

Supporting Adult Carers

**RQD - Evidence reviews for work, education and
training**

NICE guideline tbc

Evidence reviews

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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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1 Supporting adult carers to enter, remain in 2 or return to work, education and training

3 Review question

4 What are the most effective, cost-effective and acceptable interventions, tools or approaches
5 to support adult carers to enter, remain in, and/or return to (i) work, (ii) education, and (iii)
6 training?

7 Introduction

8 Currently, 3 million people in the UK are juggling the complex issues of paid work and care.
9 Around one in nine people in England are carers (Census, 2011). Many of these carers will
10 be between 45 and 64 years, at the peak of their careers in terms of skills and experience,
11 but evidence indicates that many carers experience considerable practical and financial
12 difficulties in balancing employment with their caring responsibilities. Carers UK (2013) found
13 that 31% of carers of working age retired prematurely or reduced their working hours
14 because support services were either not available or were too expensive or their employer
15 did not understand the requirements of carers in their workforce. Their premature retirement
16 is not only significant in terms of financial impact on the family but also a major loss to their
17 employers. It is also significant because Pickard (2008) and data from the Census (2011)
18 clearly indicate that demographic change will see growing numbers of families with multiple
19 inter-generational responsibilities needing to balance caring with skills which are vital to a
20 modern economy.

21 The Care Act 2014 acknowledges the importance of access to training and employment for
22 carers, expecting local authorities to ensure that carers' assessments take account of carers'
23 wishes to enter, remain in or return to employment (and of any necessary related education
24 or training to make this possible). However, ongoing challenges include access to the
25 education and training necessary for skills expected in 21st century workforces (a key issue
26 for young adult carers with education disrupted through their caring roles), employer attitudes
27 (including the right to flexible working and carer leave) and reliable replacement care.

28 For many carers, remaining or entering employment will depend on a range of factors.
29 Personal Budgets (for carers as well as for those they support) have the potential to provide
30 greater flexibility around replacement care. Employers themselves have a role to play,
31 Employers for Carers (2019) noting the positive impact on carers in developing carer friendly
32 workplaces and demonstrating the value to the business sector of carer recruitment and
33 retention (one carer friendly employer, Centrica, citing a potential cost saving of £2.5m
34 through increased staff retention). Particular issues for further development include support
35 for young adult carers and the management of their transition to adult services and
36 education, training and employment.

37 Summary of protocol

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

1 **Table 1: Summary of the protocol (PICO table)**

Population	<ul style="list-style-type: none"> • 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	<p>Any intervention, tool or approach whose primary aim is to support adult carers to enter, remain in, and/or return to work, including:</p> <ul style="list-style-type: none"> • return to work plans (including paid or unpaid work) • workplace support (for example flexible working hours) • individualised support (for example Carers' Lead, work coach/adviser at Job Centre Plus) • financial assistance (for example Carer's Allowance, Flexible Support Fund) • interventions, tools or approaches to improve carers' education, or provide training opportunities/work placements for carers (including volunteering) • interventions, tools or approaches for improving carers' ability to enter, remain or return to education or training (for example information about working rights/benefits) • work-specific carer passports.
Comparison	<p>For studies evaluating the effectiveness of an intervention:</p> <ul style="list-style-type: none"> • no intervention • different types of intervention within each category.
Outcome	<p>Quantitative outcomes:</p> <p>Critical</p> <ul style="list-style-type: none"> • short and long-term employment or course attendance (relative to level of education/training) as measure for sustainability of, or ability to remain in work etc. <p>Important</p> <ul style="list-style-type: none"> • short and long-term carer quality of life, including carer satisfaction/experience • productivity • household income/financial issues or burden • carer mental health (include only measures that assess anxiety, depression, or stress/emotional wellbeing). <p>Qualitative outcomes:</p> <ul style="list-style-type: none"> • satisfaction with the intervention • perceived appropriateness of the intervention • perceived acceptability of the intervention • barriers and facilitators.

2 For full details see review protocol in appendix A.

3 **Evidence**4 **Included studies**

5 This is a mixed-methods review so qualitative and quantitative studies were eligible for
6 inclusion. The objective of this review was to determine what the best ways are to support
7 adult carers to enter, remain in, and/or return to work, education, and/or training.

8 For the quantitative part of the review, we looked for systematic reviews and randomised
9 controlled trials (RCTs). For the qualitative part of the review, we looked for studies that
10 collected and analysed data using qualitative methods (including focus groups, interviews,

1 thematic analysis, framework analysis and content analysis). Surveys restricted to reporting
2 descriptive data that were analysed quantitatively were excluded.

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

5 **Quantitative component of the review**

6 From the search for quantitative studies for this review, 1 RCT (Boezeman 2018) and 2
7 observational studies (Pickard 2018, and Pickard 2015) were included, these studies are
8 summarised in Table 2.

9 The RCT was carried out in the Netherlands and included 128 adult working carers
10 (Boezeman 2018). This study aimed to compare the effectiveness of a role-focused self-help
11 intervention to a wait list control group, to support carers who suffered stress due to
12 combining paid work with caregiving.

13 The 2 observational studies were performed in the UK and included 166 working carers
14 (Pickard 2018) and 6304 working carers (Pickard 2015), respectively. One study aimed to
15 evaluate the causal association between 'replacement care' and carers' employment in
16 carers who were employed in the public sector in England (Pickard 2018). The aim of the
17 other study was to assess the effectiveness of paid services in supporting unpaid carers'
18 employment in England, by examining the association between the use of paid social care
19 services by the cared-for person and the employment rates of unpaid carers (Pickard 2015).

20 **Qualitative component of the review**

21 From the search for qualitative studies for this review, 9 qualitative studies were identified
22 (Arksey 2003, Arksey 2005, Bernard 2007, Carmichael 2008, Pickard 2018, Seddon 2004,
23 Sempik 2014, Vickerstaff 2009, and Yeandle 2007). Two further papers were used only for
24 data collection (Arksey 2007, and Arksey 2008) as they included the same study's population
25 (n=80 carers and 59 health and social care professionals) as reported in Arksey, 2005.

26 Table 3 provides a summary of the included qualitative evidence. The 9 qualitative analyses
27 aimed to examine what employment supports are needed for carers currently in work or
28 those who are currently caring or have recently ended a spell of caring and want to return to
29 paid employment. These studies concentrated on experiences, acceptability, barriers and
30 facilitators of carers, who had given up work to care; or who, as carers, were finding it difficult
31 to enter or return to work.

