>73.8 (18.3)</td><td>106</td><td>69.9 (18.1)</td></tr>
<tr><td>Caring-related morbidity: mood - depression (HADS depression scale)</td><td>96</td><td>6.03 (4.00)</td><td>106</td><td>6.71 (4.18)</td></tr>
<tr><td>Caring-related morbidity: mood - anxiety (HADS</td><td>96</td><td>6.55 (4.54)</td><td>106</td><td>7.55 (4.47)</td></tr>
</table>
</td>
<td></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>East London Mental Health Trust.</td><td></td><td></td><td></td><td>
<table>
<tr><td>anxiety scale)</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Caring-related morbidity: mood – loneliness (loneliness scale)</td><td>96</td><td>2.21 (2.27)</td><td>106</td><td>2.57 (2.23)</td></tr>
<tr><td>Caring-related morbidity: mood – affect (PANAS—positive affect)</td><td>96</td><td>30.5 (8.22)</td><td>106</td><td>30.5 (8.02)</td></tr>
</table>
*Intention to treat population
24 months follow-up
<table>
<tr><td>Outcomes</td><td>N =*</td><td>Mean (SD)</td><td>N =*</td><td>Mean (SD)</td></tr>
<tr><td>Social support: Perceived support (MSPSS)</td><td>92</td><td>44.5 (10.29)</td><td>97</td><td>45.4 (9.17)</td></tr>
</table>
</td><td></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></td><td></td><td></td><td></td><td>
<table>
<tr><td>Carer quality of life (EQ-5D global VAS)</td><td>92</td><td>72.5 (19.7)</td><td>96</td><td>68.1 (18.2)</td></tr>
<tr><td>Caring-related morbidity: mood - depression (HADS depression scale)</td><td>93</td><td>6.25 (4.12)</td><td>97</td><td>6.35 (4.59)</td></tr>
<tr><td>Caring-related morbidity: mood - anxiety (HADS anxiety scale)</td><td>93</td><td>6.55 (4.49)</td><td>97</td><td>6.97 (4.50)</td></tr>
<tr><td>Caring-related morbidity: mood – loneliness (loneliness scale)</td><td>93</td><td>2.24 (2.39)</td><td>97</td><td>2.63 (2.30)</td></tr>
</table>
</td><td></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></td><td></td><td></td><td></td><td><table><tr><td>Caring-related morbidity: mood – affect (PANAS—positive affect)</td><td>92</td><td>30.1 (8.73)</td><td>95</td><td>31.2 (8.34)</td></tr></table>* Intention to treat population</td><td></td></tr>
</table>

F: Female; M: Male; I: intervention group; C: Control group; N/R: not reported; SD: Standard deviation; TAU: Treatment as usual; RCT: Randomised controlled trial

Qualitative component of the review

Table 6: Evidence tables for the qualitative studies

Study details	Participants	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
Full citation Institute For, Research, Innovation In Social, Services, Rest assured: a study of unpaid carers' experiences of short breaks, 53p., 2012 **Ref Id** 722821 **Country/ies where the study was carried out**	**Sample size** N=48 adult carers: • 36= focus group • 12= interviews **Characteristics** **Carer** • Carer age = More than 18 years old (mean age/range - years: N/R) • Carer gender (M/F: N)=N/R	**Details** • **Recruitment methods:** Carers were recruited purposively from the sample of a postal survey (n=7000) in Scotland. The carer sample was given the option to complete their contact details if they would be interested in	• Perceived benefits of peer support: ‘‘You are not alone • Perceived benefits of peer support: Emotional Support and Release: • Perceived benefits of peer support: Enjoyment of Peer Support ".	**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

Study details	Participants	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
UK: Scotland **Study type** mixed-methods original research (no peer-reviewed) **Aim of the study** This study is stage three of a broader research agenda. The aim of this project was to gather the experiences of unpaid carers in accessing and using short breaks in their area. **Study dates** - Publication **date**: 2012 - **Data collection**: August to September 2011 **Source of funding** Scottish Government	- "Relationship to care recipient"= N/R **Professionals** - N/A **Care recipient** Condition = Range of conditions (for example physical disability, learning disability, long-term condition, old age etc.) **Inclusion criteria** - N/R **Exclusion criteria** - N/R	being involved in further research (focus groups or interviews). To ensure the research included those from different geographic contexts, each postcode provided by the respondents was distinguished between urban, rural and remote areas within Scotland. Once each postcode from the respondents was classified, a random sample of each classification was invited to take part in a telephone interview. - **Data collection & analysis methods:** Data were collected through (face-to-face and telephone) semi-structured interviews and 4 focus group. All interviews were audio-taped, and transcribed. Focus groups were typically an hour and	- Perceived benefits of peer support: support in managing their situations - Perceived benefits of peer support: gaining different perspectives - Drawbacks, Challenges, and Limitations for Carers and Peer Volunteers (former carers of people living with dementia)" - Volunteer–carer relationship	- **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: It is unclear whether saturation has been achieved in the analysis of data gathered from the interviews - **Q6**: Has the relationship between researcher and participants been adequately considered? - Unclear: The role of the authors is not clearly reported (in relation to potential bias/influence during data analysis, data collection, or carers' recruitment) - **Q7**: Have ethical issues been taken into consideration? - Yes - **Q8**: Was the data analysis sufficiently rigorous? - Unclear: : no clear description

Study details	Participants	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
		a half long. All focus group discussions were audio recorded and transcribed. No details are reported about the data analysis.		of the data analysis approach used - **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
Full citation Greenwood, N., Habibi, R., Mackenzie, A., Respite: carers' experiences and perceptions of respite at home, BMC geriatrics, 12, 42, 2012 **Ref Id** 722899 **Country/ies where the study was carried out** UK:England - London **Study type** qualitative original research (peer-reviewed) **Aim of the study** The aims of this qualitative study were to explore carers'	**Sample size** N=12 adult carers **Characteristics** **Carer** - Carer age = range (years): 41 to 90 - Carer gender (M/F: N)=3/9 - "Relationship to care recipient"= parents (n): 1; spouses (n): 5; daughters-sons (n): 3; sibling; friends; others (n): 3 **Professionals** - N/A **Care recipient**	**Details** - **Recruitment methods:** Carers were recruited purposively through an organisation providing respite and asked if they would be willing to be interviewed. - **Data collection & analysis methods:** Data were collected through (face-to-face) semi-structured interviews. A topic guide containing open ended questions was used; topics covered included carers' experiences with	- Experience of respite: What carers do during respite - Experience of respite: Benefits for the carer - Care workers: What care workers do during respite - Care workers: Characteristics of good care workers - Context of being a carer: Constant responsibility - Context of being a carer: Trust	**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	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
experiences of in-home respite, their perceptions of care workers and their perceptions of the impact of respite on themselves and their cared for. **Study dates** • **Publication date**: 2012 • **Data collection**: N/R **Source of funding** South Thames Crossroads	• Condition = Range of conditions (for example dementia, stroke and Parkinson's disease) **Inclusion criteria** • carers currently receiving respite or to have been receiving it until very recently • carers have received respite for a minimum of three months • carers either aged over 60 years themselves or to be supporting someone aged over 60 years. **Exclusion criteria** • N/R (see the inclusion criteria)	the respite service and their perceptions of the impact of respite on themselves and their cared for. All interviews were audio-taped, and transcribed verbatim. Data were analysed by hand to identify themes in the interviews. Thematic analysis is 'a method for identifying, analysing, and reporting patterns (themes) within data'.	• Context of being a carer: Carers' low expectations and powerlessness	• **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? - Unclear: the role of the authors is not clearly reported (in relation to potential bias/influence during data analysis, data collection, or carers' recruitment) • **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
Full citation Greenwood, Nan, Habibi, Ruth, Mackenzie, Ann, Drennan, Vari,	**Sample size** N=9 adult carers	**Details** • **Recruitment methods:** Carers were	• Perceived benefits of peer support: "You are not alone"	**Limitations (assessed using the CASP checklist for qualitative studies)**

Study details	Participants	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
Easton, Nicky, Peer support for carers: A qualitative investigation of the experiences of carers and peer volunteers, American Journal of Alzheimer's Disease and other Dementias, 28, 617-626, 2013 **Ref Id** 721933 **Country/ies where the study was carried out** UK: England - London **Study type** qualitative original research (peer-reviewed) **Aim of the study** The aim of this qualitative study was to explore the experiences of carers, peer volunteers (former carers) and people cared for, with a peer support service. **Study dates** • **Publication date**: 2013 • **Data collection**: 2008-2011 **Source of funding**	**Characteristics** **Carer** • Carer age = mean - range (years): 64 - 49 to 80 • Carer gender (M/F: N)=1/8 • "Relationship to care recipient"= parents (n): 0; spouses (n): 4; daughters-sons (n): 5; sibling (n): 0; friends (n): 0; others-N/R (n): 0 **Professionals** • N = 4 peer volunteers (former carers) **Care recipient** • Condition = Dementia **Inclusion criteria** • N/R **Exclusion criteria** • N/R	recruited purposively through a peer support service developed in South London. During the study period, and on completion of their peer support, all carers were contacted by the service facilitator. • **Data collection & analysis methods:** Data were collected through (face-to-face) semi-structured interviews. All interviews were digitally audio-taped, and transcribed. The analysis used draws on ethnography framework with the identification of recurrent themes. Analysis followed ‘‘conventional content analysis’’ and began during data collection, allowing emerging themes to be explored.	• Perceived benefits of peer support: Emotional Support and Release: • Perceived benefits of peer support: Enjoyment of Peer Support • Perceived benefits of peer support: support in managing their situations • Perceived benefits of peer support: gaining different perspectives • Drawbacks, Challenges, and Limitations for Carers and Peer Volunteers • Volunteer–carer relationship	• **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: not enough information were provided on the methods and rationale of the recruitment approach • **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? - Unclear: role of the authors is not clearly reported (in relation to potential bias/influence during data analysis, data collection, or carers' recruitment)

Study details	Participants	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
The Modernisation Initiative End of Life Care Programme 2008-2011				• **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
Full citation Harding, Richard, Higginson, Irene J., Leam, Celia, Donaldson, Nora, Pearce, Alison, George, Rob, Robinson, Vicky, Taylor, Liz, Evaluation of a Short-Term Group Intervention for Informal Carers of Patients Attending a Home Palliative Care Service, Journal of Pain and Symptom Management, 27, 396-408, 2004 **Ref Id**	**Sample size** N=24 adult carers **Characteristics** **Carer** • Carer age = range (years): 60 - 26 to 88 • Carer gender (M/F: N)=N/R • "Relationship to care recipient"= N/R **Professionals** • N/A **Care recipient**	**Details** • **Recruitment methods:** Both eligible and ineligible carers were identified to research staff by their clinical nurse specialists, and eligible carers were referred to the study. • **Data collection & analysis methods:** Data were collected from the intervention attendees using semi-structured interviews, which was	• Motivations for accepting the intervention • Benefits of attending • Group processes • Access issues • Intervention design	**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? - Unclear: not enough information on the qualitative study design justification

Study details	Participants	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
716023 **Country/ies where the study was carried out** UK: England - London **Study type** Mixed-methods original research (peer-reviewed) **Aim of the study** The aims of this mixed-methods study were to evaluate a short-term group intervention (Group support + informal teaching) for informal carers of patients with a range of conditions attending a home palliative care service (for example Cancer, HIV, motor neuron disease, Bechet's disease, congestive heart failure, Leigh's syndrome and Parkinson's) **Study dates** - **Publication date**: 2004 - **Data collection**: N/R	- Condition = Range of conditions (for example Cancer, HIV, motor neuron disease, Bechet's disease, congestive heart failure, Leigh's syndrome and Parkinson's) **Inclusion criteria** - Adult carers of patients attending either of two home palliative care services in London, UK. **Exclusion criteria** - N/R (see the inclusion criteria)	administered immediately following the quantitative measures post-intervention. Qualitative data were tape-recorded and transcribed verbatim. The analysis used a content analysis matrix of principal categories, with independent peer review of categorization.		- **Q4:** Was the recruitment strategy appropriate to the aims of the research? - Unclear: not enough information were provided on the methods and rationale of the recruitment approach - **Q5**: Were the data collected in a way that addressed the research issue? - Unclear: It is unclear whether saturation has been achieved in the analysis of data gathered from the interviews - **Q6**: Has the relationship between researcher and participants been adequately considered? - Unclear: The role of the authors is not clearly reported (in relation to potential bias/influence during data analysis, data collection, or carers' recruitment) - **Q7**: Have ethical issues been taken into consideration? - Yes - **Q8**: Was the data analysis sufficiently rigorous? - Unclear:

Study details	Participants	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
Source of funding NHS Executive Research and Development London Region				no clear description of the data analysis approach used - **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:** major
Full citation Keyes Sarah E, et al.,, "We're all thrown in the same boat ... ": a qualitative analysis of peer support in dementia care, Dementia: The International Journal of Social Research and Practice, 15, 560-577, 2016 **Ref Id** 724801 **Country/ies where the study was carried out** UK: England **Study type**	**Sample size** N=68 adult carers **Characteristics** **Carer** - Carer age = More than 18 years old (mean age/range - years: N/R) - Carer gender (M/F: N)=N/R - "Relationship to care recipient"= N/R **Professionals** - N = 82 **Care recipient** - (condition) = Dementia **Inclusion criteria**	**Details** - **Recruitment methods:** Carers were recruited purposively - **Data collection & analysis methods:** The methodological framework used for the study was a qualitative case study design. Data were collected through (face-to-face) semi-structured interviews. All interviews were audio-taped and transcribed verbatim. The analysis used was a five-stage process: 1- coding	- Commonality of experience - Reciprocity - Direct experience - Quality of peer relationships	**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

Study details	Participants	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
mixed-methods original research (peer-reviewed) **Aim of the study** This study is part of a broader research agenda -the Healthbridge study. The aims of this mixed-methods study were to evaluate peer support by and for people living with dementia and carers within initiatives which prioritise peer support as well as peer support that occurred as a result of or alongside services which prioritise advice and information provision. **Study dates** • **Publication date**: 2016 • **Data collection**: N/R **Source of funding** Department of Health Policy Research Programme	• N/R **Exclusion criteria** • N/R	framework developed; 2-further development of the framework; 3-development of emerging themes; 4-modelling of themes and 5-verification of models based on the entire data set.		research issue? - Unclear: It is unclear whether saturation has been achieved in the analysis of data gathered from the interviews • **Q6**: Has the relationship between researcher and participants been adequately considered? - Unclear: role of the authors is not clearly reported (in relation to potential bias/influence during data analysis, data collection, or carers' recruitment) • **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	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
Full citation Larkin Mary, Group support during caring and post-caring: the role of carers groups, Groupwork, 17, 28-51, 2007 **Ref Id** 714256 **Country/ies where the study was carried out** UK **Study type** qualitative original research (peer-reviewed) **Aim of the study** The aims of this qualitative study were to explore the role role of face-to-face carers groups in supporting former carers **Study dates** • **Publication date**: 2007 • **Data collection**: N/R	**Sample size** N=37 former carers **Characteristics** **Carer** • Carer age = range (years): 30 to 80+ (modal age: 60 to 69 years) • Carer gender (M/F: N)=11/26 • "Relationship to care recipient"= parents (n): 10; spouses (n): 24; daughters-sons (n): 5; sibling (n): 1; friends (n): 0; others-N/R (n): 0 **Professionals** • N/A **Care recipient** • Condition = Former carer - no condition specific **Inclusion criteria** • N/R **Exclusion criteria**	**Details** • **Recruitment methods:** Unclear sampling/recruitment strategy • **Data collection & analysis methods:** Data were collected through (face-to-face) semi-structured interviews. All interviews were audio-taped and transcribed. The analysis used a grounded theory process. In accordance with the use of grounded theory, amendments were regularly made to the interview schedule and technique in the light of the ongoing review of the literature, relevant sources of data, and data analysis.	• The role of carers groups during caring • The role of carers groups post-caring • Limitations of carers groups for carers and former carers	**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: not enough information were provided on the methods and rationale of the recruitment approach • **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? – Unclear. The role of the authors is not clearly reported (in relation to potential

Study details	Participants	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
Source of funding N/R	• N/R			bias/influence during data analysis, data collection, or carers' recruitment) • **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
Full citation Locock Louise, Brown Janice B, 'All in the same boat'? Patient and carer attitudes to peer support and social comparison in Motor Neurone Disease (MND), Social Science and Medicine, 71, 1498-1505, 2010 **Ref Id** 718401	**Sample size** N=22 adult carers **Characteristics** **Carer** • Carer age = More than 18 years old (mean/range -years: N/R) • Carer gender (M/F: N)=N/R • "Relationship to care recipient"= N/R **Professionals**	**Details** • **Recruitment methods:** This was a secondary analysis pooling the findings of two UK qualitative studies: Brown 2008: Participants were recruited in/the study through the MND Association's Regional Care Development Advisors RCDAs), unclear	• Practical comparison • Camaraderie and social comparison • emotional impact • Practical access problems	**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

Study details	**Participants**	**Methods**	**Themes and Findings (see appendix M for more details on the quotes obtained from the papers)**	**Methodological quality**
Country/ies where the study was carried out UK: England - Southeast **Study type** qualitative secondary research (peer-reviewed) **Aim of the study** The aims of this qualitative secondary research were to explore attitudes and views to peer support among people with Motor Neurone Disease (MND) and their family carers. It reports findings from a secondary analysis of data from two UK qualitative studies. **Study dates** - **Publication date**: 2010 - **Data collection**: This was a secondary analysis pooling the findings of two UK qualitative studies: Brown 2008: 2005-2006; Locock 2009: 2006-2007	- N/A **Care recipient** - Condition = Motor Neurone Disease **Inclusion criteria** - N/R **Exclusion criteria** - N/R	if the sampling strategy was purposeful or self-selected; Locock 2009: Carers were recruited purposively through MND specialist clinics, GPs, the MND Association, and an independent online forum for people with the condition. Variation was sought across demographic variables as well as type of caring experience - **Data collection & analysis methods:** Data were collected by pooling qualitative findings of 2 studies conducted previously by the authors in the UK (Brown 2008; Locock 2009). Brown's study had a smaller number of participants who were interviewed twice, whereas participants in Locock's study were interviewed once.		- **Q4:** Was the recruitment strategy appropriate to the aims of the research? - Unclear: Sampling of this secondary qualitative study has been obtained by pooling two original qualitative studies. The appropriateness of the final sample to the aims of the study is unclear. - **Q5**: Were the data collected in a way that addressed the research issue? - Unclear: It is unclear whether saturation has been achieved in this secondary analysis of data gathered by pooling two original qualitative studies - **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

Study details	Participants	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
Source of funding MND Association, the National Institute for Health Research Service Delivery and Organisation programme, and the Health Foundation		However, Locock's study included a wider range of people interviewed at varying lengths of time since diagnosis, and many people offered reflections on their changed attitudes over time. Locock's study included video interviewing and online dissemination illustrated by video and audio extracts. First step was to identify relevant narrative extracts from their own dataset, which were exchanged for independent reading by the researchers and used for initial thematic analysis. At this stage the authors focused on on each other's data to bring fresh insight. The social comparison theory was used.		- **Q10**: Is the research valuable for the UK (1. Contribution to literature and 2. Transferability)? - Yes **Overall methodological concerns:** minor
Full citation Mansell, Ian, Wilson, Christine, Current perceptions of respite care: Experiences of family and	**Sample size** N=151 adult carers (N=15 carers focus group)	**Details** - **Recruitment methods:** A convenience sample of carers was recruited	- Quality in terms of time away from caring role - Professional misconceptions	**Limitations (assessed using the CASP checklist for qualitative studies)**

Study details	Participants	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
informal carers of people with a learning disability, Journal of Intellectual Disabilities, 13, 255-267, 2009 **Ref Id** 719198 **Country/ies where the study was carried out** UK: Wales **Study type** mixed-methods original research (peer-reviewed) **Aim of the study** The aims of this mixed-methods study were to evaluate carers' perceptions of respite care services offered to them by their local authority. The focus was on carers of people with a learning disability. **Study dates** - **Publication date**: 2009 - **Data collection**: N/R	**Characteristics** **Carer** - Carer age = range (years): 25 to 75 - Carer gender (M/F: N)=26/135 - "Relationship to care recipient"= N/R **Professionals** - N/A **Care recipient** - Condition = Learning disability **Inclusion criteria** - N/R **Exclusion criteria** - N/R	through a parent/carer federation, a charity set up and run by parents and informal carers of people with intellectual disabilities for the purpose of providing help and support to its members. The sample (n=151) represented just under a quarter of the entire sample population (n=647). - **Data collection & analysis methods:** Data were collected through a semi-structured questionnaire including both qualitative and quantitative data, and further qualitative data came from two focus groups. The topics covered in the questionnaire included issues relevant in the learning disability literature. The data reported here cover the section of the	- Lack of information regarding respite access criteria - Equity of access	- **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? - No: self-selected study sample. - **Q5**: Were the data collected in a way that addressed the research issue? - Unclear: It is unclear whether saturation has been achieved in the analysis of data gathered from the focus groups - **Q6**: Has the relationship between researcher and participants been adequately considered? - Unclear: The role of the authors is not clearly reported (in relation to potential bias/influence during data

Study details	Participants	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
Source of funding N/R		questionnaire relevant to health and social care services and information. The focus groups were audiotaped and transcribed; transcripts were read and reread by two members of the research team. The ultimate aim was to develop themes that both emerged from and did justice to the data. A coding frame was developed. Thematic analysis was used to capture emerging categories and themes.		analysis, data collection, or carers' recruitment) - **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:** major
Full citation McSwiggan, Linda C., Marston, Judith, Campbell, Martin, Kelly, Timothy B., Kroll, Thilo, Information-sharing with respite care services for older adults: A qualitative exploration of carers' experiences, Health & social care in the community, 25, 1404-1415, 2017	**Sample size** N=24 adult carers **Characteristics** **Carer** - Carer age = More than 18 years old (mean age/range - years: N/R) - Carer gender (M/F: N)=N/R	**Details** - **Recruitment methods:** Carers were recruited purposively through carer support groups and community groups in voluntary organisations. Purposive sampling was utilised to recruit carers of different	- ‘Reaching a point’ – including ‘Barriers and facilitators’, ‘Modes of information-sharing’, ‘Use of ICTs’, - ‘Trying it out’ – including as above - ‘Settled in’ – including as above	**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