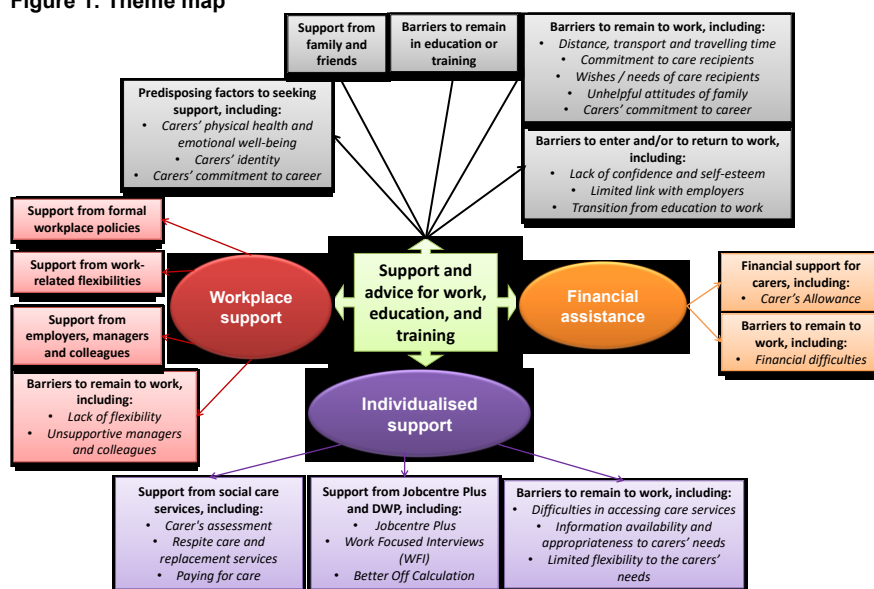
32 Six of the included studies were published before 2008 (Arksey 2003, Arksey 2005, Bernard
33 2007, Carmichael 2008, Seddon 2004, and Yeandle 2007) and included a study population
34 of adult carers, with only 2 studies including both adult carers and health and social care
35 professionals (Seddon 2004, and Arksey 2005), and 1 study including young adult carers
36 (Sempik 2014).

37 The majority of included qualitative studies collected data via semi-structured or unstructured
38 interviews, with only 1 study that used an online survey questionnaire (Sempik 2014). Data
39 analysis methods included content analysis and thematic analysis, with the latter being the
40 most common method across included studies. All studies were conducted in the UK:

- 41 • Four studies took place in North England (Arksey 2003; Carmichael 2008 and Arksey
42 2005), and 1 in Central England (Bernard 2007); or in England nation-wide (Pickard
43 2018).
- 44 • Three studies were conducted throughout the UK (Sempik 2014; Yeandle 2007; and
45 Vickerstaff 2009).
- 46 • And 1 study in Wales (Seddon 2004).

1 As shown in the theme map (Figure 1), the concepts identified in the included evidence have
 2 been explored in a number of central themes and subthemes.

3 **Figure 1: Theme map**



4 **Excluded studies**

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

7 **Summary of studies included in the evidence review**

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

10 **Quantitative component of the review**

11 **Table 2: Summary of included quantitative studies**

Study	Details	Participants	Intervention groups evaluated (as named in the paper) ^A	Comparison (in the review)
Boezeman 2018	<p>Setting Netherlands</p> <p>Study type RCT</p> <p>Aim of the study The aims of this RCT was to compare the effectiveness of a role-focused self-</p>	<p>N = 128</p> <p>Carer characteristics:</p> <ul style="list-style-type: none"> Mean Age – years, Mean (SD): <ul style="list-style-type: none"> I = 51.3 (7.10) C = 50.9 (7.30) Gender (M/F - N): 	<ul style="list-style-type: none"> I = Role-focused self-help course (that is E-book plus a non-obligatory internet support module) C = Waiting list control (Control group carers received the self- 	<ul style="list-style-type: none"> Interventions, tools or approaches for improving carers' ability to enter, remain or return to education or training

Study	Details	Participants	Intervention groups evaluated (as named in the paper) ^A	Comparison (in the review)
	help intervention (to support carers who suffered stress because they combine paid work with informal caregiving) to a wait list control Study dates 2015 to 2016 Follow-up 1 and 2 months	<ul style="list-style-type: none"> o I = 8/57 o C = 5/58 Care recipient characteristics: <ul style="list-style-type: none"> • Condition: Dementia 	help course after follow-up measurements)	
Pickard 2018	Setting UK Study type Longitudinal observational study Aim of the study The aims of this mixed-methods research were to evaluate causal association between 'replacement care' and carers' employment in carers who were employed in the public sector in England Study dates 2012 to 2015 Follow-up N/A	N = 166 Carer characteristics: <ul style="list-style-type: none"> • Mean age – years (%): <ul style="list-style-type: none"> o <35: 3.7 o 35 to 44: 14.2 o 45 to 54: 50.6 o 55 to 64: 31.5 • Gender (M/F – N): 27/139 Care recipient characteristics: <ul style="list-style-type: none"> • Condition: N/R 	<ul style="list-style-type: none"> • Dependent variable: <ul style="list-style-type: none"> o carer's employment • Independent variables: <ul style="list-style-type: none"> o receipt of 'key services' by the care recipient o characteristics of the carer o carer's work o characteristics of care provided o and the care-recipient's characteristics 	• Individualised support
Pickard 2015	Setting UK Study type Cross-sectional observational study Aim of the study The aims of this quantitative observational research were to explore the effectiveness of paid services in supporting unpaid carers' employment in England Study dates 2009 to 2010 Follow-up N/A	N = 6304 Carer characteristics: <ul style="list-style-type: none"> • Mean age – years: 53,7 • Gender (M/F – N): 2198/4106 Care recipient characteristics: <ul style="list-style-type: none"> • Condition: N/R 	<ul style="list-style-type: none"> • Dependent variable: <ul style="list-style-type: none"> o carer's employment • Independent variables: <ul style="list-style-type: none"> o receipt of 'key services' by the care recipient o characteristics of the carer o carer's work o characteristics of care provided o and the care-recipient's characteristics 	• Individualised support

1 A: This column displays 1) the intervention groups evaluated for the RCT, and 2) the main features for the dependent and the independent variables evaluated in the observational studies

2

1

2 See appendix D for full evidence tables.

3 Qualitative component of the review

4 Table 3: Summary of included qualitative studies

Study	Participants	Methods	Themes
<p>Arksey 2003</p> <p>Aim of the study The aims of this mixed-methods research were to evaluate People into Employment (PIE), a pilot employment project in the north-east of England designed to support people with disabilities, carers and former carers in gaining mainstream work</p>	<p>Carers</p> <ul style="list-style-type: none"> • N = 28 adult carers <ul style="list-style-type: none"> ○ Age= not reported ○ Gender (n)-M/F= not reported ○ Caring and working/Caring and not working (n): not reported <p>Professionals</p> <ul style="list-style-type: none"> • N = 0 	<p>Data collection: 2001</p> <p>Data collection & analysis:</p> <ul style="list-style-type: none"> ○ Data were collected through (face-to-face and telephone) semi-structured interviews ○ The analysis used a framework approach (Ritchie and Spencer 1994) 	<ul style="list-style-type: none"> • Limited flexibility to the carers' needs (Difficulties in accessing social services support) • Lack of confidence and self-esteem
<p>Arksey 2005</p> <p>Aim of the study The aims of this qualitative research were to assess the effectiveness of financial (Carer's Allowance) and labour market support (Job Centre Plus) in England to encourage carers to work. This article is complementary to the evidence presented in Arksey (2007) and Arksey (2008)</p>	<p>Carers</p> <ul style="list-style-type: none"> • N = 80 adult carers <ul style="list-style-type: none"> ○ Age= range (years): 25 to 64 ○ Gender (n)-M/F= 22/58 ○ Caring and working/Caring and not working (n): 43/37 <p>Professionals</p> <ul style="list-style-type: none"> • N = 59 	<p>Data collection: 2004</p> <p>Data collection & analysis:</p> <ul style="list-style-type: none"> ○ Data were collected through (face-to-face and telephone) semi-structured interviews and focus group ○ The analysis used a framework approach (Ritchie and Spencer 1994) 	<ul style="list-style-type: none"> • Difficulties in accessing services (Difficulties in accessing social services support) • Information availability and appropriateness to carers' needs (Difficulties in accessing social services support) • Working hours and Flexibility • Unsupportive managers & colleagues • Financial difficulties • Distance, transport and travelling time • Commitment to care recipient (Barriers to remain work) • Wishes and/or needs of care recipients (Barriers to remain work) • Carers' physical health and emotional well-being • Carers' personal factors (for example identity, commitment to career) • Carer's assessment (Support from social care services) • Limited opportunities to discuss carers' employment issues

Study	Participants	Methods	Themes
			<ul style="list-style-type: none"> • Jobcentre Plus • Better Off Calculation • Financial support for carers (for example Carer's Allowance) • Formal workplace policies • Supportive employers, managers and colleagues
<p>Bernard 2007</p> <p>Aim of the study The aims of this qualitative research were to explore how working carers and managers in two public sector organizations combined their work and caring responsibilities, and to explore to what extent existing family-friendly policies were being utilised</p>	<p>Carers</p> <ul style="list-style-type: none"> • N = 48 adult carers ○ Age= mean age - range (years): 51 - 32 to 70 ○ Gender (n)-M/F= 8/40 ○ Caring and working/Caring and not working (n): 48/0 <p>Professionals</p> <ul style="list-style-type: none"> • N = 0 	<p>• Data collection: 2000/2</p> <p>• Data collection & analysis:</p> <ul style="list-style-type: none"> ○ Data were collected through semi-structured interviews ○ No details are reported about the data analysis 	<ul style="list-style-type: none"> • Distance, transport and travelling time • Unhelpful attitudes of family or friends • Work-related flexibility and help • Supportive employers, managers and colleagues • Support from family and friends
<p>Carmichael 2008</p> <p>Aim of the study The aims of this qualitative research were to consider the impact that caring responsibilities have on carers' employment in England</p>	<p>Carers</p> <ul style="list-style-type: none"> • N = 30 adult carers ○ Age= range (years): 45 to 65 ○ Gender (n)-M/F= 5/25 ○ Caring and working/Caring and not working (n): 30/0 <p>Professionals</p> <ul style="list-style-type: none"> • N = 0 	<p>• Data collection: 2015</p> <ul style="list-style-type: none"> ○ Data collection & analysis: Data were collected through a (self-administered) questionnaires (n=264) and semi-structured interviews (n=26) ○ No details are reported about the data analysis, even though it seems that a thematic analysis has been used 	<ul style="list-style-type: none"> • Working hours and Flexibility • Financial difficulties • Commitment to care recipient (Barriers to remain work) • Wishes and/or needs of care recipients (Barriers to remain work) • Factors related to the carer: commitment to career (Barriers to obtain work or to return work) • Carers' personal factors (for example identity, commitment to career) • Financial support for carers (for example Carer's Allowance)
<p>Pickard 2018</p> <p>Aim of the study The aims of this mixed-methods research were to consider the qualitative experiences of working carers (working in the public sector) to improve the understanding of the</p>	<p>Carers</p> <ul style="list-style-type: none"> • N = 40 adult carers ○ Age= range (years): 25 to 64 ○ Gender (n)-M/F= 8/32 ○ Caring and working/Caring and not working (n): 40/0 <p>Professionals</p> <p>N = 0</p>	<p>• Data collection: 2005</p> <ul style="list-style-type: none"> ○ Data collection & analysis: Data were collected through telephone semi-structured interviews ○ The main analytical technique applied to this data was 	<ul style="list-style-type: none"> • Difficulties in accessing services • Information availability and appropriateness to carers' needs • Support from social care services

Study	Participants	Methods	Themes
mechanisms by which services for the care-recipient may help carers to combine care and work		inductive thematic analysis	
<p>Seddon 2004</p> <p>Aim of the study The aims of this qualitative research were to consider the qualitative experiences of family carers for older people who are in employment, paying particular attention to their support needs</p>	<p>Carers</p> <ul style="list-style-type: none"> • N = 46 adult carers ○ Age= mean age - range (years): 51 - 26 to 63 ○ Gender (n)-M/F= Not reported ○ Caring and working/Caring and not working (n): 46/0 <p>Professionals</p> <ul style="list-style-type: none"> • N = 40 	<p>• Data collection: Not reported</p> <p>• Data collection & analysis:</p> <ul style="list-style-type: none"> ○ Data were collected through semi-structured interviews. ○ The main analytical technique applied to this data was latent content analysis 	<ul style="list-style-type: none"> • Information availability and appropriateness to carers' needs (Difficulties in accessing social services support) • Limited link with employers • Carer's assessment (Support from social care services) • Timing and setting for carers' assessment
<p>Sempik 2014</p> <p>Aim of the study The aims of this qualitative research were to explore the experiences and perceptions of carers who are in employment, or not in employment, education or training (NEET)</p>	<p>Carers</p> <ul style="list-style-type: none"> • N = 77 young adult carers ○ Age= mean age (years): 21 ○ Gender (n)-M/F= 15/62 ○ Caring and working/Caring and not working (n): 39/38 <p>Professionals</p> <ul style="list-style-type: none"> • N = 0 	<p>• Data collection: 2013</p> <p>• Data collection & analysis:</p> <ul style="list-style-type: none"> ○ Data were collected as part of an online survey questionnaire. ○ No details are reported about the data analysis 	<ul style="list-style-type: none"> • Difficulties in balancing education/training and care • Working hours and Flexibility • Unsupportive managers & colleagues • Transition from education to work
<p>Vickerstaff 2009</p> <p>Aim of the study The aims of this qualitative research were to examine what employment supports are needed for carers currently in work or those who are currently caring or have recently ended a spell of caring and want to return to paid employment</p>	<p>Carers</p> <ul style="list-style-type: none"> • N = 55 adult carers ○ Age= Under 50/Over 50 years (n): 24/31 ○ Gender (n)-M/F= 13/42 ○ Caring and working/Caring and not working (n)/former carers: 26/16/13 <p>Professionals</p> <ul style="list-style-type: none"> • N = 0 	<p>• Data collection: 2007</p> <p>• Data collection & analysis:</p> <ul style="list-style-type: none"> ○ Data were collected through semi-structured interviews ○ The interviews were coded interpretively for references to factors affecting continued working or ability to return to work and respondents' experience of the support and help they received from informal and formal sources 	<ul style="list-style-type: none"> • Information availability and appropriateness to carers' needs • Unsupportive managers & colleagues • Financial difficulties • Distance, transport and travelling time • Unhelpful attitudes of family or friends • Factors related to the carer: commitment to career (Barriers to obtain work or to return work) • Carers' physical health and emotional well-being • Carers' personal factors (for example identity, commitment to career) • Respite care (Support from social care services) • Paying for care • Voluntary organisations