Study details	Participants	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
Ref Id 723491 **Country/ies where the study was carried out** UK: Scotland **Study type** qualitative original research (peer-reviewed) **Aim of the study** The aims of this qualitative study were to explore the carers' perceptions on the scope, quality and fit of information-sharing between carers, older people and respite services. **Study dates** - **Publication date**: 2017 - **Data collection**: 2013-2014 **Source of funding** The Queen's Nursing Institute Scotland (QNIS Project	- "Relationship to care recipient"= parents (n): 9; spouses (n): 15; daughters-sons (n): 0; sibling (n): 0; friends (n): 0; others-N/R (n): 0 **Professionals** - N/A **Care recipient** - Condition = Older people (for example Cognitive, Dysphasia, Visual and auditory) **Inclusion criteria** - carers supporting an older adult who had limitations in their abilities to represent themselves (for example sensory and/or cognitive impairments) - carers who have accessed residential, day centre, in home,one-to-one or host family respite services within the past year **Exclusion criteria**	ages and gender, who had been supporting different durations and for people with a range of physical and mental health needs. - **Data collection & analysis methods:** Data were collected through semi-structured interviews. All interviews were audio-taped and transcribed verbatin. The analysis used a framework approach (Gale 2013) and was an iterative process taking place alongside data generation and transcription. Thematic analysis was undertaken by two researchers.		- **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: it is unclear whether saturation has been achieved in the analysis of data gathered from the interviews - **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

Study details	**Participants**	**Methods**	**Themes and Findings (see appendix M for more details on the quotes obtained from the papers)**	**Methodological quality**
ELCRI01), Edinburgh, Scotland.	• carers supporting an older adult who were fully autonomous in their abilities to represent themselves (for example older adults who have loss of motor function only)			**Overall methodological concerns:** minor
Full citation Moule, Pam, Pollard, Katherine, Clarke, Jackie, Fear, Christine, Lawson, Bob, Thompson, Rennie, Young, Pat, An integrated approach for individualised support: carer's views, Journal of Integrated Care, 22, 253-262, 2014 **Ref Id** 720722 **Country/ies where the study was carried out** UK: England - Soutwest **Study type**	**Sample size** N=40 adult carers **Characteristics** **Carer** • Carer age = range (years): 21 to 90 • Carer gender (M/F: N)=9/31 • "Relationship to care recipient"= parents (n): 9; spouses (n): 18; daughters-sons (n): 13; sibling (n): 0; friends (n): 4; others-N/R (n): 0 **Professionals** • N/A **Care recipient** • Condition = Range of conditions (for example Alzheimer's disease, Lewy Body disease, Down's	**Details** • **Recruitment methods:** Carers were recruited purposively from two support groups from the South-East of England. To capture a spectrum of views, the groups included one that was set up by the carers themselves, without professional input, from within a single small town; and one that was initiated by a professional, who drew membership from carers across her organisation's geographic county 'catchment' area, but had eventually	• [nature of] the break • Effects of the break • Administration of the scheme • Carer circumstances	**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

Study details	Participants	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
Qualitative original research (peer-reviewed) **Aim of the study** The aims of this qualitative study were to explore carers' views of a service which offers support to carers in the form of a one-off payment - which they can use for anything they choose. **Study dates** • **Publication date**: 2014 • **Data collection**: 2012-2013 **Source of funding** The Bristol City Council and the Bristol Clinical Commissioning Group	syndrome, epilepsy, multiple sclerosis, autism and attention deficit hyperactivity disorder (ADHD), impairment results from a stroke and cancer) **Inclusion criteria** • Carers of patient living at home; • Carers of patient receiving informal care **Exclusion criteria** • Carers of people referred for curative surgery; • Carers of patient living in residential accommodation; • Carers unable to give consent because dementia or other mental impairment.	withdrawn herself from the group. • **Data collection & analysis methods:** Data were collected through (telephone) semi-structured interviews. All interviews were audio-taped and comprehensive notes were made. The interviews addressed three main topics (1) carer's experience of the assessment process for the break; (2) nature of the break chosen; and (3) possible impact of the break on the carer and the care recipient. The analysis used a thematic framework using a recognised process to support content analysis (Miles and Huberman, 1994).		• **Q6**: Has the relationship between researcher and participants been adequately considered? - Unclear: role of the authors is not clearly reported (in relation to potential bias/influence during data analysis, data collection, or carers' recruitment) • **Q7**: Have ethical issues been taken into consideration? - Yes • **Q8**: Was the data analysis sufficiently rigorous? - No: no sufficient data are presented to support the findings • **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
Full citation Munn-Giddings, C., McVicar, A., Self-help groups as mutual support: What do carers	**Sample size** N=15 adult carers **Characteristics**	**Details** • **Recruitment methods:** Carers were recruited purposively	• Motivation for joining the group (carers self-help groups):	**Limitations (CASP- checklist for qualitative studies)**

Study details	Participants	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
value?, Health and Social Care in the Community, 15, 26-34, 2007 **Ref Id** 738270 **Country/ies where the study was carried out** UK: England - Southeast **Study type** qualitative original research (peer-reviewed) **Aim of the study** The aims of this qualitative study were to explore carers' views of attending self-help/mutual aid groups. **Study dates** - **Publication date**: 2007 - **Data collection**: N/R **Source of funding** N/R	**Carer** - Carer age = range (years): 50 to 67 - Carer gender (M/F: N)=6/9 - "Relationship to care recipient"= parents (n): 0; spouses (n): 9; daughters-sons (n): 2; sibling; friends; others-N/R (n): 4 **Professionals** - N/A **Care recipient** - Condition = Range of conditions (for example Alzheimer's disease, Lewy Body disease, and Dementia) **Inclusion criteria** - N/R **Exclusion criteria** - N/R	through an initial survey of questionnaires, in which carers were asked to volunteer to take part in follow-up interviews. Purposive sample were selected to represent a wide range of characteristics (for example age of carers, age of person cared for, relationship, number of people being cared for, ethnicity, gender, length of time caring and nature of condition leading to requirement for care). - **Data collection & analysis methods:** The methodological framework used for the study was a qualitative case study design. Data were collected through (face-to-face) semi-structured interviews. All interviews were audio-taped and transcribed, and	- Personal gains from attending the group: Empathy - Personal gains from attending the group: Emotional coping - Personal gains from attending the group: Experiential knowledge - Personal gains from attending the group: Practical information - Personal gains from attending the group: Peer support/friendships - Contrasting self-help groups with professional services	- **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? - Unclear: It is unclear whether saturation has been achieved in the analysis of data gathered from the interviews - **Q6**: Has the relationship between researcher and participants been adequately considered? - Unclear: The role of the Authors it is unclearly reported (in relation to potential bias/influence during carers' recruitment)

Study details	**Participants**	**Methods**	**Themes and Findings (see appendix M for more details on the quotes obtained from the papers)**	**Methodological quality**
		participants were offered the opportunity to see, amend and agree their transcript. The interview schedule was designed following a pre-study literature review. The analysis used a thematic approach, with emergent themes identified as units derived from patterns in the transcripts. For verification, this process was undertaken independently by two researchers who agreed the final themes.		• **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
Full citation Ryan, P. J., Howell, V., Jones, J., Hardy, E. J., Lung cancer, caring for the caregivers. A qualitative study of providing pro-active social support targeted to the carers of patients with lung cancer, Palliative Medicine, 22, 233-8, 2008	**Sample size** N=20 adult carers **Characteristics** **Carer** • Carer age = range (years): 37 to 88 • Carer gender (M/F: N)=4/16 • "Relationship to care recipient"= parents (n): 0; spouses (n): 14; daughters-	**Details** • **Recruitment methods:** Carers were recruited from a single rural DGH lung cancer clinic and delivered additional support to carers in their own homes. It is unclear whether the sample was selected purposively or was a self-selected sample.	• Factors enabling carers to receive support and the care workers to provide it • Whether the service improved the quality of life for the carer • To what extent the MCP aims were accomplished • Caring for patients with lung cancer in general	**Limitations (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

Study details	Participants	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
Ref Id 719843 **Country/ies where the study was carried out** UK: England - Southeast **Study type** Qualitative original research (peer-reviewed) **Aim of the study** The aims of this qualitative study were to explore the views of carers of patients with lung cancer (compared with professionals) in relation to the provision of a pro-active social support intervention (Macmillan Carers Project -MCP). **Study dates** - **Publication date**: 2008 - **Data collection**: N/R (18 months recuiment period) **Source of funding** N/R	sons (n): 5; sibling (n): 0; friends (n): 1; others-N/R (n): 0 **Professionals** - N= 21 **Care recipient** - Condition = Lung cancer **Inclusion criteria** - N/R **Exclusion criteria** - N/R	- **Data collection & analysis methods:** The methodological framework used for the study was a qualitative case study design. Data were collected through (face-to-face) semi-structured interviews. All interviews were audio-taped and transcribed. The interviews were structured around the aims of the intervention but with flexibility to allow unexpected issues and themes to emerge. The analysis used the thematic approach. Validity was ensured by data triangulation (carers and professionals) and methodological triangulation (interviews, structured questionnaires and researcher observations and notes)		- **Q4:** Was the recruitment strategy appropriate to the aims of the research? - Unclear: not enough information were provided on the methods and rationale of the recruitment approach - **Q5**: Were the data collected in a way that addressed the research issue? - Unclear: It is unclear whether saturation has been achieved in the analysis of data gathered from the interviews - **Q6**: Has the relationship between researcher and participants been adequately considered? - Unclear: role of the Authors it is unclearly reported (in relation to potential bias/influence during carers' recruitment) - **Q7**: Have ethical issues been taken into consideration? - Yes - **Q8**: Was the data analysis sufficiently rigorous? - no: no sufficient data are presented to support the findings

Study details	Participants	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
				• **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:** major
Full citation Skilbeck,J.K., Payne,S.A., Ingleton,M.C., Nolan,M., Carey,I., Hanson,A., An exploration of family carers' experience of respite services in one specialist palliative care unit, Palliative Medicine, 19, 610-618, 2005 **Ref Id** 166711 **Country/ies where the study was carried out** UK: England - North (Sheffield) **Study type**	**Sample size** N=25 adult carers **Characteristics** **Carer** • Carer age = mean - range (years): 61 - 38 to 78 • Carer gender (M/F: N)=N/R • "Relationship to care recipient"= N/R **Professionals** • N/A **Care recipient** • Condition = Range of conditions (for example Cancer and neurological conditions)	**Details** • **Recruitment methods:** Carers were recruited from an independent hospice in the north of England. It is unclear whether the sample was selected purposively or was a self-selected sample. • **Data collection & analysis methods:** Data were collected through (face-to-face and telephone) semi-structured interviews. Telephone interviews took place prior to respite admission to explore care experiences and expectations of	• Experience of respite service provision • Service evaluation: Continuity of care • Service evaluation: Providing new opportunities for care • Better here than elsewhere • Dissatisfaction with aspects of the service received	**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: not enough information were provided on the methods and rationale of the recruitment approach

Study details	Participants	Methods	Themes and Findings (see appendix M for more details on the quotes obtained from the papers)	Methodological quality
Mixed-methods original research (peer-reviewed) **Aim of the study** The aims of this mixed-methods study were to explore experiences and expectations of carers whose relative had been admitted to the local hospice for inpatient respite care **Study dates** • **Publication date**: 2004 • **Data collection**: May to October 2003 **Source of funding** N/R	**Inclusion criteria** • N/R **Exclusion criteria** • N/R	respite; face-to-face interviews were administered following respite stay to explore whether expectations had been met. All interviews were audio-taped and transcribed. The analysis used a process of constant comparison; this involved detailed reading of the transcripts and independent coding of the data by members of the researcher team		• **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

F: Female; M: Male; N: Number; N/R: not reported; N/A: not applicable

Appendix E – Forest plots

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

Appendix F – GRADE and GRADE-CERQual tables

GRADE tables for review question: What practical, social and community support interventions for adult carers are effective, cost-effective, and acceptable to them?

Multi-faceted informational support

Table 7: Evidence profile for multi-faceted information for supporting adult carers

Quality assessment							Number of partcipiants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Web-based support	Folder-based support	Relative (95% CI)	Absolute		
Caring-related morbidity: stress (Perceived Stress Scale) - 4 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	120[4]	121[4]	-	MD 1.3 lower (3.17 lower to 0.57 higher)	VERY LOW	CRITICAL
Caring-related morbidity: stress (Perceived Stress Scale) - 8 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	120[4]	121[4]	-	MD 0.2 lower (2.54 lower to 2.14 higher)	VERY LOW	CRITICAL
Caring-related morbidity: well-being (Well-Being Index-WHO-5) - 4 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	120[4]	121	-	MD 1 lower (6.08 lower to 4.08 higher)	VERY LOW	CRITICAL
Caring-related morbidity: well-being (Well-Being Index-WHO-5) - 8 months follow-up (Better indicated by higher values)												

Quality assessment							Number of partcipiants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Web-based support	Folder-based support	Relative (95% CI)	Absolute		
1[1]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	120[4]	121[4]	-	MD 0.9 lower (5.93 lower to 4.13 higher)	VERY LOW	CRITICAL
Caring-related morbidity: Self rated health -Very Good (customised measure) - 4 months follow-up												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	13/70 (18.6%)	19/69 (27.5%)	RR 0.67 (0.34 to 1.23)	91 fewer per 1000 (from 182 fewer to 63 more)	VERY LOW	CRITICAL
Caring-related morbidity: Self rated health -Very Good (customised measure) - 8 months follow-up												
1[1]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	23/75 (30.7%)	25/75 (33.3%)	RR 0.92 (0.55 to 1.4)	27 fewer per 1000 (from 150 fewer to 133 more)	VERY LOW	CRITICAL
Caring-related morbidity: Self rated health –Good (customised measure) - 4 months follow-up												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	43/70 (61.4%)	36/69 (52.2%)	RR 1.18 (0.86 to 1.45)	94 more per 1000 (from 73 fewer to 235 more)	VERY LOW	CRITICAL
Caring-related morbidity: Self rated health –Good (customised measure) - 8 months follow-up												
1[1]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	32/75 (42.7%)	33/75 (44%)	RR 0.97 (0.64 to 1.33)	13 fewer per 1000 (from 158 fewer to 145 more)	VERY LOW	CRITICAL
Impact of caring on carer: caring situation –negative (Cope-negative subscale) - 4 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	120[4]	121[4]	-	MD 0.5 higher (0.35 lower to 1.35 higher)	VERY LOW	CRITICAL
Impact of caring on carer: caring situation –negative (Cope-negative subscale) - 8 months follow-up (Better indicated by higher values)												

Quality assessment							Number of partcipants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Web-based support**	**Folder-based support**	**Relative (95% CI)**	**Absolute**		
1[1]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	120[4]	121[4]	-	MD 0.2 higher (0.66 lower to 1.06 higher)	VERY LOW	CRITICAL
Impact of caring on carer: caring situation –positive (Cope-positive subscale) - 4 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	no serious imprecision	none	120[4]	121[4]	-	MD 0.8 higher (0.14 to 1.46 higher)	LOW	CRITICAL
Impact of caring on carer: caring situation –positive (Cope-positive subscale) - 8 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	120[4]	121[4]	-	MD 0.5 higher (0.13 lower to 1.13 higher)	VERY LOW	CRITICAL
Impact of caring on carer: caring situation -quality of support (Cope-quality of support subscale) - 4 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	120[4]	121[4]	-	MD 0.17 lower (0.9 lower to 0.56 higher)	VERY LOW	CRITICAL
Impact of caring on carer: caring situation -quality of support (Cope-quality of support subscale) - 8 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	120[4]	121[4]	-	MD 0.02 higher (0.62 lower to 0.66 higher)	VERY LOW	CRITICAL
Carer quality of life: Self rated QoL -Very Good (customised measure) - 4 months follow-up												

Quality assessment							Number of partcipiants		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Web-based support	Folder-based support	Relative (95% CI)	Absolute		
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	30/76 (39.5%)	28/75 (37.3%)	RR 1.05 (0.68 to 1.49)	19 more per 1000 (from 119 fewer to 183 more)	VERY LOW	IMPORTANT
Carer quality of life: Self rated QoL -Very Good (customised measure) - 8 months follow-up												
1[1]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	21/82 (25.6%)	31/80 (38.8%)	RR 0.66 (0.39 to 1.04)	132 fewer per 1000 (from 236 fewer to 15 more)	VERY LOW	IMPORTANT
Carer quality of life: Self rated QoL –Good (customised measure) - 4 months follow-up												
1[1]	randomised trials	very serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	30/76 (39.5%)	28/75 (37.3%)	RR 1.05 (0.68 to 1.49)	19 more per 1000 (from 119 fewer to 183 more)	VERY LOW	IMPORTANT
Carer quality of life: Self rated QoL –Good (customised measure) - 8 months follow-up												
1[1]	randomised trials	very serious[5]	no serious inconsistency	no serious indirectness	serious[3]	none	30/82 (36.6%)	31/80 (38.8%)	RR 0.94 (0.6 to 1.34)	23 fewer per 1000 (from 155 fewer to 132 more)	VERY LOW	IMPORTANT

1 Ali 2014

2 The quality of the evidence was downgraded of 2 levels because of the potential risk of detection bias (no details on blinding of outcome assessors), and high risk of selection bias: (baseline imbalances between intervention groups: There were significant differences in stress and negative impact, with the intervention group showing lower values at baseline than the control group).

3 Non-significant result (Any statistically significant change was considered to be important for carers - for any outcome where published MIDs were not identified)

4 Intention to treat population - that is: assessment of the carers taking part in the RCT, based on the group they were initially randomly allocated to. This is regardless of whether or not they dropped out, fully adhered to the intervention protocol

5 The quality of the evidence was downgraded of 2 levels because of the potential risk of detection bias (no details on blinding of outcome assessors), and high risk of selection bias: (baseline imbalances between intervention groups: There were significant differences in stress and negative impact, with the intervention group showing lower values at baseline than the control group). In addiction quality of the evidence was lowered because of the likely risk of attrition bias (high dropout rate at 8 month follow-up, in the 8 month analysis the number of participants did not reach the power calculation - assessments were 77.5% in the web group and 71.9% of the control group).

Carer support groups – befriending scheme

Table 8: Evidence profile for carer support groups (befriending volunteer) for supporting adult carers

Quality assessment							Number of partcipiants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Befriending scheme**	**Usual care**	**Relative (95% CI)**	**Absolute**		
Caring-related morbidity: mood - depression (HADS depression scale) - 6 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	104	113	-	MD 0.19 higher (0.82 lower to 1.2 higher)	LOW	CRITICAL
Caring-related morbidity: mood - depression (HADS depression scale) - 15 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	96	106	-	MD 0.68 lower (1.81 lower to 0.45 higher)	LOW	CRITICAL
Caring-related morbidity: mood - depression (HADS depression scale) - 24 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	93	97	-	MD 0.1 lower (1.34 lower to 1.14 higher)	LOW	CRITICAL
Caring-related morbidity: mood - anxiety (HADS anxiety scale) - 6 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	104	113	-	MD 0.61 lower (1.79 lower to 0.57 higher)	LOW	CRITICAL
Caring-related morbidity: mood - anxiety (HADS anxiety scale) - 15 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	96	106	-	MD 1 lower (2.24 lower to 0.24 higher)	LOW	CRITICAL
Caring-related morbidity: mood - anxiety (HADS anxiety scale) - 24 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	93	97	-	MD 0.42 lower (1.7 lower to 0.86 higher)	LOW	CRITICAL
Caring-related morbidity: mood – loneliness (loneliness scale) - 6 months follow-up (Better indicated by lower values)												

Quality assessment							**Number of partcipiants**		**Effect**		**Quality**	**Importance**
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Befriending scheme**	**Usual care**	**Relative (95% CI)**	**Absolute**		
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	104	112	-	MD 0.15 lower (0.72 lower to 0.42 higher)	LOW	CRITICAL
Caring-related morbidity: mood – loneliness (loneliness scale) - 15 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	96	106	-	MD 0.36 lower (0.98 lower to 0.26 higher)	LOW	CRITICAL
Caring-related morbidity: mood – loneliness (loneliness scale) - 24 months follow-up (Better indicated by lower values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	93	97	-	MD 0.39 lower (1.06 lower to 0.28 higher)	LOW	CRITICAL
Caring-related morbidity: mood – affect (PANAS—positive affect) - 6 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	103	111	-	MD 1.4 lower (3.6 lower to 0.8 higher)	LOW	CRITICAL
Caring-related morbidity: mood – affect (PANAS—positive affect) - 15 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	96	106	-	MD 0 higher (2.24 lower to 2.24 higher)	LOW	CRITICAL
Caring-related morbidity: mood – affect (PANAS—positive affect) - 24 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	92	95	-	MD 1.1 lower (3.55 lower to 1.35 higher)	LOW	CRITICAL
Social support: Perceived support (MSPSS) - 6 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	102	113	-	MD 0.3 lower (2.73 lower to 2.13 higher)	LOW	IMPORTANT
Social support: Perceived support (MSPSS) - 15 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	95	106	-	MD 0.6 lower (3.38 lower to 2.18 higher)	LOW	IMPORTANT

Quality assessment							Number of partcipiants		Effect		Quality	Importance
Number of studies	**Design**	**Risk of bias**	**Inconsistency**	**Indirectness**	**Imprecision**	**Other considerations**	**Befriending scheme**	**Usual care**	**Relative (95% CI)**	**Absolute**		
Social support: Perceived support (MSPSS) - 24 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	92	97	-	MD 0.9 lower (3.68 lower to 1.88 higher)	LOW	IMPORTANT
Carer quality of life (EQ-5D global VAS) - 6 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	101	112	-	MD 2.8 higher (1.86 lower to 7.46 higher)	LOW	IMPORTANT
Carer quality of life (EQ-5D global VAS) - 15 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	95	106	-	MD 3.9 higher (1.14 lower to 8.94 higher)	LOW	IMPORTANT
Carer quality of life (EQ-5D global VAS) - 24 months follow-up (Better indicated by higher values)												
1[1]	randomised trials	serious[2]	no serious inconsistency	no serious indirectness	serious[3]	none	92	96	-	MD 4.4 higher (1.03 lower to 9.83 higher)	LOW	IMPORTANT

1 Charlesworth 2008
2 The quality of the evidence was downgraded by 1 level because of the potential risk of performance bias (no blinding of carers to the allocated intervention).
3 Non-significant result (Any statistically significant change was considered to be important for carers - for any outcome where published MIDs were not identified)

GRADE - CERQual tables for review question: What practical, social and community support interventions for adult carers are effective, cost-effective, and acceptable to them?