Study	Participants	Methods	Themes
			<ul style="list-style-type: none"> • Jobcentre Plus • Work Focused Interviews • Better Off Calculation • Financial support for carers (for example Carer's Allowance) • Work-related flexibility and help • Supportive employers, managers and colleagues • Support from family and friends
<p>Yeandle 2007</p> <p>Aim of the studyThe aims of this qualitative research were to explore how services are used by carers of working age to support them in managing caring alongside paid employment, and to explore the situation and perspectives of those who have given up work to care, or who, as carers, are finding it difficult to enter or return to work</p>	<p>Carers</p> <ul style="list-style-type: none"> • N = 143 adult carers ○ Age= not reported ○ Gender (n)-M/F= not reported ○ Caring and working/Caring and not working (n): 93/50 <p>Professionals</p> <ul style="list-style-type: none"> • N = 0 	<ul style="list-style-type: none"> • Data collection: 2006/7 • Data collection & analysis: <ul style="list-style-type: none"> ○ Data were collected through semi-structured interviews ○ Data were analysed using thematic analysis 	<ul style="list-style-type: none"> • Information availability and appropriateness to carers' needs (Difficulties in accessing social services support) • Limited flexibility to the carers' needs (Difficulties in accessing social services support) • Limited flexibility to the carers' needs (Difficulties in accessing social services support) • Working hours and flexibility • Factors related to the carer: commitment to career (Barriers to obtain work or to return work) • Wishes of care recipients (Barriers to obtain work or to return work) • Carers' personal factors (for example identity, commitment to career) • Respite care • Financial support for carers (for example Carer's Allowance) • Supportive employers, managers and colleagues • Support from family and friends

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

2 See the full evidence tables in appendix D.

3

1 Quality assessment of studies included in the evidence review

2 See the evidence profiles in appendix F.

3 Economic evidence

4 Included studies

5 A systematic review of the economic literature was conducted but no studies were identified
6 which were applicable to this review question.

7 Excluded studies

8 Studies not included in this review with reasons for their exclusion are listed in Appendix K –
9 Excluded studies.

10 Summary of studies included in the economic evidence review

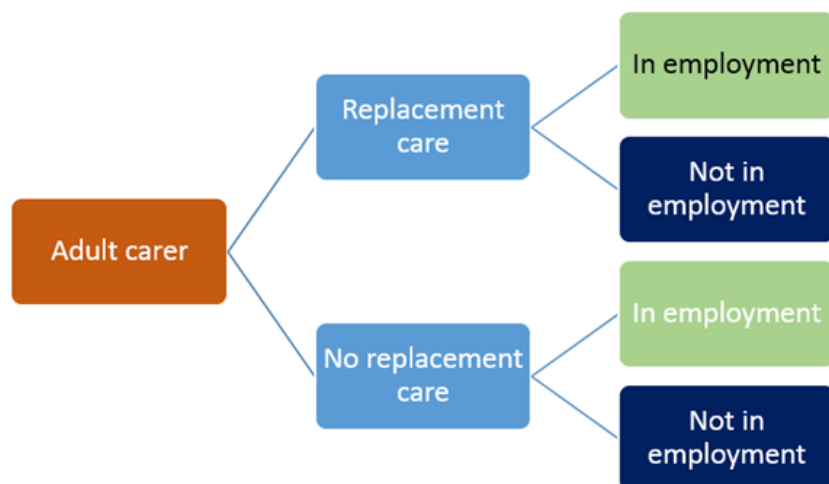
11 No economic evidence was identified for this review (and so there are no economic evidence
12 tables)

13 Economic model

14 No new economic evidence was identified for this review and therefore an original model was
15 developed for this guideline update to evaluate the the costs and cost-utility of replacement
16 care provided to adult carers to support them to return to work. The model is summarised
17 below with full details available in appendix J.

18 The model compared an intervention of replacement care for adult carers not working
19 because caring to no replacement care, as illustrated in Figure 2 below.

Figure 2: Replacement care model decision tree



1 The model used national statistics and other published data to estimate the number of adult
2 carers not working because caring across age categories of 18-24 years, 25-49 years, 50-64
3 years and 65 years and older. Using published data on the likelihood of being in employment
4 according to hours of caring, the model was able to estimate the number of adult carers who
5 would return to work for a given number of hours of replacement care per week. In the base
6 case analysis it was assumed that 1 hour of replacement care would be provided per week
7 but sensitivity analysis explored the impact of greater provision of replacement care.

8 Costing was undertaken from a societal perspective and in addition to the costs of
9 replacement care the model also took into account savings to the public sector from higher
10 tax receipts and reduced welfare payments as well as increased economic output in the
11 formal labour market arising from a return to work. A time horizon of 1-year was chosen
12 primarily for ease of exposition. The model treats the number of carers out of work as a result
13 of caring as a “stock. It does not model “flows” into and out of a caring role other than as a
14 function of the number of hours caring. As the intervention would be on-going the relationship
15 between costs and outcomes over time would be a linear one.

16 Although there was no published data linking hours of caring to health state utility it has been
17 suggested that those with caring responsibilities do experience poorer health compared to
18 those not caring. Therefore a “what-if” cost-utility analysis was undertaken alongside the
19 costing to recognise that the provision of replacement care could potentially improve health
20 related quality of life in addition to well-being more generally.

21 The base case results estimated that the provision of 1 hour of replacement care per week to
22 adult carers not working would result in 39,914 adult carers returning to work for a net
23 societal benefit of £302 million or an average of £1,412 per recipient of care. The “what-if”
24 cost-utility analysis suggested that replacement care would dominate not providing
25 replacement care with higher QALYs and a net societal benefit. Sensitivity analysis
26 suggested that providing up to a maximum of approximately 15 hours of replacement care
27 could be cost-effectiveness. A Tornado analysis showed that model results were particularly
28 sensitive to the cost of replacement care.

29 The model has a number of limitations and, in particular, the effectiveness of replacement
30 care is not based on a randomised study design. To assess the impact replacement care has
31 on the probability of work, the analysis assumes that, by reducing the number of hours spent
32 caring by the provision of replacement care, the carer would have the same probability of
33 being in work as somebody who was doing that number of hours caring without the provision
34 of replacement care. However, it may be that there are systematic differences between
35 carers providing different amounts of care which mean they would have different labour
36 market participation rates as a result of less hours caring. Subject to these limitations in the
37 evidence, this analysis suggested that replacement care could be cost-effective when
38 provided to adult carers not working because caring. Other groups of adult carers were not
39 explicitly addressed in the model but the more general principle that replacement care can be
40 expected to make a positive contribution to human capital applies.

41 Evidence statements

42 Each evidence statement has an identifying code to ensure ease of reference to the data
43 during presentation and committee discussions. The code is derived from the title of the
44 review and in this case is ‘ETW’ and then a number. ETW stands for education, work and
45 training.

1 **Quantitative and qualitative components of the review.**

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

5 **Return to work plans**

- 6 • **ETW1** No evidence (neither quantitative nor qualitative) was identified about this
7 intervention category

8 **Workplace support**

9 **Short and long-term employment**

- 10 • **ETW2** No data reporting on this outcome

11 **Short and long-term carer quality of life**

- 12 • **ETW3** No data reporting on this outcome

13 **Productivity**

- 14 • **ETW4** No data reporting on this outcome

15 **Financial issues or burden**

- 16 • **ETW5** No data reporting on this outcome

17 **Carer mental health**

- 18 • **ETW6** No data reporting on this outcome

19 **Qualitative themes**

- 20 • **ETW7 Support from formal workplace policies.** There is very low quality evidence from
21 1 UK study that some adult carers described how their organisation had invited them to
22 register their caring role with their manager so it could be taken into account should a
23 problem ever arise. In some carers' and employers' view, this was useful because it
24 helped ensure that carers were identified as a specific group, it recognised their existence
25 and it prevented them from remaining invisible.

- 26 • **ETW8 Support from work-related flexibilities.** There is moderate quality evidence from
27 three UK studies that some workplace-related actions would help carers to work while
28 caring. Carers felt that flexibility in relation to days/hours worked, and working at home,
29 would help them deal with emergencies and planned appointments.

- 30 • **ETW9 Support from employers, managers and colleagues.** There is moderate quality
31 evidence from four UK studies that many adult carers valued supportive and
32 understanding managers and colleagues; this could lead to good working relationships
33 and meant the carer knew where they stood in terms of formal and informal flexibility.

- 34 • **ETW10 Barriers to remain to work: lack of flexibility.** There is moderate quality
35 evidence from 5 UK studies that many adult carers felt the lack of flexibility in work hours
36 and practices was a particular problem. Several carers emphasised the importance of
37 working part-time to allow them to combine working and caring. In addition, some carers
38 expressed specific needs within the workplace that, although relatively simple for
39 employers to administer, were not always met and this made their lives difficult (like
40 having a mobile phone). The same evidence also suggests that adult carers working in
41 private sector organisations had difficulty managing time boundaries at work (this is in
42 contrast to public or voluntary organisations).

- 43 • **ETW11 Barriers to remain to work: unsupportive managers and colleagues.** There is
44 moderate quality evidence from 3 UK studies that many adult carers perceived, often
45 based on experience, that employers would view their caring responsibilities as an

1 unwelcome intrusion. The result of this situation, and often hiding their true circumstances
2 from employers was stress, often accompanied by feelings of guilt.

3 **Individualised support**

4 **Short and long-term employment**

5 • **ETW12** There is low quality evidence that many paid services for the cared-for person are
6 positively associated to women carers' employment. A cross-sectional study including
7 4104 women carers in the UK found a significant association between the employment
8 rate of women carers and care-recipients' use of services:

- 9 – of home care only
- 10 – of day care only
- 11 – of personal assistant only
- 12 – of meals-on-wheels only
- 13 – of home care and day care
- 14 – of day care and care home
- 15 – of day care and personal assistant
- 16 – of meals-on-wheels and homecare
- 17 – of home care, day care and care home
- 18 – of home care, day care and personal assistant
- 19 – of other combination of services

20 • **ETW13** There is low quality evidence that many paid services for the cared-for person are
21 positively associated to men carers' employment. A cross-sectional study including 2198
22 men carers in the UK found a significant association between the employment rate of men
23 carers and care-recipients' use of services:

- 24 – of home care only
- 25 – of personal assistant only
- 26 – of home care and day care
- 27 – of home care and care home
- 28 – of meals-on-wheels and homecare
- 29 – of other combination of services

30 • **ETW14** There is low quality evidence from 1 UK longitudinal study that when the care-
31 recipient did not receive at least one 'key service ' (that is home care/personal assistant,
32 day care, meals and/or short-term breaks), the carer was subsequently more likely to
33 leave employment because of caring.

34 • **ETW15** There is low quality evidence from 1 UK longitudinal study that when a working
35 carer was aged 53 years and over, provided care (to the care recipient) for 20 or more
36 hours a week at baseline, or cared for two or more people, the carer was subsequently
37 more likely to leave employment because of caring.

38 **Short and long-term carer quality of life**

39 • **ETW16** No data reporting on this outcome

40 **Productivity**

41 • **ETW17** No data reporting on this outcome

42 **Financial issues or burden**

43 • **ETW18** No data reporting on this outcome

44 **Carer mental health**

45 • **ETW19** No data reporting on this outcome

1 Qualitative themes

- 2 • **ETW20 Support from social care services: carers' assessment.** There is very low
3 quality evidence from 2 UK studies about the perceived support from carers at the
4 moment of their needs' assessment. This evidence pointed to the limited opportunities to
5 discuss carers' employment issues during the course of the carers' assessment and to the
6 fact that the timing and setting for assessments should be flexible to accommodate the
7 needs of carers in employment.
- 8 • **ETW21 Support from social care services: respite care and replacement care**
9 **services.** There is low quality evidence from 3 UK studies that many adult carers felt that
10 the services and support they had in place (including respite care and replacement care
11 services) were very beneficial to improve their ability to remain in, or return to, work.
- 12 • **ETW22 Support from social care services: paying for care.** There is very low quality
13 evidence from 2 UK studies on the positive perceptions of working carers about a number
14 of financial benefits (provided by social services departments) to buy in their own care;
15 including vouchers for carers, direct payments or welfare benefits.
- 16 • **ETW23 Support from Jobcentre Plus and DWP.** There is low quality evidence from 2
17 UK studies that many adult carers have mixed views about their experiences with
18 Jobcentre Plus. On one hand, they reported that advisers gave carers useful advice in
19 relation to, say, claiming benefits such as Carer's Allowance or Jobseeker's Allowance
20 (JSA). In contrast carers expressed a need for someone in Jobcentre Plus with specific
21 expertise on carers, and who are able to understand or offer the kind of flexible jobs that
22 carers need.
- 23 • **ETW24 Support from 'Work Focus Interview'.** There is low quality evidence from 2 UK
24 studies that adult carers who experienced a Work Focus Interview (WFI) did not find it
25 particularly useful; carers reported that WFIs tended to be short and the discussions with
26 a personal adviser were unlikely to influence carers' decisions about obtaining paid work.
- 27 • **ETW25 Support from 'Better Off Calculation'.** There is low quality evidence from 2 UK
28 studies that some adult carer who experienced a 'Better Off Calculation' felt slightly
29 affronted by the experience of having such support, as they had not gone back to work for
30 the money.
- 31 • **ETW26 Barriers to remain to work: difficulties in accessing care services.** There is
32 low quality evidence from 2 UK study that adult carers' perceptions on the availability of
33 services, together with the way in which they were provided, influenced their decisions
34 about whether, when and how much to work. In addition, paperwork, bureaucracy and red
35 tape emerged as key obstacles that inhibited carers' use of services.
- 36 • **ETW27 Barriers to remain to work: information availability and appropriateness to**
37 **carers' needs.** There is moderate quality evidence from 5 UK studies that adult carers
38 experienced difficulties in accessing services. These difficulties were associated with the
39 limited information on support services, carer problems in understanding and assimilating
40 this information and carers' limited time and energies to identify sources of support.
41 Additionally, many adult carers identified the fragmented nature of the 'support system'
42 and the fact that they have to go to a number of different agencies to get information as
43 factors inhibiting their use of services.
- 44 • **ETW28 Barriers to remain to work: limited flexibility to the carers' needs.** There is
45 very low quality evidence from 2 UK studies that many adult carers believe the number
46 and timing of appointments they were required to attend hindered or disrupted their work
47 routines. Some carers experienced this as a conflict between work and care or a barrier to
48 employment and felt appointments could be arranged to be more sensitive to their needs
49 at work.