Multi-faceted informational support

Table 9: Summary of evidence (GRADE-CERQual), Theme 1: Multi-faceted support (information provision + emotional support + practical support)

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**
Failure to identify as carers and impact on support seeking							
1(Ryan 2008)	Semi-structured interviews	Many carers did not identify themselves as actual carers, as they felt they were only the spouses, parents and children fulfilling a natural role for their loved ones. This had implications for whether a carer will seek practical support.	Serious concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	VERY LOW
Factors enabling carers to seek support.							
1(Ryan 2008)	Semi-structured interviews	Many professionals delivering a multi-faceted support intervention [Macmillan Carers Project] felt that carers of people with lung cancer were more likely to seek support if they were emotionally resilient, pro-active, organised (for example, they had routines, lists and knowledge of where	Serious concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	VERY 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
		to seek information), in good health, financially secure; and had good family relations and support, supportive employment, confidence to admit difficulty with coping and to ask for help, good communication skills and the ability to network.					
Benefits for carers and the person they support.							
1(Ryan 2008)	Semi-structured interviews	Many adult carers often felt that a multi-faceted support intervention [Macmillan Carers Project] enabled their care recipients to stay at home longer, rather than being admitted to hospital and even to die at home (according to the care recipients' wishes). Some carers felt it was important to talk to someone outside of their family or friends, and the medical or nursing team, this was perceived as one of the main benefits of the intervention.	Serious concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	VERY LOW
The importance of a non-medical perspective.							

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(Ryan 2008)	Semi-structured interviews	Many adult carers felt a non-medical, social work background was appropriate for the professionals delivering a multi-faceted support intervention [Macmillan Carers Project]. In addition, several carers felt that the Macmillan Carers Project workers provided information (about the illness, the investigation and treatment process plus future care options) and acted as a useful point of contact, besides giving emotional and practical support.	Serious concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	VERY LOW

1 Evidence was downgraded because serious methodological limitations (no sufficient data are presented to support the findings, not enough information were provided on the methods and rationale of the recruitment approach, and it is unclear whether saturation has been achieved in the analysis of data gathered from the interviews). Finally, the role of the Authors it is unclearly reported (in relation to potential bias/influence during carers' recruitment)
2 Evidence was downgraded because major concerns with the adequacy of data, as only 1 study supported the review's findings (offering poor data)

Respite care and breaks

Table 10: Summary of evidence (GRADE-CERQual), Theme 2: Respite care and breaks

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
Impact of caring on support seeking: Physical, mental and emotional impact							

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 (Dali 2012, Greenwood 2012)	1: Semi-structured interviews and focus groups; 1: Semi-structured interviews	Many carers reported feelings of exhaustion and lack of sleep, with some who described experiencing mental health problems including depression. In addition, many carers felt a constant sense of responsibility for their cared for, often making it difficult to leave them.	Minor concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	LOW
Impact of caring on support seeking: Family and social life							
1 (Dali 2012)	Semi-structured interviews and focus groups;	Carers reported the impact of caring on their family life and on their social lives, including not being able to pursue personal interests, hobbies or see friends.	Moderate concerns[3]	No or very minor concerns	No or very minor concerns	Serious concerns[4]	VERY LOW
Impact of caring on support seeking: Employment and finances							
1 (Dali 2012)	Semi-structured interviews and focus groups;	Many employed carers felt that work was fundamental to their sense of self and also provided a break from their caring role. Other carers struggled to juggle a job and caring, and some of them experienced loss of income, loss of opportunities for promotion and in some cases had to give up work.	Moderate concerns[3]	No or very minor concerns	No or very minor concerns	Serious concerns[4]	VERY 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**
Failure to identify as carers and impact on support seeking							
1 (Dali 2012)	Semi-structured interviews and focus groups;	Many adult carers did not identify themselves as actual carers, as they felt they were only fulfilling a natural role. This had implications for whether they will seek respite care and breaks.	Moderate concerns[3]	No or very minor concerns	No or very minor concerns	Serious concerns[4]	VERY LOW
The influence of guilt and low expectations							
2 (Dali 2012, Greenwood 2012)	1: Semi-structured interviews and focus groups; 1: Semi-structured interviews	Many adult carers experienced feelings of guilt about using respite care and short breaks; for example, some carers felt taking a break amounted to 'admitting defeat'. This could often inhibit them from seeking a break from caring and/or using the breaks they did take. In addition, many adult carers reported feelings of powerlessness and low expectations of respite support; for example some carers felt that they were lucky to receive any help at all and therefore should neither criticise the professional providing respite	Minor concerns[1]	No or very minor concerns	No or very 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
		nor ask them to do additional tasks					
Service design barriers to seeking support.: Lack of appropriate provision							
2 (Dali 2012, McSwiggan 2017)	1: Semi-structured interviews and focus groups; 1: Semi-structured interviews	Some carers perceived respite services as unacceptable because the poor quality or because age-inappropriate, resulting in carers turning down the services offered	Minor concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	LOW
Service design barriers to seeking support.: Lack of information regarding respite access criteria							
4 (Dali 2012, Skilbeck 2005, Mansell 2009, McSwiggan 2017)	1: Semi-structured interviews and focus groups; 2: Semi-structured interviews; 1: open-ended questionnaires	Many carers reported about not knowing their entitlements and the difficulty in finding out information, with most of them would have liked more information about the respite unit and the service it offered. This may led to a problematic accessing to respite and short breaks Some carers also reported that they took responsibility for finding out information for themselves, as lack of information from GPs and social work services	Minor concerns[5]	No or very minor concerns	No or very minor concerns	Minor concerns[6]	MODERATE[7]
Service design barriers to seeking support: Battling to be heard							

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
3 (Dali 2012, Mansell et al 2009, Greenwood 2012)	1: Semi-structured interviews and focus groups; 2: Semi-structured interviews	Many carers felt that an important barrier to accessing respite care and breaks was their difficulty when engaging with statutory social services. It was reported that local health authorities had set criteria that determined how individuals accessed respite provision (but no local health authority had a clear understanding of this criteria) Many carers reported the planning processes to access respite care and breaks as impersonal, time consuming, overly bureaucratic and stressful.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Moderate concerns[8]	MODERATE
Service design barriers to seeking support: Changes in break provision							
3 (Dali 2012, Skilbeck 2005, McSwiggan 2017)	1: Semi-structured interviews and focus groups; 2: Semi-structured interviews	Many carers reported that changes in provision of respite care could impact on the care recipient	No or very minor concerns	No or very minor concerns	No or very minor concerns	Moderate concerns[8]	MODERATE
The importance of a person centred approach to respite care: Misconceptions about the role of carers during periods of respite							
1 (Mansell 2009)	Open-ended questionnaires	Many carers felt professionals to have unrealistic understanding of individuals' circumstances	Moderate concerns[2]	No or very minor concerns	No or very minor concerns	Serious concerns[4]	VERY 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
		and how natural life stages were different for carers under these circumstances					
The importance of a person centred approach to respite care: Characteristics of effective respite delivery							
3 (Dali 2012, Skilbeck 2005, Greenwood 2012)	1: Semi-structured interviews and focus groups; 2: Semi-structured interviews	Carers felt that professionals had to reflect and be responsive to the needs of the care recipient in order to be effective. Carers felt it was very important to have a personal, trusting relationship with professionals delivering respite support. Trust in these professionals included characteristics such as their reliability and sensitivity to the person's needs. Other carers felt that a good respite professional had to have particular qualities, including good communication, understanding and being adaptable as well as being able to stimulate or motivate the person being supported	No or very minor concerns	No or very minor concerns	No or very minor concerns	Moderate concerns[8]	MODERATE
Carer perceptions about the ideal length and nature of respite.							
2 (Dali 2012, Mansell 2009)	1: Semi-structured interviews and focus groups; 1:	Many adult carers had mixed views in relation to the type of break offered and the duration of the break. Most	Minor concerns[5]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	VERY 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
	open-ended questionnaires	carers suggested an overnight stay was required for the 'break' to be considered by them as respite. Many carers reported the need to have sufficient time to feel refreshed by the break and this was necessary for them to feel that they had received something that was of value to them. Other carers felt that any length of break had a positive impact.					
The importance of consistency.							
2 (Dali 2012, Greenwood 2012)	1: Semi-structured interviews and focus groups; 1: Semi-structured interviews	Many adult carers reported that a benefit of having respite at regular time points was the ability to plan their time. Some carers felt that having an infrequent or irregular break actually had a detrimental effect on their ability to cope with the caring role	Minor concerns[1]	No or very minor concerns	No or very minor concerns	Serious concerns[2]	LOW

1 Evidence was downgraded because minor methodological limitations in 1 study (Dali 2012: it is unclear whether saturation has been achieved in the analysis of data gathered from the interviews, and the role of the Authors it is unclearly reported -in relation to potential bias/influence during carers' recruitment, and a self-selected study sample was used)
2 Evidence was downgraded because substantial concerns with the adequacy of data, as only 2 studies supported the review's findings (offering poor data)
3 Evidence was downgraded because moderate methodological limitations (it is unclear whether saturation has been achieved in the analysis of data gathered from the interviews, the role of the Authors it is unclearly reported -in relation to potential bias/influence during carers' recruitment, and no clear description of the data analysis approach used)
4 Evidence was downgraded because major concerns with the adequacy of data, as only 1 study supported the review's findings (offering poor data)

5 Minor methodological limitations in 2 studies (Dali 2012, Mansell 2009: unclear whether saturation has been achieved in the analysis of data gathered from the interviews, and the role of the Authors it is unclearly reported -in relation to potential bias/influence during carers' recruitment, and unclear recruitment strategy)
6 Minor concerns on adequacy of data, as 4 studies supported the review's findings (offering thin data)
7 Evidence was downgraded because minor methodological limitation and adequacy of data
8 Evidence was downgraded because minor concerns with the adequacy of data, as only 3 studies supported the review's findings (offering poor data)

Carer support groups

Table 11: Summary of evidence (GRADE-CERQual), Theme 3: Carer support groups (including self-help groups/mutual support and peer-support)

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**
Factors enabling carers to joining the carers support group							
2 (Munn Giddings 2007, Harding 2004)	Semi-structured interviews	For adult carers factors prompting carers to join the carers support group included; feelings of loneliness, perceived diminishing support available via their usual social networks and the need to meet people who were in very similar circumstances.	Minor concerns[2]	No or very minor concerns	No or very minor concerns	Moderate concerns[3]	LOW
Barriers for carers to accessing support groups.							
1 (Locock 2010)[1]	Semi-structured interviews[1]	Most carers experienced practical access problems, which prevented them from attending face-to-face support groups. For example, some carers [of people with NMD] who were working full-time reported that attending	Moderate concerns[4]	No or very minor concerns	No or very minor concerns	Serious concerns[5]	VERY 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
		daytime meetings was difficult. In addition, transport services were important in facilitating carers' [] attendance at the support group, especially for older carers and those who could not drive.					
Perceived benefits from attending carer support groups: Empathy							
3 (Munn Giddings 2007, Harding 2004, Keyes 2016)	Semi-structured interviews	Many carers reported they had gained from being part of the group was meeting others who could do more than sympathise with their situation, and who could empathise from their own experience	Moderate concerns[6]	No or very minor concerns	No or very minor concerns	Minor concerns[7]	LOW
Perceived benefits for carers from attending carer support groups: Emotional coping							
4 (Munn Giddings 2007, Locock 2010[5], Harding 2004, Larkin 2007)	Semi-structured interviews	The regular group meetings offered a forum in which carers monitored one another's problems, and assessed whether they were coping (for example during points of crisis). Sharing of stories enabled carers to pass on ways of coping which they had found useful. Some carer reported emotional benefits also from sharing less 'positive' emotions e including	Moderate concerns[8]	No or very minor concerns	No or very minor concerns	No or very minor concerns	MODERATE

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**
		sadness, fear, anger and sometimes guilt.					
Perceived benefits for carers from attending carer support groups: Experiential knowledge							
3 (Munn Giddings 2007, Harding 2004, Keyes 2016)	Semi-structured interviews	By attending support groups, many carers improved their collective knowledge, which was reported to offer carers with both practical and emotional support	Moderate concerns[6]	No or very minor concerns	No or very minor concerns	Minor concerns[7]	LOW
Perceived benefits for carers from attending carer support groups: Practical information							
4 (Munn Giddings 2007, Locock 2010[5], Harding 2004, Larkin 2007)	Semi-structured interviews	Many carers felt that an important advantage of support groups was getting advice on accessing specific local services, advice about claiming benefits, and suggesting coping strategies to each other	Moderate concerns[8]	No or very minor concerns	No or very minor concerns	No or very minor concerns	MODERATE
Perceived benefits for carers from attending carer support groups: Peer support/friendships							
5 (Munn Giddings 2007, Locock 2010[5], Harding 2004, Larkin 2007,	Semi-structured interviews	Many carers felt that an important advantage of support groups was the relationships built between peers in the group (that seemed to lie in the comfort of knowing that others could be contacted at any time, even	Moderate concerns[8]	No or very minor concerns	No or very minor concerns	No or very minor concerns	MODERATE

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
Keyes et al 2016)		though few members actually met outside the group) The reciprocity of the relationship was reported to be central. Many carers found new 'friends' in their groups, and the reciprocity of the relationship was reported to be central. This led to an atmosphere which offered a 'safe place' where carers were able to express guilt and 'off-load' legitimately					
Perceived benefits from attending carer support groups: Instrumental support							
1 (Larkin 2007)	Semi-structured interviews	Many carers felt that an important advantage of support groups was getting instrumental support including help from advocacy workers when fighting for suitable medical care for their dependants) and practical support with caring appraisal support (including help with decision-making, and dealing with feedback)	Very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[5]	LOW
Contrasting carers support groups with professional services.							
2 (Munn Giddings 2007,	Semi-structured interviews	Many carers expressed concern at the general lack of appreciation by professional	Very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[3]	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
Keyes 2016)		carers of the scope and breadth of their caring responsibilities, and of the importance of their relationship with the person they support (especially in relation to those professionals with whom they did not have long-term contact). For some carers, the support group held significance because they had lost their trust in the ability of services and professionals to meet their needs.					

1 Data were collected by pooling qualitative findings of 2 studies conducted previously by the authors in the UK (Brown 2008, Locock 2009). Both studies used semi-structured interviews to collect data.

2 Evidence was downgraded because minor methodological limitations in 1 study (Harding 2004: it is unclear whether saturation has been achieved in the analysis of data gathered from the interviews, and the role of the Authors it is unclearly reported -in relation to potential bias/influence during carers' recruitment, and no clear description of the data analysis approach used).

3 Evidence was downgraded because substantial concerns with the adequacy of data, as only 2 studies supported the review's findings (offering poor data)

4 Evidence was downgraded because unclear methodological limitations (Sampling of this secondary qualitative study has been obtained by pooling 2 original qualitative studies. The appropriateness of the final sample to the aims of the study is unclear.). In addition, it is unclear whether saturation has been achieved in this secondary analysis of data gathered by pooling 2 original qualitative studies.

5 Evidence was downgraded because major concerns with the adequacy of data, as only 1 study supported the review's findings (offering poor data)

6 Evidence was downgraded because moderate methodological limitations in 2 studies (Harding 2004; and Keyes 2016: in both studies, it is unclear whether saturation has been achieved in the analysis of data gathered from the interviews, and the role of the Authors it is unclearly reported -in relation to potential bias/influence during carers' recruitment, and no clear description of the data analysis approach used).

7 Evidence was downgraded because minor concerns wit the adequacy of data, as only 3 studies supported the review's findings (offering poor data)

8 Evidence was downgraded because moderate methodological limitations in 1 study [Harding 2004, and Locock 2010: it is unclear whether saturation has been achieved in the analysis of data gathered from the interviews, and the role of the Authors it is unclearly reported -in relation to potential bias/influence during carers' recruitment, and no clear description of the data analysis approach used. In addition, it is unclear whether saturation has been achieved 1 secondary analysis of qualitative data gathered by pooling 2 original qualitative studies (Locock 2010)]

Table 12: Summary of evidence (GRADE-CERQual), Theme 4: Carer support groups for former carers

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
Perceived benefits for former carers to attend support groups: Empathy							
1 (Larkin 2007)	Semi-structured interviews	Carer support groups could also meet other more complex post-caring needs, that is why former carers saw them as a valuable form of support post-caring (such as compensating for the loss of the role of carer and providing a sense of belonging). Some former carers felt that continuing to belong to the same carers group that had been attended during caring can provide this sort of post-caring support	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW
Perceived benefits for former carers to attend support groups: Emotional coping/friendships and appraisal support							
1 (Larkin 2007)	Semi-structured interviews	Many former carers felt that as during caring, support groups were a source of friendship that provided social, emotional and appraisal support (that is means help with decision-making, dealing with feedback and agreeing courses of action.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW
Limitations of carers groups for carers and former carers							

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 (Larkin 2007)	Semi-structured interviews	Many former carers suggested that potential factors that can limit the value of carers groups specific for their post-caring needs, such as individual members' professional backgrounds, previous caring experiences, feelings about participation in groups and gender	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW

1 Evidence was downgraded because major concerns with the adequacy of data, as only 1 study supported the review's findings (offering poor data)

Volunteer support

Table 13: Summary of evidence (GRADE-CERQual), Theme 5: Volunteer peer support (former carers – carers)

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**
Perceived benefits of peer support: Empathy and social support							
1 (Greenwood 2013)	Semi-structured interviews	Peer support benefitted carers and volunteers (former carer of people living with dementia) with the realization that they were not alone in their experiences and emotions. Carers attending peer support felt that they were not unusual and less isolated; former carers also felt better meeting	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	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
		other former carers during training and learning (this helped them to realise that their experiences were not unusual and helpful).					
Perceived benefits of peer support: Emotional Support and Release							
1 (Greenwood 2013)	Semi-structured interviews	Both carers and volunteers (former carer of people living with dementia) described emotional support and release gained from receiving and giving peer support	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW
Perceived benefits of peer support: Enjoyment of Peer Support							
1 (Greenwood 2013)	Semi-structured interviews	Both carers and volunteers described peer support as enjoyable and emphasised the pleasure of social interaction. In particular, the volunteers enjoyed meeting new people which sometimes reduced their own isolation.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW
Perceived benefits of peer support: Experiential knowledge							
1 (Greenwood 2013)	Semi-structured interviews	Many carers felt that peer support it was an opportunity to understand there were many different ways of approaching a problem or that there might be no perfect answer. Peer support helped many carers cope by giving	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	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
		them different perspectives of caring and by allowing them to appreciate the importance of their role					
Limitations of peer support							
1 (Greenwood 2013)	Semi-structured interviews	Many adult carers of people living with dementia perceived the peer support offered as insufficient, providing only short-lived benefit. One other limitation of peer support was the diversity of carers' reactions to caring and to peer support, which restricted how much the volunteer could help	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW
Volunteer–carer relationship							
1 (Greenwood 2013)	Semi-structured interviews	Carers and volunteers reported that a key element of the peer volunteer–carer relationship was the shared experience of supporting someone with dementia. In addition, several carers reported they could talk to volunteers about things that they were unable to talk about elsewhere (including among family).	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW

1 Evidence was downgraded because major concerns with the adequacy of data, as only 1 study supported the review's findings (offering poor data)

Financial assistance

Table 14: Summary of evidence (GRADE-CERQual), Theme 6: Financial assistance (one-off payment for breaks)

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
Preferences over the type of break.							
1 (Moule 2014)	Semi-structured interviews	Many adult carers receiving an individualised financial support (a one-off payment for funding any form of respite) appreciated having a free choice on the nature of their break. They reported that a range of factors influenced the breaks chosen, including short breaks away (with or without the person being cared for); alternative care for the person with support needs; swimming, gym or exercise classes/membership; and transport for carers to travel with or without the care recipient.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW
Effects of the carers' breaks scheme.							
1 (Moule 2014)	Semi-structured interviews	Many adult carers receiving an individualised financial support (a one-off payment for funding any form of respite) had mixed views about whether they should or should not receive	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	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
		funding to spend on themselves, with some feeling of "cheating" and not deserving it. Carers associated an improvement in their own well-being and, or ability to care with a positive impact on the care recipient. Finally, for some carers, although the financial support had had positive effects for them, it was perceived as being limited					
Administration of the carers' breaks scheme.							
1 (Moule 2014)	Semi-structured interviews	Many adult carers receiving an individualised financial support (a one-off payment for funding any form of respite) became aware of the Carers' Breaks scheme through a variety of sources, including GP practices, social services, community nurses, the voluntary sector and word of mouth. In addition, they found the assessment for accessing the scheme to be a positive experience, especially when conducted face-to-face.	No or very minor concerns	No or very minor concerns	No or very minor concerns	Serious concerns[1]	LOW

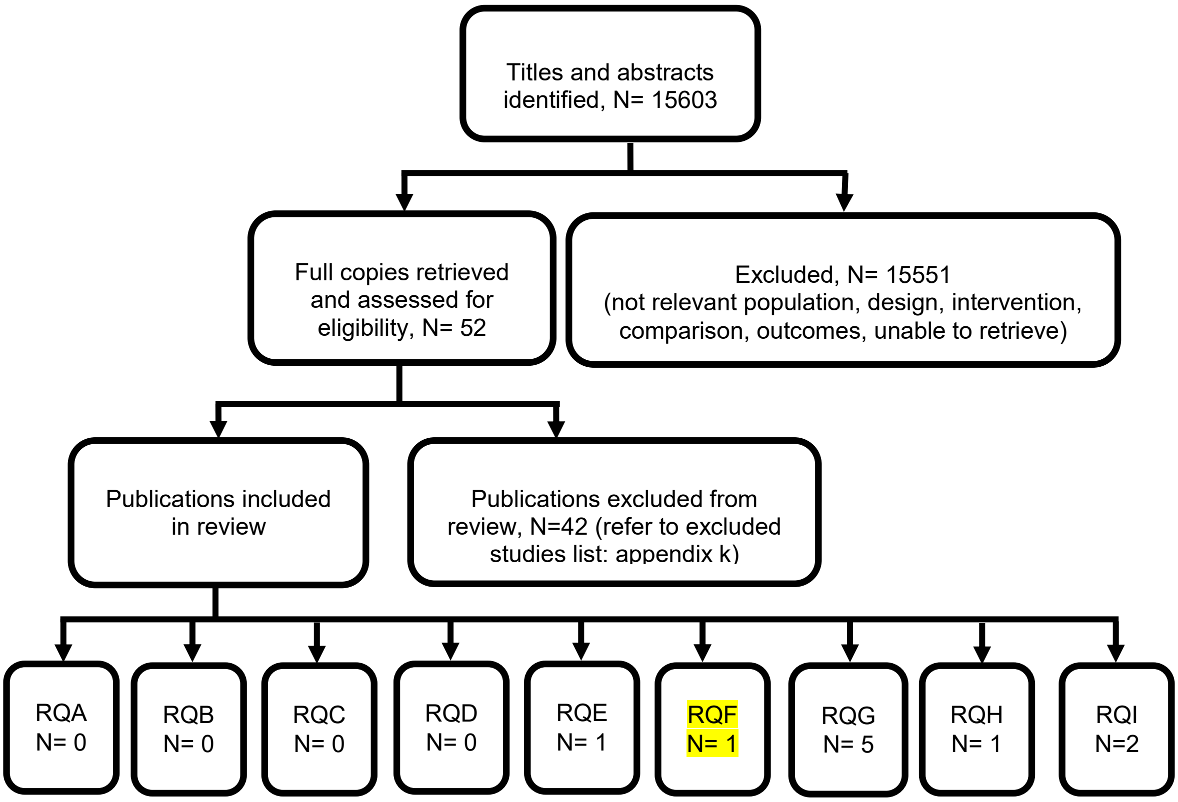
1 Evidence was downgraded because major concerns with the adequacy of data, as only 1 study supported the review's findings (offering poor data)

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: What practical, social and community support interventions for adult carers are effective, cost-effective, and acceptable to them?

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, 1 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 skills- and educational- based interventions are effective, cost-effective, and acceptable to carers for training them to provide practical support to the person receiving care?

Table 15: Economic evidence tables

Study Country Study design	Intervention Details:	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
• Study: Charlesworth 2008 • Country: UK • Study design Cost-utility analysis	• Intervention: Social support intervention: access to a befriending volunteer (emotional support, informational support or "signposting") + TAU • Control: TAU only • Interventions details: ○ Participants assessed at baseline and 6, 15 and 24 months post-randomisation ○ Befriending scheme defined as the provision	• Study population: N=236 Carers of people living with dementia ○ Intervention, n=116 ○ Control, n=120 • Characteristics [Intervention; Control] ○ Age (years) Mean (SD): I = 68.4 (11.3); C = 20.5 (2.6) ○ Sex (M/F): I (n): 40/76; C (n): 44/76 • Data sources: ○ Source of clinical effectiveness data: Randomised control trial (N=236) * ○ EQ-5D health profiles, for befriended carers and control group carers, were	• Cost description: ○ Cost categories included direct costs (that is costs of providing the intervention, primary and secondary care resource use, out-of-pocket expenses and travel costs incurred by care recipients or carers, and family care cost), indirect costs (that is carers' value of time spent in the caring role). ○ Incremental Costs Value: £ 1,813 (CI 95% -£11,312 to £14,984) • Outcome description: ○ Carer QALYs calculated from the EQ-5D by applying societal weights from a UK sample. ○ Incremental Outcome Value:	• ICER £105,954 / QALY [a] • Sensitivity analysis: ○ Probabilistic sensitivity analyses: Intervention has a 42.2% probability of being at cost-effective at a threshold of £30,000/QALY over 15 months. ○ Deterministic sensitivity analyses: Looking from alternative perspectives or extending the time-frame did not offer any positive evidence in favour of the intervention.	• Perspective: ○ Base case: society ○ Alternative scenarios: 1) statutory sector (NHS, social services and other government-funded services); 2) the voluntary sector ○ the household sectors • Currency: GBP • Cost year: 2005 - 2006 • Time horizon: 15 months ○ time horizon as per the RCT endpoint • Discounting: N/A • Applicability: directly applicable • Quality: potentially serious limitations

Study Country Study design	Intervention Details:	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
	of emotional support and some 'signposting' to information and services ○ The target duration for befriending relationships was 6 months or more. ○ Befriending carers was facilitated by trained social workers ○ The intervention was not a replacement for any other service (health, social or voluntary). • TAU details: typical social and voluntary services for carers, such as short-term and longer term respite support	collected at in order to calculate QALYs. ○ Source of resource use data: Randomised control trial (N=236) * ○ Source of unit costs: Unit costs were from NHS and national sources (NHS Ref. Costs; PSSRU); Time spent by carers, friends and family in supporting their relative was valued at average UK gross income rates for 2005, derived from Office for National Statistics. * Charlesworth G, Shepstone L, Wilson E, Thalanany M, Mugford M, Poland F. Does befriending by trained lay workers improve psychological well-being and quality of life for carers of people living with dementia, and at what cost? A	0.017 (CI 95% -0.051 to 0.083) QALYs		

Study Country Study design	Intervention Details:	Study population Data sources	Costs: description and values Outcomes: description and values	Results: Cost-effectiveness	Comments
	services, information, support groups, and luncheon clubs.	randomised controlled trial. Health Technol Assess 2008;12(4):iii, v-ix, 1-78.			

C: Control group; EQ-5D: EuroQol 5 Dimensions; F: Female; I: intervention group; ICER: Incremental cost-effectiveness ratio; N/A: not applicable; N/R: not reported; QALY: Quality-adjusted life year; RCT: Randomised controlled trial; SD: Standard deviation; TAU: Treatment as usual.

a: When cost–utility analysis was done using the QALYs for dyads (i, e. carers and care recipients) showed that the intervention to be borderline cost-effective (ICER = £26,848/QALY, with a 51.4% probability of being below £30,000 per QALY gained)

Appendix I – Economic evidence profiles

Economic evidence profiles for review question: What practical, social and community support interventions for adult carers are effective, cost-effective, and acceptable to them?

Table 16: Economic evidence profiles

Study and country	Limitations	Applicability	Other comments	Incremental costs	Incremental effects	ICER	Uncertainty
• Author & year: Charlesworth 2008 • Country: UK • Interventions: Social support intervention (access to a befriending volunteer) + TAU *versus* TAU only	Potentially serious limitations [a]	Directly applicable	• Type of economic analysis: Cost Utility analysis • Time horizon: 15 months • Primary measure of outcome: QALY	• £1,813 (-£11,312 to £14,984)	• 0.017 (CI 95% -0.051 to 0.083) QALYs	• £105,984 / QALY	• Probabilistic sensitivity analyses: Intervention has a 42.2% probability of being at cost-effective at a threshold of £30,000/QALY over 15 months.

C: Control group; EQ-5D: EuroQol 5 Dimensions; F: Female; I: intervention group; ICER: Incremental cost-effectiveness ratio; N/A: not applicable; N/R: not reported; QALY: Quality-adjusted life year; RCT: Randomised controlled trial; SD: Standard deviation; TAU: Treatment as usual.

a: 1) Potential risk of bias in the estimates of effects of the interventions in the original RCT (potential risk of performance bias: no blinding of carers to be allocated intervention); 2) The Authors described as a potential limitation to the findings of their economic analysis the restriction of the base case analysis to the utility of the carer when a case could be made that the utility of the care dyad is more appropriate (that is "Given the importance of care recipient well-being to family carers, it could be argued that economic analyses of interventions for family carers should include care recipient quality of life as part of the primary analysis", Author quote – page 37)

Appendix J – Economic analysis

Economic evidence analysis for review question: What practical, social and community support interventions for adult carers are effective, cost effective, and acceptable to them?

No economic analysis was conducted for this review question.

Appendix K – Excluded studies

Excluded studies for review question: What practical, social and community support interventions for adult carers are effective, cost effective, and acceptable to them?

Quantitative component of the review

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

Study	Reason for Exclusion
Adriaansen, J. J., van Leeuwen, C. M., Visser-Meily, J. M., van den Bos, G. A., Post, M. W., Course of social support and relationships between social support and life satisfaction in spouses of patients with stroke in the chronic phase, Patient Education & Counseling, 85, e48-52, 2011	Not an RCT.
Aggar, C., Ronaldson, S., Cameron, I. D., Residential respite care is associated with family carers experiencing financial strain, Australasian Journal on Ageing, 33, 93-98, 2014	Not an RCT.
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.
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.
Barber, F. D., Effects of social support on physical activity, self-efficacy, and quality of life in adult cancer survivors and their caregivers, Oncology Nursing Forum, 40, 481-489, 2013	Not an RCT.
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	Conference abstract.
Barrett, M., Wheatland, B., Haselby, P., Larson, A., Kristjanson, L., Whyatt, D., Palliative respite services using nursing staff reduces hospitalization of patients and improves acceptance among carers, International Journal of Palliative Nursing, 15, 389-95, 2009	Study design (review): reviews have been excluded. References have been hand-searched for relevant studies.
Beaulieu, R., Humphreys, J., Evaluation of a telephone advice nurse in a nursing faculty managed pediatric community clinic, Journal of Pediatric Health Care, 22, 175-81, 2008	Not relevant to the PICO for RQF (maybe relevant for RQE and RQG).
Boots, L. M. M., Vugt, M. E. de, Knippenberg, R. J. M. van, A systematic review of internet-based supportive interventions for caregivers of patients with dementia, International Journal of Geriatric Psychiatry, 29, 2014	Study design (review): reviews have been excluded. References have been hand-searched for relevant studies.
Bramble, M., Moyle, W., Shum, D., A quasi-experimental design trial exploring the effect of a partnership intervention on	Not an RCT.

Study	Reason for Exclusion
family and staff well-being in long-term dementia care, Aging & Mental Health, 15, 995-1007, 2011	
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.
Carretero Stephanie, Garces Jorge, Rodenas Francisco, Evaluation of the home help service and its impact on the informal caregiver's burden of dependent elders, International Journal of Geriatric Psychiatry, 22, 738-749, 2007	Not an RCT.
Chang, Bl, Nitta, S, Carter, Pa, Markham, Yk, Perceived helpfulness of telephone calls--providing support for caregivers of family members with dementia, Journal of Gerontological Nursing, 30, 14-21, 2004	Not an RCT.
Charlesworth Georgina, et al.,, Befriending carers of people living with dementia: randomised controlled trial, British Medical Journal, 7, 1295-1297, 2008	This study was a duplicate of an RCT already included (Charlesworth 2008).
Charlesworth, G., Burnell, K., Crellin, N., Hoare, Z., Hoe, J., Knapp, M., Russell, I., Wenborn, J., Woods, B., Orrell, M., Peer support and reminiscence therapy for people living with dementia and their family carers: a factorial pragmatic randomised trial, Journal of Neurology, Neurosurgery & Psychiatry, 87, 1218-1228, 2016	Not relevant to the PICO for RQF (maybe relevant for RQG).
Charlesworth, Georgina, Shepstone, Lee, Wilson, Edward, Befriending carers of people living with dementia, British Medical Journal, 336, 7656	This study was a duplicate of an RCT already included (Charlesworth 2008).
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	Population. Trial examines outcomes in people living with dementia.
Chien, W. T., Norman, I., The effectiveness and active ingredients of mutual support groups for family caregivers of people with psychotic disorders: A literature review, International journal of nursing studies, 46, 1604-1623, 2009	Study design (review): reviews have been excluded. References have been hand-searched for relevant studies.
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.
Chih, My, DuBenske, Ll, Hawkins, Rp, Brown, Rl, Dinauer, Sk, Cleary, Jf, Gustafson, Dh, Communicating advanced cancer patients' symptoms via the Internet: a pooled analysis of two randomized trials examining caregiver preparedness, physical burden, and negative mood, Palliative Medicine, 27, 533-543, 2013	Not relevant to the PICO for RQF.
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	Not relevant to the PICO for RQF - study regarding ethnic/racial differences in use of formal/informal support.
Chu, H, Yang, C Y, Liao, Y H, Chang, L I, Chen, C H, Lin, C C, The effects of a support group on dementia caregivers' burden	Study conducted in Taiwan.

Study	Reason for Exclusion
and depression, Journal of aging and health, 23, 228-241, 2011	
Cohen, C, Kampel, T, Verloo, H, Acceptability of an intelligent wireless sensor system for the rapid detection of health issues: findings among home-dwelling older adults and their informal caregivers, Patient Preference and Adherence, 10, 1687-1695, 2016	Population: not adult carers of adults or young people (16).
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 provided to professional carer workers.
Drentea, P, Clay, Oj, Roth, Dl, Mittelman, Ms, Predictors of improvement in social support: five-year effects of a structured intervention for caregivers of spouses with Alzheimer's disease, Social science & medicine (1982), 63, 957-967, 2006	This study does not report enough data to be analysed in the evidence review.
Droes, Rose Marie, Meiland, Fjm, Schmitz, M, Tilburg, W, Effect of combined support for people living with dementia and carers versus regular day care on behaviour and mood of persons with dementia: results from a multi-centre implementation study, Tijdschrift-voor-gerontologie-en-geriatrie, 36, 60-71, 2005	Not an RCT.
Eliasov, L., Zalman, D., Flechter, E., Vorobeichik, M., Halevi-Gurevich, M., Levi, I., Bar-Sela, G., A preliminary report on innovative group therapy in an oncology in-patient department: a patient-family-staff community meeting, Psycho-Oncology, 20, 1126-9, 2011	Study conducted in Israel.
Forducey, P. G., Glueckauf, R. L., Bergquist, T. F., Maheu, M. M., Yutsis, M., Telehealth for persons with severe functional disabilities and their caregivers: facilitating self-care management in the home setting, Psychological Services, 9, 144-162, 2012	Not relevant to the PICO for RQF.
Franzén-Dahlin, A, Larson, J, Murray, V, Wredling, R, Billing, E, A randomized controlled trial evaluating the effect of a support and education programme for spouses of people affected by stroke, Clinical Rehabilitation, 22, 722-730, 2008	This paper may potentially be included in the transitions -RQI as subgroup of RQF.
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	Letter.
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	Introduction to special issue of journal.
Geldmacher, D. S., Maintaining patients with Alzheimer's disease in the home environment, Advanced Studies in Medicine, 4, 308-313, 2004	General (non-systematic) review.
Grant, I, McKibbin, Cl, Taylor, Mj, Mills, P, Dimsdale, J, Ziegler, M, Patterson, Tl, In-home respite intervention reduces plasma epinephrine in stressed Alzheimer caregivers, American Journal of Geriatric Psychiatry, 11, 62-72, 2003	Study conducted in the USA.
Hamilton, G, Gallagher, M, Pierson, K, Lowes, S, Lin, Py, Ortega, R, Palliative care for dementia: a randomized controlled study of a replicable and financially viable model for	Conference abstract.

Study	Reason for Exclusion
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	Study conducted in the USA.
Harmon, C., Warner, C., RESOURCEFULNESS AND SUPPORT IN STRESS, REWARDS AND MENTAL HEALTH OF GRANDMOTHER CAREGIVERS, The Gerontologist, 48, 236, 2008	Conference abstract.
Hartke, Rj, King, Rb, Telephone group intervention for older stroke caregivers, Topics in Stroke Rehabilitation, 9, 65-81, 2003	This paper may potentially be include in the transitions -RQI as subgroup of RQF.
Heller, T., Caldwell, J., Supporting aging caregivers and adults with developmental disabilities in future planning, Mental Retardation, 44, 189-202, 2006	Not an RCT.
Herman, Ds, Bishop, D, Anthony, Jl, Chase, W, Trisvan, E, Lopez, R, Stein, Md, Feasibility of a telephone intervention for HIV patients and their informal caregivers, Journal of clinical psycholology in medical settings, 13, 81-91, 2006	Not relevant to the PICO for RQF.
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.
Irving, C. B., Adams, C. E., Rice, K., Crisis intervention for people with severe mental illnesses, Cochrane Database of Systematic Reviews, (4) (no pagination), 2009	Population: not adult carers.
Jardim, Claudia, Pakenham, Kenneth I., Pilot investigation of the effectiveness of respite care for carers of an adult with mental illness, Clinical Psychologist, 13, 87-93, 2009	Not an RCT.
Korn, L., Logsdon, R., Polissar, N., Gomez-Beloz, A., Waters, T., Ryser, R., A RANDOMIZED TRIAL OF A COMPLEMENTARY/ALTERNATIVE MEDICINE APPROACH FOR STRESS REDUCTION IN AMERICAN INDIAN FAMILY CAREGIVERS, The Gerontologist, 48, 81, 2008	Conference abstract.
Lilley, S. A., Lincoln, N. B., Francis, V. M., A qualitative study of stroke patients' and carers' perceptions of the stroke family support organizer service, Clinical Rehabilitation, 17, 540-7, 2003	Qualitative study design.
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	RQI.
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	General survey study.
Martindale-Adams, Jennifer, Nichols, Linda O., Burns, Robert, Graney, Marshall J., Zuber, Jeffrey, A trial of dementia caregiver telephone support, CJNR: Canadian Journal of Nursing Research, 45, 30-48, 2013	Not relevant to the PICO for RQF (maybe relevant for RQG).

Study	Reason for Exclusion
Marziali Elsa, Donahue Peter, Caring for others: internet video-conferencing group intervention for family caregivers of older adults with neurodegenerative disease, Gerontologist, 46, 398-403, 2006	Not relevant to the PICO for RQF (maybe relevant for RQG).
Marziali, E, Donahue, P, Crossin, G, Caring for others: internet health care support intervention for family caregivers of persons with Alzheimer's, stroke, or Parkinson's Disease, Proquest psychology journals, 86, 375-383, 2005	Not relevant to the PICO for RQF (maybe relevant for RQG).
Marziali, E., Garcia, L. J., Dementia caregivers' responses to 2 Internet-based intervention programs, American Journal of Alzheimer's Disease & Other Dementias, 26, 36-43, 2011	Not an RCT.
Mavandadi, Shahrzad, Wright, Erin M., Graydon, Meagan M., Oslin, David W., Wray, Laura O., A randomized pilot trial of a telephone-based collaborative care management program for caregivers of individuals with dementia, Psychological Services, 14, 102-111, 2017	Not relevant to the PICO for RQF (maybe relevant for RQG).
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	Intervention primarily for care recipient.
McLoughlin, K., Rhatigan, J., McGilloway, S., Kellehear, A., Lucey, M., Twomey, F., Conroy, M., Herrera-Molina, E., Kumar, S., Furlong, M., Callinan, J., Watson, M., Currow, D., Bailey, C., INSPIRE (INvestigating Social and PractIcal suppoRts at the End of life): Pilot randomised trial of a community social and practical support intervention for adults with life-limiting illness, BMC Palliative Care, 14, 65, 2015	Research protocol.
Menn, P, Holle, R, Kunz, S, Donath, C, Lauterberg, J, Leidl, R, Marx, P, Mehlig, H, Ruckdäschel, S, Vollmar, Hc, Wunder, S, Gräßel, E, Dementia care in the general practice setting: a cluster randomized trial on the effectiveness and cost impact of three management strategies, Value in Health, 15, 851-859, 2012	Not relevant to the PICO for RQF (maybe relevant for RQG): This RCT evaluated an intervention focused on HC professionals rather than on caregivers.
Mierlo, Ld, Meiland, Fj, Ven, Pm, Hout, Hp, Dröes, Rm, Evaluation of DEM-DISC, customized e-advice on health and social support services for informal carers and case managers of people living with dementia; a cluster randomized trial, International Psychogeriatrics, 27, 1365-1378, 2015	Not relevant to the PICO for RQF.
Mortenson, W. B., Demers, L., Fuhrer, M. J., Jutai, J. W., Lenker, J., DeRuyter, F., Effects of an assistive technology intervention on older adults with disabilities and their informal caregivers: an exploratory randomized controlled trial, American Journal of Physical Medicine & Rehabilitation, 92, 297-306, 2013	No intervention of interest: not practical, social and community support interventions for adult carers.
Musil, Carol M., Morris, Diana L., Warner, Camille B., Saeid, Hala, Issues in Caregivers' Stress and Providers' Support, Research on Aging, 25, 505-526, 2003	Not an RCT.
Oh, Mh, Park, Km, The Effect of a Social Support Program on Family Caregivers' Role Strain in Elderly Long-term Home Care, J korean acad community health nurs, 25, 137-145, 2014	Not an RCT.

Study	Reason for Exclusion
Piette, J. D., Striplin, D., Marinec, N., Chen, J., Trivedi, R. B., Aron, D. C., Fisher, L., Aikens, J. E., A Mobile Health Intervention Supporting Heart Failure Patients and Their Informal Caregivers: A Randomized Comparative Effectiveness Trial, Journal of Medical Internet Research, 17, e142, 2015	Not relevant to the PICO for RQF.
Piette, Jd, Striplin, D, Marinec, N, Chen, J, Aikens, Je, A randomized trial of mobile health support for heart failure patients and their informal caregivers: impacts on caregiver-reported outcomes, Medical Care, 53, 692-699, 2015	Not relevant to the PICO for RQF.
Pot, Anne Margriet, Willemse, Bernadette M., Horjus, Sarah, A pilot study on the use of tracking technology: Feasibility, acceptability, and benefits for people in early stages of dementia and their informal caregivers, Aging & Mental Health, 16, 127-134, 2012	Not an RCT.
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	General survey about use of services and satisfaction with them.
Robison, J, Curry, L, Gruman, C, Porter, M, Henderson, Cr, Pillemer, K, Partners in caregiving in a special care environment: cooperative communication between staff and families on dementia units, Gerontologist, 47, 504-515, 2007	Study design (review): reviews have been excluded. References have been hand-searched for relevant studies.
Rodakowski, J., Skidmore, E. R., Rogers, J. C., Schulz, R., Does social support impact depression in caregivers of adults ageing with spinal cord injuries?, Clinical Rehabilitation, 27, 565-575, 2013	Not an RCT.
Rodakowski, J., Skidmore, E. R., Rogers, J. C., Schulz, R., Role of social support in predicting caregiver burden, Archives of Physical Medicine & Rehabilitation, 93, 2229-36, 2012	Not an RCT.
Smeets, S. M., Van Heugten, C. M., Geboers, J. F., Visser-Meily, J. M., Schepers, V. P., Respite care after acquired brain injury: The well-being of caregivers and patients, Archives of Physical Medicine and Rehabilitation, 93, 834-841, 2012	Not an RCT.
Stephen, J., Collie, K., McLeod, D., Rojubally, A., Fergus, K., Speca, M., Turner, J., Taylor-Brown, J., Sellick, S., Burrus, K., Elramly, M., Talking with text: communication in therapist-led, live chat cancer support groups, Social Science & Medicine, 104, 178-86, 2014	Not relevant to the PICO for RQF.
Stirling, C., Leggett, S., Lloyd, B., Scott, J., Blizzard, L., Quinn, S., Robinson, A., Decision aids for respite service choices by carers of people living with dementia: development and pilot RCT, BMC Medical Informatics & Decision Making, 12, 21, 2012	Not an RCT.
Szmukler, G., Kuipers, E., Joyce, J., Harris, T., Leese, M., Maphosa, W., Staples, E., An exploratory randomised controlled trial of a support programme for carers of patients with a psychosis, Social Psychiatry & Psychiatric Epidemiology, 38, 411-8, 2003	Not relevant to the PICO for RQF (maybe relevant for RQG).