50 Financial assistance

51 Short and long-term employment

- 52 • **ETW29**No data reporting on this outcome

1 **Short and long-term carer quality of life**

- 2 • **ETW30** No data reporting on this outcome

3 **Productivity**

- 4 • **ETW31** No data reporting on this outcome

5 **Financial issues or burden**

- 6 • **ETW32** No data reporting on this outcome

7 **Carer mental health**

- 8 • **ETW33** No data reporting on this outcome

9 **Qualitative themes**

- 10 • **ETW34 Support from 'Carer's Allowance'**. There is moderate quality evidence from 4
11 UK studies that adult carers who experienced 'Carer's Allowance' sometimes found this
12 benefit complex to access and use, inflexible in terms of application rules, and of relatively
13 low monetary value.
- 14 • **ETW35 Barriers to remain to work: financial difficulties**. There is moderate quality
15 evidence from four UK studies that the decisions made by many adult carers centred on
16 finances (balancing their caring responsibilities and financial hardship), in particular the
17 necessity to earn 'good' salaries and plan retirement. Also, carers reported that their
18 decision to give up work to care was not an easy one, since it puts them under
19 considerable financial pressure.

20 ***Interventions, tools or approaches to improve carers' education, or provide training
21 opportunities/work placements for carers***

- 22 • **ETW36** No evidence (neither quantitative nor qualitative) was identified about this
23 intervention category

24 ***Interventions, tools or approaches for improving carers' ability to enter, remain or return
25 to education or training***

26 **Short and long-term employment**

- 27 • **ETW37** No data reporting on this outcome

28 **Short and long-term carer quality of life**

- 29 • **ETW38** No data reporting on this outcome

30 **Productivity**

- 31 • **ETW39** No data reporting on this outcome

32 **Financial issues or burden**

- 33 • **ETW40** No data reporting on this outcome

34 **Carer mental health**

- 35 • **ETW41** Low quality evidence from 1 RCT from the Netherlands, including 128 adult carers
36 who suffered stress because they combine paid work with informal caregiving, found
37 improved levels of perceived stress and distress in carers receiving a role-focused self-
38 help intervention versus those who received the same intervention after 2 months (Wait
39 list control) at 1 and 2 months follow-up

40 **Qualitative themes**

- 41 • **ETW42** No qualitative evidence was identified about this intervention category

1 Work-specific carer passports.

- 2 • **ETW43** No evidence (neither quantitative nor qualitative) was identified about this
3 intervention category

4 Other qualitative themes

- 5 • **ETW44 Predisposing factors to seeking support: carers' physical health and**
6 **emotional well-being** There is very low quality evidence from 1 UK study that many adult
7 carers felt paid work contributed to their sense of self-esteem, physical health and
8 emotional well-being. This could be a predisposing factor to seeking support to enter or
9 remain in work.
- 10 • **ETW45 Predisposing factors to seeking support: identity.** There is low quality
11 evidence from 2 UK studies that many adult carers felt that their decision about whether to
12 take on a caring role, was influenced by the extent to which they identified themselves as
13 primarily a worker or a carer.
- 14 • **ETW46 Predisposing factors to seeking support: commitment to career.** There is
15 moderate quality evidence from four UK studies that many adult carers felt their
16 opportunities for career development were restricted because of their caring
17 responsibilities.
- 18 • **ETW47 Support from family or friends.** There is low quality evidence from three UK
19 studies that many adult carers praised the majority of relatives and friends for providing
20 practical support, for relieving them so they can go out to work or help out in emergencies.
- 21 • **ETW48 Barriers to remain in education or training.** There is very low quality evidence
22 from 1 UK study that many young adult carers would like more support from their teachers
23 and schools in order to balancing education/training needs and caring duties.
- 24 • **ETW49 Barriers to remain in work: distance, transport and travel time difficulties.**
25 There is moderate quality evidence from three UK studies that many adult carers gave
26 serious consideration to the practicalities of getting to the workplace and back in decisions
27 about paid work. Distances between work and home and lengthy travel times raised real
28 challenges.
- 29 • **ETW50 Barriers to remain in work: commitment to care recipient.** There is very low
30 quality evidence from 2 UK studies that many adult carers often give up paid work
31 because they didn't believe that it was compatible with their caring role or because
32 combining caring and employment would be too difficult or stressful.
- 33 • **ETW51 Barriers to remain in work: wishes and/or needs of care recipients.** There is
34 very low quality evidence from 2 UK studies that the wishes and/or needs of care
35 recipients influenced carers' decisions about working and caring.
- 36 • **ETW52 Barriers to remain in work: unhelpful attitudes of family.** There is very low
37 quality evidence from 2 studies that many adult carers perceived a lack of interest of
38 negative attitudes among their family.
- 39 • **ETW53 Barriers to remain to work: commitment to career.** There is moderate quality
40 evidence from 3 UK studies that carers' opportunities for career development were
41 restricted because of their caring responsibilities. Many adult carers in professional jobs
42 were committed to their careers; and as a consequence, they were unwilling to lose the
43 investment they had built up over their working life.
- 44 • **ETW54 Barriers to enter and/or to return to work: lack of confidence and self-**
45 **esteem.** There is very low quality evidence from 1 UK study that many adult carers and
46 agency staff felt that the lack of confidence and self-esteem among carers was a potential
47 barrier to attending job interviews.
- 48 • **ETW55 Barriers to enter and/or to return to work: limited link with employers.** There
49 is very low quality evidence from 1 qualitative study from the UK that local authority staff
50 reported that developments in employment practice for carers occur in isolation from

- 1 health and social care initiatives. Links between statutory service providers and employers
2 were deemed to be limited and appear to be forged on an ad hoc basis.
- 3 • **ETW56 Barriers to enter and/or to return to work: transition from education to work.**
4 There is very low quality evidence from 1 UK study that young adult carers felt that they
5 had not received good career advice at school; and that the advice did not consider their
6 caring role. This could be an impeding factor to enter work or training from school.

7 **Economic component of the review**

- 8 • **ETW57** Evidence from the guideline economic analysis suggested that replacement care
9 for adult carers not working because caring could be cost saving from a societal
10 perspective up to a maximum of 15 hours replacement care per adult carer per week. The
11 economic analysis is directly applicable to the NICE decision-making context and is
12 characterised by serious limitations.

13 **The committee's discussion of the evidence**

14 **Interpreting the evidence**

15 **The outcomes that matter most**

- 16 This evidence review includes both qualitative and quantitative outcomes.
- 17 Short and long-term employment or course attendance (relative to level of education/training)
18 were considered to be critical outcomes for the quantitative component for this question.
19 Carer quality of life, productivity, household income/financial issues, and carer mental health
20 were considered to be the important outcomes, when discussing the evidence and drafting
21 recommendations. Quantitative evidence was identified only in relation to short and long term
22 employment, and carer mental health.
- 23 The committee focussed their discussion mainly on the following 11 qualitative outcomes (or
24 themes): workplace support for a carer to enter, remain in, or return to work (including
25 support from formal workplace policies, support from work-related flexibilities, and support
26 from employers, managers and colleagues); workplace-related barriers for carers to remain
27 in work (including the lack of flexibility, and unsupportive managers and colleagues);
28 individualised support for carers from social care services (including support resulting from
29 carers' assessment, support from respite care and replacement services, and paying for
30 care); individualised support for carers from Jobcentre Plus and the Department for Work
31 and Pensions (including Jobcentre Plus, Work Focused Interviews, and the 'Better Off
32 Calculation'); individual support-related barriers for carers to remain in work (including
33 difficulties in accessing care services, the lack of information and appropriateness to carers'
34 needs of services, the limited flexibility of available support); financial support for carers
35 (including 'Carer's Allowance'); predisposing factors for carers to seek support (including
36 carers' physical health and emotional well-being, and carers' personal factors –such as
37 identity and commitment to their career); support from family and friends; barriers to remain
38 in education or training, additional barriers for carers to remain to work (including distance,
39 transport and travelling time, carers' commitment to the care recipient, wishes and/or needs
40 of care recipients, unhelpful attitudes among families, and carers' commitment to career
41 development); and barriers for carers to enter and/or to return to work (including the lack of
42 confidence and self-esteem, limited link with employers, and the transition from education to
43 work). All of these themes were reported qualitatively.
- 44 Furthermore, the committee were aware of the carers' credit and its impact on future
45 finances but found no evidence relating specifically to this. Instead, they concentrated on the
46 financial issues for a working age carer at the time of work.

1 **The quality of the evidence**

2 In terms of quantitative evidence, only 1 RCT and 2 observational studies were included. The
3 quality of the evidence across all outcomes was rated as low (according to the GRADE
4 methodology) and was mostly downgraded because of design limitations (risk of bias) in the
5 included studies. The quality of the evidence for the outcomes evaluated in the RCT was
6 downgraded because of the high risk of attrition bias (due to amount of incomplete outcome
7 data), and high risk of other bias, such as the high risk of self-selection bias and the high risk
8 of contamination bias (because intervention adherence was not monitored and a waiting-list
9 control condition was used).

10 The evidence for the various themes identified in the qualitative review ranged from very low
11 to moderate quality (according to the GRADE-CERQual methodology) and covered a
12 number of areas. The quality of the included evidence was mostly downgraded due to
13 'adequacy of data', as there was sufficient data for only a few themes to develop an
14 understanding of the phenomenon of interest, either because of insufficient studies (offering
15 poor data) or a lack of diversity of study participants. The small number of included studies
16 (and the fact that almost none were published since 2008) was also noted by the committee
17 when drafting their recommendations. Nevertheless the committee acknowledged that the
18 populations of carers in the studies were mixed (in terms of age, gender, and conditions of
19 people cared for, and employment status). They therefore agreed that the data from the
20 included studies were applicable across the entire UK population of adult carers.

21 **Synthesis of quantitative and qualitative data**

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

25 One RCT, and 2 observational studies provided quantitative evidence about the
26 effectiveness of interventions to support adult carers to enter, remain in, and/or return to
27 work. The RCT provided low quality data about a role-focused self-help intervention, to
28 support carers who suffered stress due to combining paid work with caregiving. They
29 demonstrated small improvements in carers' stress and distress. The 2 observational studies
30 provided low quality evidence about the causal association between 'replacement care' and
31 carers' employment in carers who were employed in the public sector in England.

32 Given its overall relatively poor quality, the committee made limited use of the quantitative
33 evidence, focussing more on the strength of the qualitative component. In addition, the
34 committee supplemented the evidence with expert witness testimony supported by their
35 experience and knowledge of what information and support was likely to be of benefit to
36 carers, to enter, remain in, and/or return to work, education, and training.

37 No evidence was found on the effectiveness, the cost-effectiveness and acceptability of
38 interventions to support young adult carers during transitions, on the effects of carers'
39 assessments, and on carers' benefit traps (that is benefit payments as a barrier to returning
40 to work), so the committee did not draft any recommendations relating to these areas. They
41 agreed to recommend further research in these areas as they considered these topics of
42 high priority for research funding.

43 **Benefits and harms**

44 **Conducting carers' assessments**

45 Qualitative evidence about the conduct of carers' assessments demonstrated that little
46 attention is paid to carers' needs and wishes in relation to employment or training. The
47 committee agreed that in their experience carers would have little opportunity to discuss
48 employment issues during carers' assessments, which is why they recommended that

1 practitioners conducting assessments have knowledge and awareness about potential
2 opportunities for employment, training and education.

3 The evidence also demonstrated that the provision of replacement care enabled carers to
4 remain in or return to work. The committee therefore agreed to maximise the benefits of
5 carer's assessments through ensuring that practitioners conducting them can provide tailored
6 information about community support for returning to work.

7 **The provision of advice and information**

8 Qualitative data showed that a lack of comprehensible information combined with the
9 fragmented nature of local services made it difficult for carers to access support from health
10 and social care, which might enable them to return to or remain in employment. In discussing
11 this evidence, the committee highlighted the information giving requirement mandated by the
12 Care Act 2014. In addition, they took account of the quantitative evidence which
13 demonstrated that information for carers needs to be multi-faceted. Therefore, in order to
14 address the harmful effects of a lack of information the committee recommended that
15 information covering a range of elements should be provided in a way that shows an
16 understanding of carers' particular needs around employment and training.

17 Data from 1 study also highlighted particular disadvantages experienced by young adult
18 carers endeavouring to balance work or education with a caring role. The committee added
19 to this from their own expertise noting that carers often lack confidence about their suitability
20 for employment, especially if they have spent many years in a caring role instead of in
21 education or training. The committee therefore drafted a recommendation to overcome this
22 through providing help to carers to convey transferable skills to potential employers.

23 Furthermore, evidence from this review suggested that carers struggle to identify sources of
24 information and support. The committee believed this was relevant to the review about
25 information for carers (RQB) and drafted a recommendation that carers should be told where
26 to turn locally for support and information.

27 **Flexibilities to support employment**

28 The committee agreed that the research evidence, supported by the expert testimony
29 demonstrated harmful effects on carers who try to balance their caring role with work,
30 education or training, for example being overlooked for promotion. They also agreed that the
31 evidence showed there can be a harmful, stigmatising effect on carers when they identify
32 themselves as carers within the workplace. For these reasons the committee agreed to draft
33 recommendations about the provision of flexibilities in the work place to enable them to
34 balance caring responsibilities with employment and to ensure that advice and information
35 are available within that context. Specific suggestions for adjustments in the workplace were
36 identified from the expert witness testimony and the committee incorporated these examples
37 in the recommendations.

38 **Replacement care to support employment**

39 The committee considered the potentially harmful effect from the perspective of the care
40 recipient if their carer entered employment, training or education. The evidence found that
41 the attitude of the care recipient acted to discourage carers from pursuing opportunities for
42 work and education with the cared for person unhappy about receiving replacement care
43 from 'strangers'. In drafting recommendations about replacement care the committee tried to
44 balance the benefits of the carer entering or remaining in work with the harms of this, as
45 perceived by the care recipient. In doing so they agreed good quality replacement care
46 should be made available and that outcomes related to keeping people in work and
47 education should be taken into account in the design and delivery of these services.

1 Replacement care should also be flexible to meet the changing needs of working carers and
2 the people they support.

3 **Cost-effectiveness and resource use**

4 The committee acknowledged that there were resource implications in providing
5 interventions that would support adult carer participation in the workforce and training,
6 particularly with regard to replacement care. However, the committee believed that the costs
7 of replacement services would be more than offset by the wider productivity gains to society
8 from enhanced participation in formal employment and training. An economic analysis
9 developed for this guideline suggested that providing replacement care to adult carers, who
10 were not working because of caring, was cost-effective from a societal perspective. This was
11 because the gains from increased labour market participation outweighed the costs of
12 replacement care. The gains included increased taxation, lower welfare payments and
13 increased output in the formal economic sector. The committee also noted that their
14 recommendations for carer replacement were consistent with the Care Act (2014) which
15 includes the duty of local authorities to promote individual well-being through participation in
16 work or education.