Study	Reason for Exclusion
Taati, F, Bahramnezhad, F, Seyedfatemi, N, Sharifi, F, Navab, E, The effect of participation in support groups on depression, anxiety and stress in family caregivers of people with Alzheimer's: randomized clinical trail, International journal of medical research & health sciences, 5, 256-262, 2016	Study conducted in Iran.
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	A description of an intervention, not an evaluation.
Treasure, Janet, Todd, Gill, Interpersonal maintaining factors in eating disorder: Skill sharing interventions for carers, 125-137, 2016	A description of an intervention, not an evaluation (same as Treasure 2008).
Tremont, G., Davis, J. D., Ott, B. R., Galioto, R., Crook, C., Papandonatos, G. D., Fortinsky, R. H., Gozalo, P., Bishop, D. S., Randomized Trial of the Family I : Telephone Tracking-Caregiver for Dementia Caregivers: Use of Community and Healthcare Resources, Journal of the American Geriatrics Society, 65, 924-930, 2017	Study conducted in the USA.
Tretteteig, S., Vatne, S., Rokstad, A. M., The influence of day care centres for people living with dementia on family caregivers: an integrative review of the literature, Aging & Mental Health, 20, 450-62, 2016	Study design (review): reviews have been excluded. References have been hand-searched for relevant studies.
van Mierlo, L. D., Meiland, F. J., Droes, R. M., Dementelcoach: effect of telephone coaching on carers of community-dwelling people living with dementia, International Psychogeriatrics, 24, 212-22, 2012	Not an RCT. Excluded as this controlled trial did not use randomisation to allocate carers across intervention groups.
Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., Verdonck, C., Annemans, L., Effectiveness of respite care in supporting informal caregivers of persons with dementia: a systematic review, International Journal of Geriatric Psychiatry, 31, 1277-1288, 2016	Study design (review): reviews have been excluded. References have been hand-searched for relevant studies.
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 via original search.
Wei, Y. S., Chu, H., Chen, C. H., Hsueh, Y. J., Chang, Y. S., Chang, L. I., Chou, K. R., Support groups for caregivers of intellectually disabled family members: effects on physical-psychological health and social support, Journal of Clinical Nursing, 21, 1666-77, 2012	Study conducted in Taiwan.
Winter, L, Gitlin, Ln, Evaluation of a telephone-based support group intervention for female caregivers of community-dwelling individuals with dementia, American Journal of Alzheimer's Disease and Other Dementias, 21, 391-397, 2006	Study conducted in the USA.
Yoo, Ek, Jeon, S, Yang, Je, The effects of a support group intervention on the burden of primary family caregivers of stroke patients, Taehan kanho hakhoe chi, 37, 693-702, 2007	Study conducted in Korea.

Qualitative component of the review

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

Study	Reason for Exclusion
Ana Karina Monte Cunha, Marques, Fátima Luna Pinheiro, Landim, Patrícia Moreira, Collares, Rafael Barreto de, Mesquita, Social support in the family caregiver experience, Ciencia & Saude Coletiva, 16, 945-955, 2011	Full text not in English.
Anngela-Cole Linda, Busch Mandee, Stress and grief among family caregivers of older adults with cancer: a multicultural comparison from Hawai'i, Journal of Social Work in End-of-Life and Palliative Care, 7, 318-337, 2011	Non UK evidence.
Araujo, Angelica da Silva, Kebbe, Leonardo Martins, Study on occupational therapy groups for caregivers of families with schizophrenia patients, Cadernos de Terapia Ocupacional da UFSCar, 22, 97-108, 2014	Non UK evidence.
Austrom, M. G., Geros, K. N., Hemmerlein, K., McGuire, S. M., Gao, S., Brown, S. A., Callahan, C. M., Clark, D. O., Use of a multiparty web based videoconference support group for family caregivers: Innovative practice, Dementia (London, England), 14, 682-690, 2015	Non UK evidence.
Azman, Azlinda, Jamir Singh, Paramjit Singh, Sulaiman, Jamalludin, Caregiver coping with the mentally ill: a qualitative study, Journal of Mental Health, 26, 98-103, 2017	Non UK evidence.
Balfe, M., Keohane, K., O'Brien, K., Sharp, L., Social networks, social support and social negativity: A qualitative study of head and neck cancer caregivers' experiences, European journal of cancer care, 26, 2017	Non UK evidence (Cork - Ireland).
Bank, Adam L., Arguelles, Soledad, Rubert, Mark, Eisdorfer, Carl, Czaja, Sara J., The Value of Telephone Support Groups among Ethnically Diverse Caregivers of Persons with Dementia, Gerontologist, 46, 134-138, 2006	Non UK evidence.
Bentelspacher Carl E, et al.,, African American informal support networks: a transactional, reciprocal exchange analysis, Social Work in Mental Health, 4, 23-43, 2006	Non UK evidence.
Blusi, Madeleine, Kristiansen, Lisbeth, Jong, Mats, Exploring the influence of Internet-based caregiver support on experiences of isolation for older spouse caregivers in rural areas: a qualitative interview study, International journal of older people nursing, 10, 211-220, 2015	Non UK evidence.
C. H. O. Jimmyoung, O. R. Y. Marcia G, Stevens Alan B, Socioecological factors and positive aspects of caregiving: findings from the REACH II intervention, Aging and Mental Health, 20, 1190-1201, 2016	Non UK evidence.
Cain, R., MacLean, M., Sellick, S., Giving support and getting help: informal caregivers' experiences with palliative care services, Palliative & supportive care, 2, 265-72, 2004	Non UK evidence.
Cartwright Luke, et al.,, Barriers to increasing the physical activity of people with intellectual disabilities, British Journal of Learning Disabilities, 45, 47-55, 2017	Non UK evidence.
Casado Banghwa Lee, Sense of need for financial support and respite services among informal caregivers of older	Non UK evidence.

Study	Reason for Exclusion
Americans, Journal of Human Behavior in the Social Environment, 18, 269-287, 2009	
Chien, Wai-Tong, Norman, Ian, Thompson, David R., Perceived Benefits and Difficulties Experienced in a Mutual Support Group for Family Carers of People with Schizophrenia, Qualitative health research, 16, 962-981, 2006	Non UK evidence.
Chou, H. K., Yan, S. H., Lin, I. C., Tsai, M. T., Chen, C. C., Woung, L. C., A pilot study of the telecare medical support system as an intervention in dementia care: the views and experiences of primary caregivers, Journal of Nursing Research, 20, 169-80, 2012	Non UK evidence.
Christensen, Erin, Gesell, Sabina B., Perceived Benefits of Peer Support Groups for Stroke Survivors and Caregivers in Rural North Carolina, 10270729, 37, 2017	Dissertation.
Chung, P. Y. F., Ellis-Hill, C., Coleman, P., Supporting activity engagement by family carers at home: maintenance of agency and personhood in dementia, International journal of qualitative studies on health and well-being, 12, 1267316, 2017	Study is about how carers engage relatives in activities.
Colvin, Jan, Caregivers of Older Adults Online: Perceptions of Internet-Based Social Support, 2708-A	Dissertation.
Colvin, Jan, Chenoweth, Lillian, Bold, Mary, Harding, Cheryl, Caregivers of Older Adults: Advantages and Disadvantages of Internet-Based Social Support, Family Relations, 53, 49-57, 2004	Non UK evidence.
Courtin, E., Jemiai, N., Mossialos, E., Mapping support policies for informal carers across the European Union, Health Policy, 118, 84-94, 2014	General focus on carers support with no specific focus on providing practical support for carers.
Crellin, N. E., Orrell, M., McDermott, O., Charlesworth, G., Self-efficacy and health-related quality of life in family carers of people living with dementia: a systematic review, Aging & Mental Health, 18, 954-969, 2014	Study design (review): reviews have been excluded. References have been hand-searched for relevant studies.
Dam, A. E. H., Boots, L. M. M., van Boxtel, M. P. J., Verhey, F. R. J., de Vugt, M. E., A mismatch between supply and demand of social support in dementia care: a qualitative study on the perspectives of spousal caregivers and their social network members, International Psychogeriatrics, 1-12, 2017	Non UK evidence.
Davis, Nicole J., Clark, Patricia C., Using telehealth to support informal caregivers of elders with urinary incontinence: A pilot/feasibility study, 3663807, 173, 2015	Dissertation.
Dollinger, S., Chwalisz, K., THE SOUTHERN ILLINOIS RURAL CAREGIVER TELEHEALTH PROJECT: A MULTI-COMPONENT INTERVENTION, The Gerontologist, 44, 653, 2004	Abstract only.
Droes Rose-Marie, et al.,, Effect of combined support for people living with dementia and carers versus regular day care on behaviour and mood of persons with dementia: results from a multi-centre implementation study, International Journal of Geriatric Psychiatry, 19, 673-684, 2004	Non UK evidence.

Study	Reason for Exclusion
Dunnigan, Lisa, A critical literature review: effectiveness of group interventions for reducing caregiver burden, Signpost, 11, 2007	Study design (review): reviews have been excluded. References have been hand-searched for relevant studies.
Exel, Job van, Graaf, G. de, Brouwer, W., Care for a break? An investigation of informal caregivers' attitudes toward respite care using Q-methodology, Health Policy, 83, 332-342, 2007	Non UK evidence.
Fang-pei, Chen, Greenberg, Jan S., A Positive Aspect of Caregiving: The Influence of Social Support on Caregiving Gains for Family Members of Relatives with Schizophrenia, Community mental health journal, 40, 423-35, 2004	Non UK evidence.
Fjelltun, Aud-Mari Sohini PhD R. N. MSc, Henriksen, Nils PhD MSc, Norberg, Astrid PhD R. N., Gilje, Fredricka PhD R. N. C. S., Normann, Hans Ketil PhD R. N. R. N. T. MSc, Carers' experiences with overnight respite care. A qualitative study, Vard i Norden, 29, 23-27, 2009	Carers' experiences with overnight respite care. A qualitative study.
Frich, Jan C., Røthing, Merete, Berge, Alf Reiar, Participants', caregivers', and professionals' experiences with a group-based rehabilitation program for Huntington's disease: a qualitative study, BMC health services research, 14, 395, 2014	Non UK evidence.
Funk, L., Stajduhar, K., Toye, C., Aoun, S., Grande, G., Todd, C., Part 2: Home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998-2008), Palliative Medicine, 24, 594-607, 2010	No study design (review): reviews have been excluded. References have been hand-searched for relevant studies.
Golden, Mindi Ann, Lund, Dale A., Identifying Themes Regarding the Benefits and Limitations of Caregiver Support Group Conversations, Journal of Gerontological Social Work, 52, 154-170, 2009	Non UK evidence.
Gorska, S., Forsyth, K., Prior, S., Irvine, L., Haughey, P., Family group conferencing in dementia care: an exploration of opportunities and challenges, International Psychogeriatrics, 28, 233-46, 2016	Phenomena of interest: This study evaluates a family intervention, as such it is not relevant to RQF but potentially eligible for RQG.
Hancock, Peter J., Jarvis, Jayne A., L'Veena, Tanja, Older carers in ageing societies, Home Health Care Services Quarterly, 26, 2007	Non UK evidence.
Hattink, B. J. J., Meiland, F. J. M., Overmars-Marx, T., de Boer, M., Ebben, P. W. G., van Blanken, M., Verhaeghe, S., Stalpers-Croeze, I., Jedlitschka, A., Flick, S. E., Leeuw, J. V. D., Karkowski, I., Dröes, R. M., The electronic, personalizable Rosetta system for dementia care: exploring the user-friendliness, usefulness and impact, Disability and Rehabilitation. Assistive Technology, 11, 61, 2016	Non UK evidence.
Hegener, Amy, Warnock, Sheila, Hokenstad, Alene, The Role of Unpaid Volunteers in a Group Caregiving Approach: Validation of the Share the Care[Trademark] Program, Journal of Gerontological Social Work, 59, 349-363, 2016	Non UK evidence.
Hudson, P., Quinn, K., Kristjanson, L., Thomas, T., Braithwaite, M., Fisher, J., Cockayne, M., Evaluation of a psycho-educational group programme for family caregivers in	Non UK evidence.

Study	Reason for Exclusion
home-based palliative care, Palliative Medicine, 22, 270-280, 2008	
Jardim, Claudia, Pakenham, Kenneth, Carers of adults with mental illness: Comparison of respite care users and non-users, Australian Psychologist, 45, 50-58, 2010	No qualitative data on adult carers.
Jarrold Kara, Yeandle Sue, 'A weight off my mind': exploring the impact and potential benefits of telecare for unpaid carers in Scotland, 43p., bibliog., 2009	Duplicate.
Jarrold, Kara, Yeandle, Sue, 'A weight off my mind': exploring the impact and potential benefits of telecare for unpaid carers in Scotland, 2011	No qualitative data on adult carers.
Jarrold, Kara, Yeandle, Sue, 'A weight off my mind': exploring the impact and potential benefits of telecare for unpaid carers in Scotland	Duplicate.
Jarvis Alison, Worth Allison, Meeting carers' information needs, Community Practitioner, 78, 322-326, 2005	No qualitative data on adult carers.
Jeon, Y. H., Chenoweth, L., McIntosh, H., Factors influencing the use and provision of respite care services for older families of people with a severe mental illness: Feature article, International Journal of Mental Health Nursing, 16, 96-107, 2007	Non UK evidence.
Jones, C., Edwards, R. T., Hounsome, B., A systematic review of the cost-effectiveness of interventions for supporting informal caregivers of people living with dementia residing in the community, International Psychogeriatrics, 24, 6-18, 2012	No qualitative data on adult carers.
Juarez, Gloria, Branin, Joan J., Rosales, Monica, The cancer caregiving experience of caregivers of Mexican ancestry, Hispanic Health Care International, 12, 120-129, 2014	Non UK evidence.
Judge, K., Bass, D., APPLIED INTERVENTIONS FOR CAREGIVING DYADS: CURRENT BARRIERS AND FUTURE DIRECTIONS, The Gerontologist, 48, 113, 2008	No qualitative data on adult carers.
Judge, Katherine S., Bass, David M., Snow, A. Lynn, Wilson, Nancy L., Morgan, Robert, Looman, Wendy J., McCarthy, Catherine, Kunik, Mark E., Partners in Dementia Care: A Care Coordination Intervention for Individuals With Dementia and Their Family Caregivers, The Gerontologist, 51, 261, 2011	No qualitative data on adult carers.
Justice Mark, Just becoming a carer: an evaluation on the work undertaken by Croydon Neighbourhood Care Association (CNCA) and its member groups during 2010/11, 11p., 2011	No qualitative data on adult carers.
Karlsberg Schaffer, S., The effect of free personal care for the elderly on informal caregiving, Economics (United Kingdom), 24, 104-117, 2015	No qualitative data on adult carers.
Katbamna Savita, et al.,, Do they look after their own?: Informal support for South Asian carers, Health and Social Care in the Community, 12, 398-406, 2004	Non UK evidence.
Kelly, Marguerite, McSweeney, Eileen, Re-visioning respite: a culture change initiative in a long-term care setting in Eire, Quality in Ageing - Policy, practice and research, 10, 4-11, 2009	No qualitative data on adult carers.

Study	Reason for Exclusion
Kempson, Diane, Conley, Virginia, Family Caregiver Provided Massage for Rural-Dwelling Chronically Ill Persons, Home Health Care Management & Practice, 21, 117-123, 2009	No qualitative data on adult carers.
Kinney, Jennifer M., Kart, Cary S., Murdoch, Latona D., Challenges in caregiving and creative solutions, Ageing International, 28, 2003	Non UK evidence.
Koopmanschap, M. A., Exel, N. J. A. van, Bos, G. A. M. van den, Berg, B. van den, Brouwer, W. B. F., The desire for support and respite care: preferences of Dutch informal caregivers, Health Policy, 68, 309-320, 2004	Non UK evidence.
Krevers, Barbro, Oberg, Birgitta, Support/Services And Family Carers Of Persons With Stroke Impairment: Perceived Importance And Services Received, Journal of Rehabilitation Medicine, 43, 204-209, 2011	Non UK evidence.
La Fontaine Jenny, et al.,, The experiences, needs and outcomes for carers of people living with dementia: literature review, 105, 2016	Study design (review): reviews have been excluded. References have been hand-searched for relevant studies.
Lamura, G., Mnich, E., Wojszel, B., Nolan, M., Krevers, B., Mestheneos, L., Dohner, H., Eurofamcare Konsortium, [The experience of family carers of older people in the use of support services in Europe: selected findings from the EUROFAMCARE project], Erfahrungen von pflegenden Angehorigen alterer Menschen in Europa bei der Inanspruchnahme von Unterstutzungsleistungen: Ausgewahlte Ergebnisse des Projektes EUROFAMCARE., 39, 429-42, 2006	Full text not in English.
Lamura, Giovanni, Mnich, Eva, Wojszel, Beata, Nolan, Mike, Krevers, Barbro, Mestheneos, Liz, Dohner, Hanneli, The Experience of Family Carers of Older People in the Use of Support Services in Europe, Kakovostna Starost, 11, 10-27, 2008	Full text not in English.
Le Bihan, Blanche, Mallon, Isabelle, Sopadzhiyan, Alis, Between relief and support: differentiated experiences of respite for carers of dementia patients, Retraite et Societe, 3, 77-98, 2014	Full text not in English.
Lethin, C., Leino-Kilpi, H., Roe, B., Soto, M. M., Saks, K., Stephan, A., Zwakhalen, S., Zabalegui, A., Karlsson, S., Formal support for informal caregivers to older persons with dementia through the course of the disease: an exploratory, cross-sectional study, BMC geriatrics, 16, 32, 2016	Non UK evidence.
Leutz Walter, Capitman John, Met and unmet needs, and satisfaction among social HMO members, Journal of Aging and Social Policy, 19, 1-19, 2007	Non UK evidence.
Lilley, S. A., Lincoln, N. B., Francis, V. M., A qualitative study of stroke patients' and carers' perceptions of the stroke family support organizer service, Clinical Rehabilitation, 17, 540-7, 2003	This paper has potentially to be include in the transitions -RQI as subgroup of RQF.
Loughlin, Dawn M., Mahoney, Kevin J., Sadler, Michele DeBarthe, Simon-Rusinowitz, Lori, Paying family caregivers: an effective policy option in the Arkansas cash and counseling	Non UK evidence.

Study	Reason for Exclusion
demonstration and evaluation, Marriage & Family Review, 37, 83-105, 2005	
Low, J. T., Roderick, P., Payne, S., An exploration looking at the impact of domiciliary and day hospital delivery of stroke rehabilitation on informal carers, Clinical rehabilitation, 18, 776-84, 2004	Not relevant to RQF but will be considered for inclusion in RQI on transitions.
Lundberg Stephan, The results from a two-year case study of an information and communication technology support system for family caregivers, Disability and Rehabilitation: Assistive Technology, 9, 353-358, 2014	Non UK evidence.
Lyons, C., Hopley, P., Burton, C., Horrocks, J., Mental health crisis and respite services: Service user and carer aspirations, Journal of psychiatric and mental health nursing, 16, 424-433, 2009	Not relevant to RQF.
Mackenzie, Jenny, Stigma and dementia, Dementia: The International Journal of Social Research and Practice, 5, 2006	No qualitative data on adult carers.
Macleod Ann, Skinner Mark W, L. O. W. Eleanor, Supporting hospice volunteers and caregivers through community-based participatory research, Health and Social Care in the Community, 20, 190-198, 2012	Non UK evidence.
Mactavish, Jennifer B., MacKay, Kelly J., Iwasaki, Yoshitaka, Betteridge, Deanna, Family Caregivers of Individuals with Intellectual Disability: Perspectives on Life Quality and the Role of Vacations, Journal of Leisure Research, 39, 127-155, 2007	Non UK evidence.
Magnusson Lennart, Hanson Elizabeth Jane, Ethical issues arising from a research, technology and development project to support frail older people and their family carers at home, Health and Social Care in the Community, 11, 431-439, 2003	No qualitative data on adult carers.
Magnusson Lennart, Hanson Elizabeth, Nolan Mike, The impact of information and communication technology on family carers of older people and professionals in Sweden, Ageing and Society, 25, 693-713, 2005	Non UK evidence.
Mant, J., Winner, S., Roche, J., Wade, D. T., Family support for stroke: one year follow up of a randomised controlled trial, Journal of Neurology, Neurosurgery & Psychiatry, 76, 1006-8, 2005	No qualitative data.
Margaret Hellie, Huyck, Ayalon, Liat, Yoder, Judy, Using mixed-methods to evaluate the use of a caregiver strain measure to assess outcomes of a caregiver support program for caregivers of older adults, International Journal of Geriatric Psychiatry, 22, 160, 2007	Non UK evidence.
Mason, Timothy, Slack, Gordon, An outline of research by the Debenham Project and its findings, Generations Review, 24, 2014	No qualitative data on adult carers.
Mayor, Susan, Better advice is needed for decisions in dementia care, British Medical Journal, 339, 769, 2009	No qualitative data on adult carers.
Mc, Conkey Roy, Mc, Cullough Joanne, Holiday breaks for adults with intellectual disabilities living with older carers, Journal of Social Work, 6, 65-79, 2006	Phenomena of interest: not about practical support for carers.

Study	Reason for Exclusion
McConkey, Roy, McConaghie, Jayne, Roberts, Paul, King, Diana, Family placement schemes for adult persons with intellectual disabilities living with elderly carers, Journal of Learning Disabilities, 8, 267-282, 2004	Phenomena of interest: not about practical support for carers.
McKeown, L. P., Porter-Armstrong, A. P., Baxter, G. D., Caregivers of people with multiple sclerosis: Experiences of support, Multiple Sclerosis, 10, 219-230, 2004	Phenomena of interest: not about practical support for carers.
Mcshane Rupert, Skelt Lindsey, GPS tracking for people living with dementia, Working With Older People, 13, 34-37, 2009	No qualitative data on adult unpaid/informal carers.
Meiland, F. J. M., Hattink, B. J. J., Overmars-Marx, T., Participation of end users in the design of assistive technology for people with mild to severe cognitive problems, International Psychogeriatrics, 26, 2014	Non UK evidence.
Meiland, Franka J. M., Bouman, Ans I. E., Savenstedt, Stefan, Bentvelzen, Sanne, Davies, Richard J., Mulvenna, Maurice D., Nugent, Chris D., Moelaert, Ferial, Hettinga, Marike E., Bengtsson, Johan E., Droes, Rose-Marie, Usability of a new electronic assistive device for community-dwelling persons with mild dementia, Aging & mental health, 16, 584-591, 2012	Non UK evidence.
Mendes, A., Palmer, S., Supporting unpaid carers in the community, British journal of community nursing, 21, 364, 2016	No qualitative data on adult carers.
Moore, Steve, Shifting the balance of power? Short breaks for carers in Wolverhampton, Quarterly Bulletin: Management Issues in Social Care, 9, p34-40, 2004	Duplicate.
Moriarty Jo, Manthorpe Jill, Social care practice with carers: what social care support is provided to family carers? What support to family carers want?, 4, 2014	No qualitative data on adult carers.
Morton, David, Mayekiso, Thoko, Cunningham, Peter, Support for volunteer caregivers and its influence on the quality of community home-based care in the Eastern Cape, South Africa, Journal of psychology in Africa, 25, 104-109, 2015	Non UK evidence.
Murray, J., Young, J., Forster, A., Herbert, G., Ashworth, R., Feasibility study of a primary care-based model for stroke aftercare, British Journal of General Practice, 56, 775-80, 2006	Phenomena of interest: not about practical support for carers.
Nakai, Michiko, Narita, Yugo, Tomimoto, Hidekazu, An Investigation of Perspectives of Respite Admission Among People Living With Amyotrophic Lateral Sclerosis and the Hospitals That Support Them, Journal of Primary Care & Community Health, 8, 163-168, 2017	Non UK evidence.
Nankervis, K., Rosewarne, A., Vassos, M., Why Do Families Relinquish Care? An Investigation of the Factors that Lead to Relinquishment into Out-of-Home Respite Care, Journal of Intellectual Disability Research, 55, 422-433, 2011	Non UK evidence.
Neville Christine, et al.,, Literature review: use of respite by carers of people living with dementia, Health and Social Care in the Community, 23, 51-63, 2015	Study design (review): reviews have been excluded. References have been hand-searched for relevant studies.

Study	Reason for Exclusion
Neville, Christine C., Byrne, Gerard J. A., Staff and Home Caregiver Expectations of Residential Respite Care for Older People, Collegian, 14, 27-31, 2007	Non UK evidence.
Newton, L., Dickinson, C., Gibson, G., Brittain, K., Robinson, L., Exploring the views of GPs, people living with dementia and their carers on assistive technology: A qualitative study, BMJ Open, 6 (5) (no pagination), 2016	Phenomena of interest: not about practical support for carers.
Norman, Ian, Redfern, Sally, Briggs, Kate, Askham, Janet, Perceptions and management of change by people living with dementia and their carers living at home, Dementia: The International Journal of Social Research and Practice, 3, 19-44, 2004	Phenomena of interest: not about practical support for carers.
O'Connor, D., Kobayashi, K., Perry, J., GENDERING FAMILY SUPPORT GROUPS: EXPLORING IMPACT, The Gerontologist, 44, 386, 2004	Abstract only.
O'Connor, Mary-Frances, Arizmendi, Brian J., Kaszniak, Alfred W., Virtually supportive: A feasibility pilot study of an online support group for dementia caregivers in a 3D virtual environment, Journal of aging studies, 30, 87, 2014	No qualitative data.
O'Halloran Sue, Cornes Michelle, Supporting rural carers: understanding the role of the voluntary sector, Research Policy and Planning, 27, 17-24, 2009	No qualitative data.
Onwumere, J., Glover, N., Whittaker, S., Rahim, S., Chu Man, L., James, G., Khan, S., Afsharzadegan, R., Seneviratne, S., Harvey, R., Georgiades, A., Raune, D., Modifying illness beliefs in recent onset psychosis carers: Evaluating the impact of a cognitively focused brief group intervention in a routine service, Early Intervention in Psychiatry., 2017	No qualitative data.
Ostroff Jamie, et al.,, Interest in and barriers to particiaption in multiple family groups among head and neck cancer survivors and their primary family caregivers, Family Process, 43, 195-208, 2004	Non UK evidence.
Ownsworth, Tamara, Henderson, Laura, Chambers, Suzanne K., Social support buffers the impact of functional impairments on caregiver psychological well-being in the context of brain tumor and other cancers, Psycho - Oncology, 19, 1116, 2010	No qualitative data.
Pagan-Ortiz, Marta E., Cortes, Dharma E., Rudloff, Noelle, Weitzman, Patricia, Levkoff, Sue, Use of an online community to provide support to caregivers of people living with dementia, Journal of Gerontological Social Work, 57, 694-709, 2014	Non UK evidence.
Pearce, Michelle J., Singer, Jerome L., Prigerson, Holly G., Religious coping among caregivers of terminally ill cancer patients: main effects and psychosocial mediators, Journal of Health Psychology, 11, 743-760, 2006	No qualitative data.
Perloff, Tara, Looking at Support for Caregivers in a New Way: The GUIDES Program, Psycho - Oncology, 23, 106, 2014	Study design (review): reviews have been excluded. References have been hand-searched for relevant studies.
Phillipson Lyn, Jones Sandra C, Residential respite care: the caregiver's last resort, Journal of Gerontological Social Work, 54, 691-711, 2011	Non UK evidence.

Study	Reason for Exclusion
Phillipson, Lyn, Jones, Sandra C., "Between the Devil and the Deep Blue Sea": The Beliefs of Caregivers of People With Dementia Regarding the Use of In-Home Respite Services, Home Health Care Services Quarterly, 30, 43-62, 2011	Non UK evidence.
Phillipson, Lyn, Jones, Sandra C., Magee, Christopher, A review of the factors associated with the non-use of respite services by carers of people living with dementia: implications for policy and practice, Health & social care in the community, 22, 1-12, 2014	No qualitative data.
Piccenna, Loretta, Lannin, Natasha A., Scott, Katherine, Bragge, Peter, Gruen, Russell, Guidance for community-based caregivers in assisting people with moderate to severe traumatic brain injury with transfers and manual handling: evidence and key stakeholder perspectives, Health & social care in the community, 25, 458-465, 2017	Phenomena of interest: not about practical support for carers.
Pickard, Joseph G., Inoue, Megumi, Chadiha, Letha A., Johnson, Sharon, The Relationship of Social Support to African American Caregivers' Help-Seeking for Emotional Problems, The Social Service Review, 85, 247, 2011	Non UK evidence.
Pierce, Linda L., Steiner, Victoria L., Khuder, Sadik A., Govoni, Amy L., Horn, Lawrence J., 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	No qualitative data.
Ponce, Monica, Goodman, Catherine Edition date, Caregivers of family members with Alzheimer's disease: Burden, depression, and benefits of support groups, AAI1466300, 3298	Dissertation.
Ray, Robin A., Street, Annette F., The dynamics of socio-connective trust within support networks accessed by informal caregivers, Health:, 15, 137-152, 2011	No qualitative data.
Research In Practice For, Adults, What are the most effective and cost-effective services for informal carers of older people?, 6p., 2006	No qualitative data.
Riley, G., Gregory, N., Bellinger, J., Davies, N., Mabbott, G., Sabourin, R., Carer's education groups for relatives with a first episode of psychosis: an evaluation of an eight-week education group, Early Intervention in Psychiatry, 5, 57-63, 2011	Phenomena of interest: not about practical support for carers.
Roberts, Samantha, Camic, Paul M., Springham, Neil, New roles for art galleries: Art-viewing as a community intervention for family carers of people with mental health problems, Arts & Health: An International Journal of Research, Policy and Practice, 3, 146-159, 2011	Phenomena of interest: not about practical support for carers.
Robertson, Michael, Respite efficacy for parents of adults with intellectual disabilities: An ethnographic perspective (Respite care, Intellectual disability, Stress, Social services), AAI1523165	Dissertation.
Robinson Andrew, et al.,, Seeking respite: issues around the use of day respite care for the carers of people living with dementia, Ageing and Society, 32, 196-218, 2012	Non UK evidence.

Study	Reason for Exclusion
Robinson, Andrew, Lea, Emma, Hemmings, Lynn, Seeking respite, Ageing and Society, 32, 2012	Non UK evidence.
Robinson, L., Iliffe, S., Brayne, C., Goodman, C., Rait, G., Manthorpe, J., Ashley, P., Moniz-Cook, E., De, NDRoN Primary Care Clinical Studies Group, Primary care and dementia: 2. Long-term care at home: psychosocial interventions, information provision, carer support and case management, International Journal of Geriatric Psychiatry, 25, 657-64, 2010	Study design (review): reviews have been excluded. References have been hand-searched for relevant studies.
Rothing, M., Malterud, K., Frich, J. C., Family caregivers' views on coordination of care in Huntington's disease: a qualitative study, Scandinavian Journal of Caring Sciences, 29, 803-809, 2015	Phenomena of interest: not about practical support for carers.
Royackers, A., Regan, S., Donelle, L., The eShift model of care: informal caregivers' experience of a new model of home-based palliative care, Progress in Palliative Care, 24, 84-92, 2016	Non UK evidence.
Runciman, P., Family carers' experiences: reflections on partnership, Nursing older people, 15, 14-6, 2003	Phenomena of interest: not about practical support for carers.
Samsi, K., Manthorpe, J., Everyday decision-making in dementia: findings from a longitudinal interview study of people living with dementia and family carers, International Psychogeriatrics, 25, 949-61, 2013	Phenomena of interest: not about practical support for carers.
Sanders Sara, Experiences of rural male caregivers of older adults with their informal support networks, Journal of Gerontological Social Work, 49, 97-115, 2007	Non UK evidence.
Sargent Penny, et al.,, Patient and carer perceptions of case management for long-term conditions, Health and Social Care in the Community, 15, 511-519, 2007	Phenomena of interest: not about practical support for carers.
Saunders, Mitzi M. R. N. PhD Acns- B. C., Perspectives From Family Caregivers Receiving Home Nursing Support: Findings from a qualitative study of home care patients with heart failure, Home Healthcare Nurse, 30, 82, 2012	Non UK evidence.
Schmitt, N., Role transition from caregiver to case manager, part 1, Lippincott's Case Management, 10, 294-302, 2005	Phenomena of interest: not about practical support for carers.
Schoenmakers, Birgitte, Buntinx, Frank, DeLepeleire, Jan, Supporting the dementia family caregiver: the effect of home care intervention on general well-being, Aging and Mental Health, 14, 44-56, 2010	No qualitative data.
Shah, S. P., Glenn, G. L., Hummel, E. M., Hamilton, J. M., Martine, R. R., Duda, J. E., Wilkinson, J. R., Caregiver tele-support group for Parkinson's disease: A pilot study, Geriatric nursing (New York, N.Y.), 36, 207-211, 2015	Non UK evidence.
Sherman, Carey Wexler, Webster, Noah J., Antonucci, Toni C., Dementia Caregiving in the Context of Late-Life Remarriage: Support Networks, Relationship Quality, and Well-being, Journal of Marriage and Family, 75, 1149-1163, 2013	Non UK evidence.
Shor, Ron, Birnbaum, Menachem, Meeting Unmet Needs of Families of Persons with Mental Illness: Evaluation of a Family	Non UK evidence.

Study	Reason for Exclusion
Peer Support Helpline, Community mental health journal, 48, 482-8, 2012	
Siegel, Scott D., Turner, Aaron P., Haselkorn, Jodie K., Adherence to Disease-Modifying Therapies in Multiple Sclerosis: Does Caregiver Social Support Matter?, Rehabilitation Psychology, 53, 73-79, 2008	Non UK evidence.
Simpson, Gaynell Marie Salina, Availability of Social Support Resources and Survival Strategies among African American Grandmother Caregivers, 4476-A	Dissertation.
Singh Swaran P, et al.,, Transition from CAMHS to adult mental health services (TRACK): a study of service organisation, policies, process and user and carer perspectives: executive summary, 5p., 2010	Phenomena of interest: not about practical support for carers.
Smerglia Virginia L, et al.,, Social support and adjustment to caring for elder family members: a multi-study analysis, Aging and Mental Health, 11, 205-217, 2007	Non UK evidence.
Smith, F., Francis, S. A., Gray, N., How pharmacists can support carers, Pharmaceutical Journal, 270, 725-727, 2003	Phenomena of interest: not about practical support for carers.
Smith, Raymond, Drennan, Vari, Mackenzie, Ann, Greenwood, Nan, Volunteer peer support and befriending for carers of people living with dementia: An exploration of volunteers' experiences, Health & social care in the community, No-Specified, 2017	Phenomena of interest: not about practical support for carers.
Solutions, Research, Public perceptions and experiences of community-based end of life care initiatives: a qualitative research report, 71, 2016	Phenomena of interest: not about practical support for carers.
Sorensen Lisbeth V, Warldorff Frans B, Waldermar Gunhild A, Early counselling and support for patients with mild Alzheimer's disease and their caregivers: a qualitative study on outcome, Aging and Mental Health, 12, 444-450, 2008	Non UK evidence.
Sutcliffe Caronline L, et al.,, People with dementia and carers' experiences of dementia care and services: outcomes of a focus group study, Dementia: The International Journal of Social Research and Practice, 14, 769-787, 2015	General focus on carers support with no specific focus on providing practical support for carers.
Tang, Judy, Ryburn, Bridget, Doyle, Colleen, Wells, Yvonne, The Psychology of Respite Care for People with Dementia in Australia, Australian Psychologist, 46, 183-189, 2011	Non UK evidence.
Tarleton, B., Committed to caring. Family-based short-break carers' views of their roles, Adoption & Fostering, 27, p36-46, 2003	Study is about short breaks carers for children and young people.
Taylor, C., Supporting the carers of individuals affected by colorectal cancer, British Journal of NursingBr J Nurs, 17, 2008	Phenomena of interest: not about practical support for carers.
Timko, Teresa A., Buckley, Kathleen M., Informal caregivers' perceptions of social support provided by parish nurses, 3354479, 126, 2009	Dissertation.
Tretteteig Signe, Vatne Solfrid, Rokstad Anne Marie Mork, The influence of day care centres for people living with dementia on family caregivers: an integrative review of the literature, Aging and Mental Health, 20, 450-462, 2016	Study design (review): reviews have been excluded. References have been hand-searched for relevant studies.

Study	Reason for Exclusion
Unadkat Shreena, Camic Paul M, Vella-Burrows Trish, Understanding the experience of group singing for couples where one partner has a diagnosis of dementia, Gerontologist, 57, 469-478, 2017	Phenomena of interest: not about practical support for carers.
Upton, N., Reed, V., Caregiver coping in dementing illness--implications for short-term respite care, International Journal of Psychiatric Nursing ResearchInt J Psychiatr Nurs Res, 10, 2005	No qualitative data.
Upton, N., Reed, V., The influence of social support on caregiver coping, The international journal of psychiatric nursing research, 11, 1256-1267, 2006	Study is about the theory of coping.
Uribe Franziska Laporte, et al.,, Caregiver burden assessed in dementia care networks in Germany: findings from the DemNet-D study baseline, Aging and Mental Health, 21, 926-937, 2017	Non UK evidence.
Van Rooyen, N., Caring for the caregiver: A holistic approach, Practising Midwife, 11, 21-22, 2008	Phenomena of interest: not about practical support for carers.
Vasileiou, Konstantina, Barnett, Julie, Barreto, Manuela, Vines, John, Atkinson, Mark, Lawson, Shaun, Wilson, Michael, Experiences of loneliness associated with being an informal caregiver: A qualitative investigation, Frontiers in Psychology Vol 8 2017, ArtID 585, 8, 2017	Phenomena of interest: not about practical support for carers.
Ware, Tricia, Matosevic, Tihana, Hardy, Brian, Knapp, Martin, Kendall, Jeremy, Forder, Julien, Commissioning care services for older people in England: The view from care managers, users and carers, Ageing & Society, 23, 411-428, 2003	Phenomena of interest: not about practical support for carers.
White, Jennis, Support group for family caregivers of Alzheimer's patients: A grant proposal, AAI1527591	Dissertation.
Whittingham, K., Pearce, D. E., Carer support from a community-based heart specialist nurse service, British journal of nursing (Mark Allen Publishing), 20, 1388-1393, 2011	Phenomena of interest: This study evaluates a multi-component intervention ("community-based heart specialist nurse service"), as such it is potentially eligible for RQG.
Willemse, Evi, Anthierens, Sibyl, Farfan-Portet, Maria Isabel, Schmitz, Olivier, Macq, Jean, Bastiaens, Hilde, Dilles, Tinne, Remmen, Roy, Do informal caregivers for elderly in the community use support measures? A qualitative study in five European countries, BMC health services research, 16, 2016	Non UK evidence.
Williams, Allison M., Forbes, Dorothy A., Mitchell, Julie, Essar, Mary, Corbett, Brad, The influence of income on the experience of informal caregiving: Policy implications, Health Care for Women International, 24, 280-291, 2003	Phenomena of interest: not about practical support for carers.
Williams, Allison, Sethi, Bharati, Duggleby, Wendy, Ploeg, Jenny, Markle-Reid, Maureen, Peacock, Shelley, Ghosh, Sunita, A Canadian qualitative study exploring the diversity of the experience of family caregivers of older adults with multiple chronic conditions using a social location perspective, International Journal for Equity in Health, 15, 2016	Non UK evidence.
Wilson, V., Supporting family carers in the community setting, Nursing Standard, 18, 47-53; quiz 54-5, 2004	No qualitative data on adult carers.

Study	Reason for Exclusion
Wolff, Jennifer L., Giovannetti, Erin R., Boyd, Cynthia M., Reider, Lisa, Palmer, Sara, Scharfstein, Daniel, Marsteller, Jill, Wegener, Stephen T., Frey, Katherine, Leff, Bruce, Frick, Kevin D., Boult, Chad, Effects of Guided Care on Family Caregivers, The Gerontologist, 50, 459, 2010	No qualitative data on adult carers.
Wolkowski, A., Carr, S. M., Does respite care address the needs of palliative care service users and carers? Their perspectives and experiences, International journal of palliative nursing, 23, 174-185, 2017	Study design (review): reviews have been excluded. References have been hand-searched for relevant studies.
Wolkowski, A., M. Carr S, L. Clarke C, What does respite care mean for palliative care service users and carers? Messages from a conceptual mapping, International Journal of Palliative Nursing, 16, 388-92, 2010	No qualitative data.
Wong, Alison G., Ki, Ppudah, Maharaj, Artie, Brown, Edna, Davis, Cindy, Apolinsky, Felice, Social Support Sources, Types, and Generativity: A Focus Group Study of Cancer Survivors and Their Caregivers, Social Work in Health Care, 53, 214-232, 2014	Non UK evidence.
Wood LaMore, Katherine, Use of Alzheimer family support group by community-residing caregivers, Groupwork, 21, 84-98, 2011	No qualitative data.
Woods, R. T., Wills, W., Higginson, I. J., Hobbins, J., Whitby, M., Support in the community for people living with dementia and their carers: a comparative outcome study of specialist mental health service interventions, International Journal of Geriatric Psychiatry, 18, 298-307, 2003	No qualitative data.
Yamada Miho, Hagihara Akihito, Nobutomo Koichi, Coping strategies, care manager support and mental health outcome among Japanese family caregivers, Health and Social Care in the Community, 16, 400-409, 2008	No qualitative data.
Yoon, Hyojin, How do cancer patients and caregivers perceive web-based interventions? A qualitative study, Western Journal of Nursing Research, 35, 1228-1229, 2013	Non UK evidence.
Yu, Zhen Li, Seow, Ying-ying, Seow, Pei Shing, Tan, Ban Leong, Kenny,, Effectiveness of a day care program in supporting patients on peritoneal dialysis and their caregivers, International Urology and Nephrology, 48, 799-805, 2016	Non UK evidence.
Zarit, Steven H. PhD, Kim, Kyungmin PhD, Femia, Elia E. PhD, Almeida, David M. PhD, Klein, Laura C. PhD, The Effects of Adult Day Services on Family Caregivers' Daily Stress, Affect, and Health: Outcomes From the Daily Stress and Health (DaSH) Study, The Gerontologist, 54, 570, 2014	Non UK evidence.
Zhou, Eric S., Kim, Youngmee, Penedo, Frank J., Who matters? The effects of sources of social support on quality of life in prostate cancer survivors and their spousal caregivers, AAI3539235	Dissertation.

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 19: 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.
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.

Study	Reason for Exclusion
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 interventions for supporting informal caregivers of people living with dementia residing in the community, International Psychogeriatrics, 24, 6-18, 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.
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).

Study	Reason for Exclusion
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.
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	This economic evaluation was conducted in the USA.

Study	Reason for Exclusion
intervention with caregivers of patients with Alzheimer's disease. J Am Geriatr Soc. 2008 Mar;56(3):413-20	
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.
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.

Study	Reason for Exclusion
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.
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 recommendation for review question: What practical, social and community support interventions for adult carers are effective, cost-effective and acceptable to them?

Why this is important

This review did not identify any evidence at all about the effectiveness or acceptability of carers' passport schemes as a means of providing practical support to carers. Carer passport schemes are intended to improve identification, recognition and support of carers. Their implementation is currently being introduced in five key settings – hospitals, employment, community, education and mental health trusts – and the committee agreed it would be a good use of research funding to establish the effectiveness of the schemes and to understand people's views and lived experiences about them to inform potential continued implementation.

Research recommendation in question format: What is the effectiveness, cost-effectiveness and acceptability of carer passport schemes?

Research question	What is the effectiveness, cost-effectiveness and acceptability of the carer passport schemes?
Importance to people or the population	The benefits of carers being able to actively participate in a wide range of social and community activities have become increasingly acknowledged and evidenced. However the ability of carers to access this support varies due to a range of factors, including limitations in local commissioning landscapes or a lack of information and awareness about availability. Carer passport schemes are intended to embed recognition of and support for carers in the day to day life of an organisation or community. The committee therefore agreed that carer passports might act as a means of facilitating access to this broader range of social and community activities and supporting carers in their roles as carers. As well as the individual benefits this access would achieve, there are likely to be wider benefits including reducing the risk of carer crisis or break down and reducing health care contacts.
Relevance to NICE guidance	NICE guidance provides advice on effective, good value health and social care including care and support for adult carers.
Relevance to NHS/ social care	The Care Act (2014) places a statutory duty on local authorities to put in place services that can prevent, reduce or delay carers from developing a need for support. The Act also introduced a general duty on local authorities to promote an individual's wellbeing. Local authorities therefore have to consider the impact of a carer's role as a carer on their wellbeing. The development of an evidence base about the potential for carers' passports to improve identification of carers and facilitate access to community support for improving wellbeing is therefore clearly relevant to the Care Act requirements.
National priorities	The Care Act (2014) places a statutory duty on local authorities to prevent, reduce or delay carers from experiencing poor outcomes as a result of caring and developing their own support needs. Maintaining carer wellbeing through identification and support is also a key national priority. Determining the effectiveness of carer passports as a means of facilitating access to tailored, appropriate services will contribute towards this objective.
Current evidence base	There is currently no published evidence about the effectiveness or acceptability of carer passports in terms of facilitating access to social and

Research question	**What is the effectiveness, cost-effectiveness and acceptability of the carer passport schemes?**
	community support services for carers and ensuring they can continue to provide support for the cared for person.
Equalities	N/A

N/A: not applicable

Criterion	**Explanation**
Population	• adults carers (18 years of age or older) who provide unpaid care for either ≥1 adults, or ≥1 young people aged 16-17 years with ongoing needs
Intervention	• carer passports
Comparator	• care as usual
Outcomes	• physical and mental health of carers • carers' health and social care related quality of life • health care contacts of carer and cared for person Expected themes from the qualitative component: • acceptability of and satisfaction with carer passport schemes • suitability of carers passport schemes as a means of identifying carers and facilitating access to social and community support • perceived areas of unmet need following the development of a carers passport
Study design	• integrated qualitative methods alongside an RCT • economic evaluation
Timeframe	• two years from randomisation

Why this is important

Social prescribing is generally understood to be a means for GPs and other primary care professionals to refer people to a range of local, non-clinical services to address needs in a holistic way. During discussions about this evidence review the committee agreed that the lack of evidence about social prescribing reflected a gap in knowledge about signposting more generally; in their minds the former being a more structured, directive type of the latter. The committee were aware of emerging evidence about the effectiveness of social prescribing more generally but they agreed to recommend research about its effectiveness and acceptability specifically as a means of supporting carers.

Research recommendation in question format: What is the effectiveness, cost-effectiveness and acceptability of social prescribing for carers?

Research question	**What is the effectiveness, cost-effectiveness and acceptability of the carer passport schemes?**
Importance to people or the population	The benefits of carers being able to actively participate in a wide range of social and community activities have become increasingly acknowledged and evidenced. However the ability of carers to access this support can be limited by a lack of information and awareness about available services. The committee agreed that this may be due to a lack of signposting to services and that social prescribing could be a means of addressing this. Through GPs and other primary care professionals referring carers to a range of local, non-clinical services the committee agreed it would help to address carers' needs and promote their well-being in a holistic way. As well as the individual benefits this access would achieve, there are likely to be wider benefits including reducing the risk of carer crisis or break down and reducing health care contacts.
Relevance to NICE guidance	NICE guidance provides advice on effective, good value health and social care including care and support to promote the health and well-being of adult carers.
Relevance to NHS/ social care	The Care Act (2014) places a statutory duty on local authorities to put in place services that can prevent, reduce or delay carers from developing a need for support. The Act also introduced a general duty on local authorities to promote an individual's wellbeing. Local authorities therefore have to consider the impact of a carer's role as a carer on their wellbeing. The development of an evidence base about the potential for social prescribing to improve access to non-clinical community support for improving wellbeing is therefore clearly relevant to the Care Act requirements.
National priorities	The Care Act (2014) places a statutory duty on local authorities to prevent, reduce or delay carers from experiencing poor outcomes and developing their own support needs as a result of caring. Determining the effectiveness and acceptability of social prescribing to facilitate access to non-clinical community support and address their needs holistically, will contribute towards this objective.
Current evidence base	There is currently no published evidence about the effectiveness, cost-effectiveness or acceptability of social prescribing for carers in terms of the promotion of well-being and other health and social care outcomes.
Equalities	N/A

N/A: not applicable

Criterion	**Explanation**
Population	• adults carers (18 years of age or older) who provide unpaid care for either ≥1 adults, or ≥1 young people aged 16-17 years with ongoing needs
Intervention	• training for carers to help them undertake care tasks
Comparator	• care as usual • different types of sign posting compared with social prescribing
Outcomes	• physical and mental health of carers • carers' health and social care related quality of life • health care contacts of carer and cared for person Expected themes from the qualitative component: • acceptability of and satisfaction with social prescribing • suitability of social prescribing as a means of facilitating access for carers to local, non-clinical services • identifying carers and facilitating access to holistic, social and community support • perceived areas of unmet need following the use of social prescribing
Study design	• integrated qualitative methods alongside an RCT • economic evaluation •
Timeframe	• two years from randomisation

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

Dali 2012

- Identifying as a carer "I said ‘I think I’m a carer’ and she says ‘oh you should see somebody’ and I said ‘I’ve never seen anyone." (Adult carer - female, page 29)
- Feelings of guilt in using short breaks "I think my ex-wife would make much of it… if I were to indicate that I was getting some respite within the time that I had him, she would go and do her nut”. (Adult carer - male, page 20); "I’ve gone through situations where I’m really exhausted, and he doesn’t realise… and that’s really a barrier because you can’t make him understand that sometimes you need to be away from him”. (Adult carer - female, page 29); “I would have appreciated a bit of help, as an intermediary, with my parents and my mum in particular, to persuade her that it’s a good idea... ” (Adult carer - female, page 29)
- Impact of short breaks “It’s wonderful because I just feel as though I am living again, instead of just being a total carer”. (Adult carer - female, page 14); “…it does help you cope… you know, shortness of temper, you know, frustration... and the thing, when you have had respite and then don’t have it, I can then look back and say ‘my God, that really saved our life’, and I mean that literally, you know, saved our family and everything”. (Adult carer - female, page 14); “Definitely patience – if I don’t treat M a certain way and patiently and all the rest of it and don’t react to certain situations, things are much better, behaviour is much better”. (Adult carer - female, page 14); “…it’s more a sort of time with my younger daughter more than respite for me”. (Adult carer - female, page 15)
- Quality of care “I thought what we had was excellent for my dad. He was well looked after and we felt confident enough for him to be in there and we knew that he was being treated well”. (Adult carer - female, page 18); “I think being with other people… it’s teaching him social skills… especially having the autism”. (Adult carer - female, page 18); “... the caring role is lightened... the burden of entertainment is shared, and the fact that the meals are prepared for them, and someone else is doing the washing up. So all of the stuff, the kind of routine grind of the day, is taken away and they can just enjoy being on holiday together... ” (Adult carer - female, page 19 “I don’t want a stranger coming into my life. And I think a lot of people might feel like that. […] It’s just trust. You have to know that the person that’s been cared for is going to like them, going to have a connection…” (Adult carer - female, page 19); “I have got consistent carers on a regular basis, he knows them and he knows what is happening with them and the only time we have hiccups is when there is a change of carers”. (Adult carer - female, page 19 “…the holiday the carers’ group can give them is far superior to a family holiday… they do ask the clients what they want and what they like and they get feedback from the holidays… a form will come in and ask me did he enjoy it and is there anything we can do to improve it […] they pretty much are tailored to his needs which is what it should be…” (Adult carer - female, page 19)
- Length of short breaks “Even if it’s a long weekend, rather than a week’s nice but it doesn’t matter just as long as you can get away from cleaning and the four walls”. (Adult carer - female, page 20); “It’s limited, I don’t feel like I can make the most of that time, because it’s such, as I say it’s not even 48 hours”. (Adult carer - female, page 20); “Well when you have to cope all the time you just do, but if you suddenly don’t have to cope, you suddenly relax and all your coping mechanisms kind of go away, and then when he comes back I kind of go to pieces because I can’t cope because I have left it behind, so I have to readjust, it takes me about another week to readjust and it’s really hard”. (Adult carer - female, page 20)

- Satisfaction with short breaks what carers consider are the indicators of quality in short break provision, the importance of length and choice of breaks, the impact of changes in provision, and how carers feel about the future of short break services". (Author quote, page 18)
- Choice available respite services: "... I am quite conscious of the fact that there isn't enough resource out there, and there isn't enough back up, you know, there is not any choices – you have no choice in it". (Adult carer - female, page 20); "Basically it meant feeling so guilty when I was going away and where they wanted to put him. I just didn't like that but the way the lady said it too, well that is it, there is nothing else". (Adult carer - female, page 20)
- Barriers to accessing short breaks: Lack of appropriate provision "Once we hit the adult services… massive problems there because although we were approved funding, there wasn't anything to spend it on because there is nothing appropriate". (Adult carer - female, page 28); "It looked to me like a kind of care home…you know the way you get an old folks home […] thought he'd be bored here, you know? What would be the point of that?" (Adult carer - female, page 28)
- Barriers to accessing short breaks: Lack of information "But last year we were offered respite, but for respite you have to give a reason, I think the reasons are for me, why I need the respite, I am not quite sure, but speaking to the social worker we decided the reason was it would give me more time with my daughter…" (Adult carer - female, page 25); "What we have found is that nobody tells you anything, anything you find out is you actually just find out talking to somebody and a chance remark, because it's nobody's job to tell carers anything, even the GP doesn't have to tell you about carers groups or DLA [Disability Living Allowance] anything like that". (Adult carer - female, page 25); "…unless you know your rights, what you are entitled to, social work don't tell you anything". (Adult carer - female, page 25)
- Barriers to accessing short breaks: Battling to be heard "…we had to put together a business case, which if I hadn't had a business background, I wouldn't have been able to do… It was an endless fight with the council – I mean literally every day". (Adult carer - female, page 26); "…I worry for people that aren't as assertive or have such good support from their friends than me… social services just say no, you can't have any respite, if I hadn't fought for that, I worry about people who can't fight like that". (Adult carer - female, page 26); "I think most people would say that bit's probably the hardest part of caring. It's not the care, you know, it's everything else that comes in. It's the filling in forms constantly […] it's easier to just watch them yourself than go through the process…". (Adult carer - female, page 27); "... the stress I went through leading up to that, I don't even know if it was worth it to send her there to be honest with you". (Adult carer - female, page 27); "…my social worker has said himself 'you need more respite, I will try and get you more". (Adult carer - female, page 27); "I used to have a great social worker; I've now got a terrible social worker […] Initially the first social worker that I had they tried to persuade me to get respite… then the new social worker took over and she is just interested in cutting back the hours". (Adult carer - female, page 27)
- Barriers to accessing short breaks: Changes in break provision "…95% of the time is horrendously hard work, and 5% of the time he was becoming violent and violent to the extent we had to ring the police to deal with him. And I mean we had two major incidences, and both of them followed a period where he had had no respite whatsoever for three months…" (Adult carer - female, page 21)
- Impact of caring: Physical and emotional impact - "It is a sheer exhaustion thing, because I don't sleep …I think it's just because I've been that used to having to be there for H if anything happens to him…" (Adult carer - female, page 9); "…it's really exhausting. So it's

24 hours for seven days or something like that. And I get worried that I might not be up to it”. (Adult carer - male, page 9); "I mean, I’ve also got a father with dementia that I have to go and support him as well so it just feels like I never have time off”. (Adult carer - female, page 9); "My mother is 90 and lives with us… I have also got… a terminally ill sister with cancer who is on her own…” (Adult carer - female, page 9)

- Impact of caring: Mental well-being “I mean I always have had a problem with depression but my sychiatrist believes that it is my son who is keeping me depressed”. (Adult carer - female, page 11); "…it’s that [breaks from caring] and the fact that I work, it keeps him out of full-time care because I think otherwise I would be suicidal”. (Adult carer - female, page 11)
- Impact of caring: family life “She [carer’s daughter] really got quite pushed to the side… we didn’t have the time… G was 24/7… it’s a shame that we missed out a wee bit on her growing up… it’s always a struggle… to kind of share yourself around… and she usually always is the loser… she’s just got to be and that’s just the way it is." (Adult carer - female, page 11);"…to be honest if I hadn’t had a younger daughter, I don’t know that I would even have requested respite to start with - but because he was so intense and we couldn’t do a lot of things with her…" (Adult carer - female, page 11)
- Impact of caring: Social life "I used to be in my darts team, come in about maybe one o’clock in the morning, put the music on, my man would get up, we’d have a wee dance. I broke down last month, I put on one of my 60’s songs, and I couldn’t stop greetin… I just realised my life had changed, because that just won’t happen again”. (Adult carer - female, page 12); "I always found with my son’s disability, the epilepsy part’s hard, but I think sometimes the autistic side is harder because it’s how the world perceives it, you know?… if somebody’s acting strangely you get a whole different response. So therefore you don’t want to go out, you avoid a lot of life…” (Adult carer - female, page 12)
- Impact of caring: Employment and finances "…I can relax and enjoy the job I am doing, which I do, and I love it, and it makes me feel a person – that is what keeps me going, because I feel a person in my own right, otherwise I am nothing but his carer. […] Having the job has allowed me to do what I am doing without going off my head." (Adult carer - female, page 12); "There is also the financial part as well with caring for my mum full-time, so I can’t go out to work, so I am relying on my carer’s allowance and my income support…" (Adult carer - female, page 12)

Greenwood 2012

- Experience of respite: What carers do during respite "Well shopping, or whatever we have to . . . my husband has these, has to go to the doctor quite often and things like that, or whatever. You know. We carry on. I might be doing a whole load of washing or something . . . Yeah . . . Daily things, yes . . . it really is a tremendous help for us" (Adult carer of a person with dementia, page 6); "…it’s good to be able to go to a movie or something . . . I did go and see a film – it just happened to work. It started at 8.15 and was finished by 10.15. So fantastic." (Adult carer of a person with dementia, page 6)
- Experience of respite: Benefits for the carer "I would just say – given me my life back and maintained my sanity. Because you need that out time, you really do. Yeah otherwise you’ll just go crazy…otherwise I would explode." (Adult carer of a person with dementia, page 6); "Um, a bit of relief I think. You know, sort of, to get out of these four walls and just to get away for a couple of hours"; (Adult carer of a person with dementia, page 6);"Yes you need to – it’s terribly easy to become isolated – not, you know emotionally isolated – you know, you think I don’t want to go out because you’re so used to not going out - it’s very easy to become a sort of stick in the mud and not get stimulated …." (Adult carer of a person living with dementia, page 7); "No it does and it sort of galvanises you into, you

know, maybe climbing out of your jeans. And thinking can I talk about anything, except what I was eating. Or ‘Has he fallen over recently?’No, no it does make you switch on to what is going on in the world a bit." (Adult carer of a person living with dementia, page 7); "Respite was sometimes seen as benefitting the cared for which could indirectly also have a positive impact on the carer." (Author quote, page 7)

- Care workers: What care workers do during respite "She brings her slippers and makes herself at home, and sits and chats with my husband and if he wants to have a sleep, she sits and watches him”. (Adult carer of a person living with dementia, page 8); "Yeah, yeah, that’s right. And using magazines and images. You know she has even brought her own magazines in sometimes . . . To chat to Mum, um, it’s really, really nice”. (Adult carer of a person living with dementia, page 8); ". . . and takes her on visits, yes. Which is excellent . . .we had the mental health nurse here yesterday, who asked her lots of questions, which she answered much better this time than she has done normally”. (Adult carer of a person living with dementia, page 8)
- Care workers: Characteristics of good care workers "Someone who can listen to her, and give her the time. That’s the main two things. And communication”. (Adult carer of a person living with dementia, page 9);"m . . . no. I mean, I think she is quite . . . she’s taken phone calls for me from the hospital, or messages. No she seems quite confident, doesn’t she? Very confident person" (Adult carer of a person living with dementia, page 9)
- Context of being a carer: Constant responsibility “. . . I cannot leave him for a minute and I actually can’t, you know, if I go upstairs . . . I can hear him in a minute. You know he starts calling – even if I say I’m just going up to get something he starts worrying . . . it’s pretty full on you know”. (Adult carer of a person living with dementia, page 5); “... .. .That’s why it make me tired sometimes. I can’t even relax for five minutes. Every five minutes to look at the clock and then I’ m rushing to give him his dinner. . [With respite] I feel relaxed. And just sometimes sit, or do shopping”. (Adult carer of a person living with dementia, page 5)
- Context of being a carer: Trust "This is regular whereas . . . whenever I rang them [previous care agency] they weren’t available. And when they did come, the person they sent was very um, er, I suppose forthright, but in a kind of an inappropriate way, and I didn’t really like to leave her with my Mum. Whereas your, the person that we get regularly now is great." (Adult carer of a person living with dementia, pages 5-6)
- Context of being a carer: Carers’ low expectations and powerlessness “. . . The only thing I think sometimes is maybe she could have helped me press my girl’s clothes you know.I never asked her but apparently she will do it if I ask her. Yes but it’s alright, I can’t complain”. (Adult carer of a person living with dementia, page 6); “I mean I don’t know if there would be anybody better, you know, who would communicate”. (Adult carer of a person living with dementia, page 6); “If somebody’s been kind enough to offer you help, you don’t want to throw it back at them”. (Adult carer of a person living with dementia, page 6); “Yeah. I’m sure she would be quite willing, and they’re well trained so I’m sure she could do it, but I just think it’s a little bit much to ask”. (Adult carer of a person living with dementia, page 6)

Greenwood 2013

- Perceived benefits of peer support: ‘‘You are not alone" “. . . it’s a perfectly normal, understandable reaction that no one is weird or freaky that they feel like that. There was anger in there too but having someone say ‘Yeah I felt like that too’ helped" (Adult carer of a person living with dementia, page 619); "It helps tremendously to just to talk to somebody and know that they’ve been through probably something worse than you . . . Because you always think ‘Oh I’m the only one who is suffering with this’ but you’re not, of course. And then there’s lots of worse cases . . . Because you are not so kind of wrapped up in your own, are you? And then you sort of think ‘Well lots of people suffer from this." (Adult carer of a person living with dementia, page 619); "Everybody (volunteers) talked quite a lot about their own experience, what they had done, how they had managed or what they had found difficult. There was a lot of, kind of, sharing our experiences really. " (Volunteer: Former carer of a person living with dementia, page 620); "I was isolated with the situation, you know, and it taught me that a lot of people are experiencing other aspects of the same thing. " (Volunteer: Former carer of a person living with dementia, page 620); ‘‘there for them.’’ Volunteers agreed: “It’s like travelling along the same road. I’ve already been on that road, so you meet somebody on the road again and you hold their hand and you travel along the road with them." (Volunteer: Former carer of a person living with dementia, page 620);

- Perceived benefits of peer support: Emotional Support and Release: “. . . it released you knowing you were talking to someone else, so emotionally it strengthens . . . suddenly we were letting out things we had kept in. That was good, so from that emotional point of view, I think we helped each other”. (Volunteer: Former carer of a person living with dementia, page 620); “You get to the stage where you think, ‘Well I can’t go on about this to everybody, I can’t put people who are my friends through it, so it is time to move on”. (Volunteer: Former carer of a person living with dementia, page 620); “We talk about her feelings and about my feelings. And how it affects me . . . And also the feeling of, um, it’s like a living bereavement”. (Adult carer of a person living with dementia, page 620)
- Perceived benefits of peer support: Enjoyment of Peer Support ". . . something for carers to look forward to at least once a week, to have a conversation . . . I think it breaks the monotony . . . just contact with the outside world." (Volunteer: Former carer of a person living with dementia, page 620); “I got used to chatting with her and having a laugh, which I hardly ever get." (Adult carer of a person living with dementia, page 620); " . . . I do find it quite interesting just meeting with these people who perhaps have a different background, to me, slightly different lifestyle, different set of circumstances . . . it’s a privilege being invited into this kind of situation and people telling you about their difficulties, and their life, and what’s going on." (Volunteer: Former carer of a person living with dementia, page 620)
- Perceived benefits of peer support: support in managing their situations. ". . . she was able to show me that it is different for everybody and there is no perfect solution . . . you try something and then if it doesn’t work then you try something else. But she was able to offer constructive suggestions about a possible way of approaching a problem”. (Adult carer of a person living with dementia, page 620); "So it’s good in that way because you realize that what you’re doing is good. Because I think you can feel a bit negative about things and are you doing enough? But you can only do so much" (Adult carer of a person living with dementia, page 620)
- Perceived benefits of peer support: gaining different perspectives "You wouldn’t blame yourself for putting her in hospital, would you? You mustn’t blame yourself for that. Because you didn’t put her in there, her illness put her in there." (Adult carer of a person living with dementia, page 621)
- Drawbacks, Challenges, and Limitations for Carers and Peer Volunteers (former carers of people living with dementia)It is not going to help. I mean for a while you can laugh and share experiences and joke around. Just making each other laugh helps, just gives you a lift . . . but . . . whatever you say and whatever you do, it’s not going to get me out of the way I am feeling”. (Adult carer of a person living with dementia, page 622); " She was very nice, she is very kind and all that, but I don’t know how much it helps or how much it doesn’t . . . it is good to talk but I don’t know, it is, it is a very hard. It is a terribly, terribly" (Adult carer of a person living with dementia, page 622); “You could share it to a certain

extent but no one ever knows what you feel inside because everyone feels different, everyone copes differently". (Adult carer of a person living with dementia, page 622); "Because it's that thinking 'Do I really want to do this or is it just too painful?' . . . Yeah, and listening to other people's points of views and what happened to them . . . 'Because I think it's important for the carers to know that that's what they should expect that you only spend an hour with them. Because you know, it does take its toll . . . you've got to look at why you're doing it, and if you're doing it because you want friendship or ... " (Volunteer: Former carer of a person living with dementia, page 622)

- Volunteer–carer relationship: "Somebody who is going through exactly similar process that you went through . . . or maybe on a slightly different journey . . . although their circumstances were very different, the emotional journey is very similar. Therefore I don't think it matters terribly who you are matched with providing they are someone who loves and cares about the person . . . Then the emotional journey is very much the same". (Volunteer: Former carer of a person living with dementia, page 622); "And because she understands, because her husband had Alzheimer's as well. So anything that I want to talk to her about she said 'I know because I've done it . . .'First of all I was 'Sorry I've got to do this', but she said 'I know what it's like, I've been through it". (Adult carer of a person living with dementia, page 622); "When I go out with my friends I don't really talk about Mum that much because I just want to talk about rubbish and laugh and not talk about it. When you end up not talking about it and you bottle things up . . . and that is when you feel isolated. I do talk to my family, but it is not the same really". (Adult carer of a person living with dementia, page 622); Peer volunteer–carers shared experiences meant also helped to create an emotional bond, where carers could be open: ". . . . She thinks now we've known each other all our lives. That's how she feels about it. So we really chat . . . and we talk freely about everything". (Volunteer: Former carer of a person living with dementia, page 622); "So yes we used to listen to each other and she used to help me and hopefully I tried to help her. Just listening . . . just to get things off your chest and someone to listen to you and say 'That must be bad". (Adult carer of a person living with dementia, page 622)

Harding 2004

- Motivations for Accepting the I : 1) "…to seek interaction with other carers, including hearing the opinions of other carers, meeting people in a similar situation as themselves, wanting to compare their situation to that of others, and reducing isolation." (Author quote -16 carers; p.401); 2 "to access education including wanting to teach and learn from others... to gain further professional advice and acquaint themselves with available resources" (Author quote -16 carers; p.402)
- Benefits of attending: 1) "... Carers commented on the value of comparing their caring situation to that of others in the group... .. .importance of being with people who understood them and of being with their peer group, and were reassured that there were others in similar situations." (Author quote, page 404); 2) "Being with people who understand your experiences was a very commonly reported benefit of the group" (Author quote - 21 carers, page 404); "Meeting other carers reduced feelings of isolation, enhanced coping, and helped them to accept their own situation, in large part because the realization that they were not alone in their experience" (Author quote, page 404); 3) "A key gain ... was the ability to have patience, which they learned from attending the group." (Author quote, page 404); "The element of having a focus of interest and care on the carer rather than the patient was important to ... [Carers]". (Author quote, page 404)
- Group processes: "New information gained was described as follows: information on the patient's illness; weakness, weight loss, and diet; drug effects; information on taking the

patient on vacation; information on funerals; practical advice on care." (Author quote; page 404)

- Access issues: 1) "transport service was important in facilitating their [elderly carers and those who could not drive] attendance at the group" (Author quote; p.402)

- Intervention design: 1) "five carers suggested further sessions or follow-up meetings, as they had remaining unanswered questions" (Author quote; page 403); 2) "Welfare was the most popular session, with 13 carers naming it as helpful. The dietician advice was found to be particularly helpful by 10 carers, and the relaxation exercises were described as helpful by five carers."; (Author quote; page 404)

Keyes 2016

- Commonality of experience: "Carers [of people living with dementia] spoke about support emerging from identification with others who were in a similar position" (Author quote, page 569)
- Reciprocity: "First of all the thing of the peer support is know you’re not alone. I think the second thing about it is hearing from them how they have dealt with various problems they have come across. What has been happening in their scenario. What might be even better was if . . . If you like, people down the road ahead of us – like, people who have relatives who are at a further advanced stage – that they would, sort of, say how they got to the point where they are." (Adult care - female: page 570); 2) practical and emotional support: "Lots of different things of meeting different people in the same situation . . . .To talk to people in the same situation, really... .. I think it’s . . . having done some of the courses and things – and you suddenly realise that, you know, mum is always forgetting her keys, or where she’s put her keys. And there are people in the same situations that say ‘‘oh, my husband does that’’ or ‘‘. . . my wife does that’’ and you think ‘‘Oh, good’’”. (Adult care - female: page 570);
- Direct experience: “you get to know other people’s you know, little mishaps ... and you seem to settle things up together, you know. And I think that’s what it’s all about. It’s getting to know each other and helping each other”. (Adult care - female: page 571)
- Quality of peer relationships: "I mean, talking to [PSN Group Facilitator] I mean she’s lovely and she comes up with all the right ideas and everything, but she’s not actually in the same position as you. Although she’s got everything at her fingertips ... she’s still, sort of like, you know, a nurse and not a person who’s in the same position as you." (Adult care - female: page 571)

Larkin 2007

- The role of carers groups during caring: "We had a walk round Oxford, all free of charge. ... In the spring we went down to the south coast, free of charge again, no sorry, I had to pay for something. And then they hired a boat on the canal, you know a long boat, at Boxstone and we went up the river up the canal to a restaurant and we had a meal at the restaurant" (Former carer - no condition specific - page 37); "... [a Former carer] described how she shared the exhaustion she endured caring for her father and her father’s antagonism to respite care with her carers group friends." (Author quote - page 37); "... .he [the group leader] said, ‘Don’t worry about it. Can you get round here Wednesday, you know, about 2 o’clock and I’ll get an Occupational Therapist from the hospital to talk to you’…... when I explained the situation she [the Occupational Therapist] started getting the ball rolling and she got Dot into Cedar House, a residential home for fi ve weeks so it was a big relief." (Former carer - no condition specific - page 38); 4” ... [former carers] found it ‘helpful’ to listen to the ‘different approaches that others used, and to be able to ‘talk and laugh about it’." (Author quote - page 38);"... [a Former carer] illustrated this when she recalled how the ‘wonderful, wonderful’ lady at the carers centre ‘got me extra money and then she got me income support." (Author quote - page 38)

- The role of carers groups post-caring: “As during caring, these groups were a source of friendship that provided emotional support”. (Author quote - page 38); “... carers groups are great because they don’t mind you coming even if you’ve finished caring. They like you to keep coming. I mean I know all the people. They have fresh people but they are happy that we carry on going ... it makes you aware that there are still others that need support. A lot of them come, and people ask for help, or they have experiences, you know ‘I’ve done that’ or ‘I’ve done this’. You can usually help somebody, we’ve all been in the same boat as well”. (Former carer - no condition specific, page 38); “... if you can get involved in a [carers] group like that then you’ve got a contact for afterwards ... I think if carers could get together, can get together beforehand, then that association could probably continue afterwards”. (Former carer - no specific condition, page 38)
- Limitations of carers groups for carers and former carers: “It was all by mistake. I’d been up to the carers centre, and just popped in, and Debbie who helped me at the hospital, she said ‘Oh Julie, there are 2 or 3 people going out for a little car ride ... do you want to go along with them?’ I said ‘Oh I don’t know about that’. She said ‘Just go out with them for half an hour’. We went out to Barham Lodge, came back and Debbie said ‘You know one of the ladies you went out here with, she’s suggested that they get a little group up ... so that you can have a little social group. ... So how would you like to have a go at it?’I thought, well I said to her ‘I’ve got no experience of secretarial work or writing letters or anything’”. (Former carer - no specific condition, page 40)

Locock 2010

- a) Practical comparison "You can compare notes with people who’ve actually got MND. For people who are carers, there are people there who’ve cared for people…You get ideas from them. Just little things, like when it’s difficult swallowing tablets, put them with some ice cream." (Adult carer of a person with NMD, page 1501)
- b) Camaraderie and social comparison: “It doesn’t matter if you talk a bit funny because everybody talks a bit funny, so you haven’t got people looking at you... It just feels like an ordinary coffee morning, you know, you go and you talk about all sorts of things. People don’t talk about MND all the time…so it just feels like going for a normal social event”. (Adult carer of a person with NMD, page 1501); “At the group they met ‘lively fantastic people’ whereas sitting at home ‘you could become quite self-centred, and focused completely on MND”. (Adult carer of a person with NMD, page 1501)
- c) Emotional impact: "Last night at that function I was moved and got emotional listening to some of the people and the speeches... A lot of emotional feelings came to the fore. Interviewer: What was positive about it then for you? Knowing there is other people in my position. I am being selfish now…Last night several people said, ‘I am at the end of the phone if you want to talk about anything’, so that was a positive thing for me”. (Adult carer of a person with NMD page 1502)
- Practical access problems “…were common reasons for not going to face-to-face support group…some carers [of people with NMD] were still working and attending daytime meetings was difficult”. (Author quote page 1502)

Mansell 2009

- Quality in terms of time away from caring role “So another confusing thing is some people get day service for a few hours, sometimes it’s very fragmented, but I am told that this is counted as respite care, I believe”. (Focus group - Adult carers of people with a learning disability, page 262); “He leaves at half past twelve and is back by three, its not much of a respite you know”. (Focus group - Adult carers of people with a learning disability, page 262); “No, it should be longer than that [a few hours day care]. I think my understanding would be not day care, it might be but it is not a real respite [a few women agreeing] you might go out and do a bit of shopping, certainly it would start with an overnight or probably two nights minimum, a week would be heaven wouldn’t it? “. (Focus group - Adult carers of people with a learning disability, page 262)
- Professional misconceptions (about the role of carers during periods of respite) " I would like a complete and utter break from my daughter, preferably overnight. When our social worker returned from holiday recently she said, ‘I really needed another week!’ It took me all week to unwind. I don’t know why it is, some time ago my daughter was, as you just said out of the house for a small number of hours, and the social worker had said to me, ‘you go off and enjoy yourself’ . . . What I want to know is why as carers we are expected to unwind like the strike of a clock and everyone else wants days to wind down. I don’t understand why we are that different, in that sense." (Focus group - Adult carers of people with a learning disability, page 263); "I think what professionals don’t recognize is the fact that the natural progression is that you have a child, they grow up, they leave home and for us that never happens." (Focus group - Adult carers of people with a learning disability, page 263)
- Lack of information regarding respite access criteria "One of the confusing things is – is respite care for the person you are looking after or respite for the carer?" (Focus group - Adult carers of people with a learning disability, page 261); Many carers felt that "... professionals looked at respite from the perspective of the person with a learning disability whilst focus group carers felt it should cover both parties, in terms of value to both the carer and the person being cared for" (Author quote, page 262); "I feel that respite to us is a period of time when our daughter is away having a great time with new people, friends in the house she meets up with and having different experiences." (Focus group - Adult carers of people with a learning disability, page 262)
- Equity of access "It does help with some people that they get on the list early. And then it is sort of recycled you know and you find that they are going for a week and a fortnight regularly, I think it is quite difficult to get offered it if you’ve not already had it before." (Focus group - Adult carers of people with a learning disability, page 263); "My friend has a child with learning disability and she had been on the list 14 years in [names geographical area] and hadn’t had any respite until the last couple of months. And yet some of her friends have had it from the age of three. I really don’t know sometimes how they actually decide to make these decisions”. (Focus group - Adult carers of people with a learning disability, page 263); some people get more [respite], obviously . . . it is led by criteria, we know . . . Single parents, divorced parents whatever? [Others agree]. There are also other huge problems, we found that if the person’s got medical conditions that’s now precluding them from a lot of respite opportunities, we were only able to access a hospice." (Focus group - Adult carers of people with a learning disability, page 264)

McSwiggan 2017

- ‘Reaching a point’ – “There is nobody who sort of says, right, you should be handing over [care]. And I honestly think it’s too late when it happens”. (Care of an older adult – page 1407); “They’re still saying, ‘We’ll give you’. I’m sorry, dear, but you won’t give me anything. You'll provide me with a service I'm entitled to. It's not within your remit to 'gift'". (Care of an older adult – page 1408); "As soon as you go in [residential respite] there are several things that strike you. It smells fresh . . . everybody seems to be smiling . . . there's lots of activity and hubbub. I noticed that immediately and thought to myself, 'This holds a lot of promise'". (Care of an older adult – page 1409); "I got a 'phone call from the social worker saying that the care home that she'd been in couldn't take her, she'd go to a different one. I balked at that because she liked the first care home . . . why change it". (Care of an older adult – page 1410);

- 'Trying it out' – "In the beginning there were little teething problems where a couple of people [respite care staff], we didn't want them back because of some issues [in-home respite] but that was ironed out [via service manager] and we got there in the end". (Care of an older adult – page 1410); "Our key worker takes her time and that just suits Alex down to the ground. He's given time to process what's being said and think about what he wants to answer, and she always [carer's emphasis] includes him in whatever she has to say". (Care of an older adult – page 1411);
- 'Settled in' – "There were days when I felt I'd really like to be out with my husband but I couldn't manage myself but Laura [in-home respite] was able to come too! So we would go to the garden centre . . . I had time to look at the plants and then we had our cup of tea together". (Care of an older adult – page 1411); "As soon as Lynn [in-home respite] comes in, Jimmy [husband] is fine. They'll talk about football . . . watch TV . . . they've worked up a good relationship". (Care of an older adult – page 1412); "I am happy with the care package at the moment, although it didn't happen overnight and I had to get seriously crabbit more than once. And occasionally I still have to get crabbit to make sure we hold on to what we've got". (Care of an older adult – page 1412); "There should be an opportunity to Skype with my wife. It would reassure her, give me a great deal of confidence . . . you don't need one in every bedroom, just one in every care home". (Care of an older adult – page 1412)

Moule 2014

- The break: "Most interviewees [carers] reported having a free choice on the nature of their break". (Author quote - page, 258); "Many carers found very useful to b engaged in telephone or face-to-face conversations with assessors". (Author quote - page, 258); "Some needed time away from their caring responsibilities. However, nine interviewees stated that they could not, or did not want to, leave the person for whom they were caring". (Author quote - page, 259); "I have had a little bit of depression and anxiety in the past ... but exercise was one of the things [that helped]". (Adult carer - condition of the care recipient N/R, page 259)
- Effects of the break: "I felt I was cheating somebody; and I suppose thinking about it now, the first time the money went into my bank it stayed there for two weeks". (Adult carer - condition of the care recipient N/R, page 259); Many carers who had received and spent at least some of their funding commented positively about the effects of the break: "It has made me feel a lot better about myself ... .. it's given me something of myself back". (Adult carer - condition of the care recipient N/R, page 259); Carers associated "... an improvement in their own well-being and/or ability to care with a positive impact on those being cared for". (Author quote, page 259); "It's not long-term, is it? It was a lovely gesture, a nice bonus, but you know like anyone in normal life, you come back from holiday and it's all back to normal". (Adult carer - condition of the care recipient N/R, page 259)
- Administration of the scheme: "I didn't know this existed... I have spoken to some other carers and they have no idea that this is available... .. it seems quite secretive at the

moment" (Adult carer - condition of the care recipient N/R, page 257); Many carers found the assessment for accessing the scheme to be a positive experience, especially when conducted face-to-face: "... .. sometimes you need to unload or unburden yourself, and maybe it was good that I was able to talk to somebody who actually understood what I was going through". (Adult carer - condition of the care recipient N/R, page 257)

- Carer circumstances: "... (Caring) takes over your whole life, morning, noon and night, and you're constantly on the go." (Adult carer - condition of the care recipient N/R, page 257); "My mum is at that stage ... she will only do everything with me". (Adult carer - condition of the care recipient N/R, page 257)

Munn Giddings 2007

- Motivation for joining the group (carers' self-help groups): "You lose all your friends and people who used to ring you up don't any more and, all of a sudden, you realise that you are alone with a big problem". (Adult carer - female, page 29); "We have always been actively involved, always, and that was a way of knowing what was going on. Unless you joined a group like that, you were in the wilderness". (Adult carer - female, page 29); Yes, going through the door is the first hurdle sometimes. It took two or three sessions before I was able to see that the others were just like me and having the same problems, expectations and so on … For the first two, I sat outside the room and just went in for the last 15 minutes …" (Adult carer - male, page 29)
- Personal gains from attending the group: Empathy "I definitely feel I come away happier and contented knowing you are not alone and there are thousands out there doing the same sort of thing with the same sort of burdens and, basically, it gives you a little more energy to carry on with everything in life knowing there are others doing the same thing." (Adult carer - Male, page 29)
- Personal gains from attending the group: Emotional coping - "We worry about one another for sure, definitely. If there has been a real, real problem with someone, you know at that next meeting we have worried about that person, and if that person is not there, why aren't they there?" (Adult carer - Male, page 29); "I learnt a lot from Sonia and Rob … because they'd been caring for so long [30 years for a son with disabilities] that, for them, it had become 'normal', it was their lives. I learned how to make things seem more 'normal' … by not making everything into an event, rather making it part of our days routine". (Adult carer - female, page 29); "Well, I like to listen to others' experiences, the social services, getting other types of help, the progression of the illness and others who have had the illness a lot longer, that sort of thing. It has been useful to me" (Adult carer - Male, page 29-30); "I suppose the real significance has been realising that there is someone else that I can turn to, at any time, for some help and some advice. To know what is available that will make life easier, that sort of thing. It is the main significance that it's had." (Adult carer - Male, page 30)
- Personal gains from attending the group: Experiential knowledge "Being in the group … [helps] … just talking about the situation. Others providing their experience, because experience is the way you learn and most of those have been caring a long time and have a wealth of knowledge to contribute." (Adult carer - Male, page 30); "We all look at it from different points of view … we all have something, different experiences, background and have done different jobs" (Adult carer - Male, page 30);
- Personal gains from attending the group: Practical information "I think being in a group like this as you listen to the different people, you realise and you learn who you can approach, yes, where maybe you didn't know that avenue was there and you just find out, all sorts of things from the group". (Adult carer - Male, page 30)

- Personal gains from attending the group: Peer support/friendships “If I felt bad, I could phone someone and I have no doubt then that they would come over …, which is nice to know”. (Adult carer - female, page 30); “Well, there is the comradeship, being one of the number hopefully, there is the emotional support and I have been able to contribute a little of my situation to the group”. (Adult carer - male, page 30); “I remember going to CRUSE [a bereavement self-help group] … they were laughing, joking, getting on with things and yet able to say how awful it all was … but to see people laughing, having survived, it stayed with me … I thought, yes, if they could survive, so could I …” (Adult carer - female, page 30)
- Contrasting self-help groups with professional services “I’m willing to answer their questions, but then, I think you’d find yourself in a vulnerable position when you are, you’re caring for someone and what the social worker is looking for is to see whether you are emotionally capable perhaps of looking after that person also. And I think I would be very loath to be the helpless female who couldn’t manage … You don’t have to put on a front, you can just be as you are”. (Adult carer - female, page 31); “When I was looking at Respite Care Convalescence, with our [named] Association, I’d found that, when I asked if I could have Respite Care … they didn’t do it. They would take any kind of illness and the carer, but they wouldn’t take Alzheimer’s. Now I was sort of horrified, so that, after raising this with them [personally], it was taken on my behalf [by Alzheimer’s selfhelp group] and was taken up by Regional Areas and then taken to a conference. Now the [named] Association is looking into having small units within their convalescent homes for Alzheimer’s people or people living with dementia”. (Adult carer - female, page 31)

Ryan 2008

- Factors enabling carers to receive support and the care workers to provide it: “... organised (for example, routines, lists, knowledge of where to seek information), in good health, financially secure, good family relations and support, supportive employment, self-sufficient, make use of available services, confidence to admit difficulty with coping and to ask for help, emotionally resilient, pro-active, good communication skills and ability to network... " (Author quote, page 236); "the most important attribute is an ability to network – to pick up the phone and involve people and let them know what is happening. " (Professional delivering the intervention, page 236); Professionals delivering the intervention felt "… that the success of the project depended on several factors, which included: good networking skills, a good relationship with the respiratory team, attendance at the lung cancer MDT, being informed about all patients from diagnosis”. (Author quote, page 236)
- Whether the service improved the quality of life for the carer: "it’s all very well having someone there at the time (of death), but you need someone thereafter, even two weeks after – she’s helped me cope." (adult carer of a person with lung cancer, pages 235-7)
- To what extent the MCP aims were accomplished: Professionals delivering the intervention “... were flexible, sometimes supporting mainly carers [of people with lung cancer], sometimes carer and patient [with lung cancer] equally. A few carers recognized the MCP [Macmillan Carers Project] as a pro-active service and appreciated being offered support, rather than having to seek it" (Author quote, page 235); “it was nice to have someone not concerned with the medical aspects”. (Adult carer of a person with lung cancer, page 235); "I suppose it sounds selfish but it is nice to know someone is thinking about me as well ’as a health professional would be orientated towards health and health problems and not fa ilies, relationships, culture and environment." (Adult carer of a person with lung cancer, page 235); "the nurses are very busy and I appreciate the extra time the project workers are able to give”. (adult carer of a person with lung cancer, page 235);

many carers felt that " …MCP [Macmillan Carers Project] workers provided information (about the illness, the investigation and treatment process, future care options), a useful point of contact and being a ‘ lifeline “ (Author quote, page 235)

- Caring for patients with lung cancer in general "enjoyed the caring role as had become closer to father and had the chance to talk to him on his own"; (adult carer of a person with lung cancer, page 235); “an extension of my marriage vow “in sickness and in health” (Adult carer of a person with lung cancer, page 235);

Skilbeck 2005

- Experience of respite service provision “I feel a bit better now than when he first came in. I knew I was ready for a break. Yes, I feel much better now. Well, I’m just not on my feet as much, you know. I try and have a sit down and have a quick read or have a rest. I can get up in a morning and take my time with nobody to worry about and go out, at night without having to see to him first, so it has been a nice break for me”. (Adult carer - female, page 612). “Well actually I was hoping to get a good rest and a good night’s sleep, but I went away with the daughters and children. I really enjoyed it you know, because I mean like I hadn’t got the wheelchair to push and I hadn’t got to worry about what S wants, but well I can’t honestly say I got much of a rest”. (Adult carer - male, page 612). “After the period of respite, most carers felt able to resume the caring role, and particularly looked forward to the next period of respite to have something to look forward to and keep them going... some carers found it difficult to resume the caring role”. (Author quote, page 612)
- Service evaluation: Continuity of care "They will do with B what is done for him everyday in this home. I mean he has dry skin so we have cream on him and they do all that, they are prepared to do it, they really are very good. And I know they cater for B’s needs as his needs are catered for at home and that is important as well”. (Adult carer - female, page 614)
- Service evaluation: Providing new opportunities for care - "A number of carers regarded the respite admission as an opportunity to get medical and other problems" (Author quote, page 614)
- Better here than elsewhere - Many carers "... perceived the hospice to have higher quality nursing care and rehabilitative facilities... " (Author quote, page 614)
- Dissatisfaction with aspects of the service received - Many carers would have liked "…more specific information was required, such as the availability of separate rooms, daily routine, and visiting patterns." (Author quote, page 614). Many carers talked about "... the hospice being believed to be a place where people came to die, and in some instances, the patients and carers had considered not accepting the respite place for this reason." (Author quote, page 614)