17 More generally, using a qualitative assessment of cost-effectiveness, the committee agreed
18 that there are economic benefits to carers and wider society from interventions that facilitate
19 adult carers' workforce participation and training. This is something that has been recognised
20 as important by the UK government (HM Government, 2013) especially in the context of
21 prevailing demographic and economic pressures. There are estimated to be 3 million adult
22 carers in the UK who combine their caring duties with paid work. However, such workers,
23 who will frequently be highly skilled and experienced, may often leave employment or reduce
24 their hours as a consequence of their caring responsibilities. It has been reported that there
25 is a substantial cost to the formal economy when an employer loses a working carer.

26 The committee noted that although interventions to support workforce participation and
27 training does have resource implications for the public sector there can be multi-agency
28 involvement with the charity/voluntary sector which may be partly funded by charitable
29 funding grants.

30 The committee agreed there could be some resource implications from their
31 recommendations with respect to carer assessments, advice and information provision but
32 they noted that these recommendations largely embodied current practice and would help
33 maximise the benefit from these interventions.

34 **Other factors the committee took into account**

35 The committee heard expert testimony from a national carers' organisation and an affiliated
36 scheme focussed on improving policies and practices among employers to enable carers to
37 remain in and enter work. They heard about the significant benefits reported by employers
38 who provide work place flexibilities to ensure carers can balance the provision of support with
39 paid employment. The benefits included reduced staff turnover, absenteeism and improved
40 retention. The flexibilities described by the expert witness gave the committee a basis for
41 drafting specific recommendations to address the problems experienced by carers and
42 described in the research. For example, recommendations about the use of employment
43 flexibilities to support carers provide specific suggestions for employers to enable carers to
44 balance work with their caring responsibilities. Specific ideas include allowing the use of
45 technology to stay in touch with the person they support.

46 In addition to research evidence and expert testimony the committee also took account of
47 Care Act requirements to provide information to carers and to assess the needs of carers in
48 their own right. They did not draft a recommendation to conduct a carers' assessment,
49 instead using the research evidence to ensure those assessments are conducted in a way
50 that meets the specific needs of carers wishing to remain in or enter employment.

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1 Appendices

2 Appendix A – Review protocols

3 Review protocol for review question: What are the most effective, cost-effective and acceptable interventions, tools or 4 approaches to support adult carers to enter, remain in, and/or return to (i) work, (ii) education, and (iii) training?

5 Table 4: Review protocol for supporting adult carers to enter, remain in or return to work, education and training

Field (based on PRISMA-P)	Content
Review question	What are the most effective, cost-effective and acceptable interventions, tools or approaches to support adult carers to enter, remain in, and/or return to (i) work, (ii) education, and (iii) training?
Type of review question	Systematic mixed studies review
Objective of the review	The objective of this review is to determine what the best ways are to support adult carers to enter, remain in, and/or return to work, education, and/or training.
Eligibility criteria – population/disease/condition/issue/domain	<ul style="list-style-type: none"> • 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.
Eligibility criteria – intervention(s)/exposure(s)/prognostic factor(s)	<p>Any intervention, tool or approach whose primary aim is to support adult carers to enter, remain in, and/or return to work, including:</p> <ul style="list-style-type: none"> • Return to work plans (including paid or unpaid work) • Workplace support (for example flexible working hours) • Individualised support (for example Carers' Lead, work coach/adviser at Job Centre Plus) • Financial assistance (for example Carer's Allowance, Flexible Support Fund) • Interventions, tools or approaches to improve carers' education, or provide training opportunities/work placements for carers (including volunteering) • Interventions, tools or approaches for improving carers' ability to enter, remain or return to education or training (for example information about working rights/benefits) • Work-specific carer passports <p>Themes from the qualitative evidence regarding views and experiences of adult carers, and related professionals, may include:</p>

Field (based on PRISMA-P)	Content
	<ul style="list-style-type: none"> • Satisfaction with the intervention • Perceived appropriateness of the intervention • Perceived acceptability of the intervention • Barriers and facilitators
Eligibility criteria – comparator(s)/control or reference (gold) standard	<p>For studies evaluating the effectiveness of an intervention:</p> <ul style="list-style-type: none"> • No intervention • Different types of intervention, tool, or approach within each category
Outcomes and prioritisation	<p>Outcomes relevant to determining the effectiveness of interventions are:</p> <ul style="list-style-type: none"> • Short and long-term carer quality of life (for example ASCOT, AC-QoL, Personal Well Being Index), including carer satisfaction/experience • Short and long-term employment (for example 2 years) or course attendance (relative to level of education/training) as measure for sustainability of, or ability to remain in work etc. • Productivity (for example number of days person remains in or is absent from work/education/training) • Household income/financial issues or burden • Carer mental health (include only measures that assess anxiety, depression, or stress/emotional wellbeing) <p><i>For the relevant outcomes above, only validated scales will be included.</i></p> <p>Results of the qualitative evidence synthesis will be determined by thematic analysis and the use, if appropriate, of thematic maps.</p> <p>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.</p>
Eligibility criteria – study design	<p>No restrictions on study designs will be made. That is, quantitative, qualitative, and mixed methods studies will all be considered.</p> <p>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.</p> <p>References</p> <ul style="list-style-type: none"> • Muir Gray, JM. (1996). Evidence-based healthcare. London, UK: Churchill Livingstone.
Other inclusion exclusion criteria	<p><i>Additional inclusion criteria</i></p> <ul style="list-style-type: none"> • 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

Field (based on PRISMA-P)	Content
	<ul style="list-style-type: none"> Only studies from the following geographical areas/countries will be included: UK, Australia, Canada, Europe, Japan, New Zealand, South Africa, and USA. Studies from other countries will not be included because substantial differences in their carer populations and/or social-/health-care systems. 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 <p><i>Exclusion criteria</i></p> <ul style="list-style-type: none"> 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 <p>A step-wise approach to the included evidence will be used if required: although only studies published in or after 2003 will be initially included, subsequent modifications to the inclusion criteria may be warranted, subject to ratification by the GC, if the volume of studies to examine is very high. For example, studies may be restricted to those conducted in the UK or a more recent date of publication may be used. If changes to the initial inclusion criteria are deemed necessary, reasons for these will be explicitly noted in the methods section of the guideline.</p>
Proposed sensitivity/sub-group analysis, or meta-regression	<p>Stratified/subgroup analysis</p> <ul style="list-style-type: none"> Category of intervention Adult carers providing support or who have provided support for people at the end of life <p>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</p>
Selection process – duplicate screening/selection/analysis	<p>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.</p>
Data management (software)	<p>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.</p> <p>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.</p>

Field (based on PRISMA-P)	Content
Information sources – databases and dates	<p>Sources to be searched:</p> <ul style="list-style-type: none"> ASSIA, CDSR, DARE, Embase, IBSS, Medline, Medline In-Process, PsycINFO, Sociological Abstracts, Social Services Abstracts, Social Policy and Practice <p>Filters:</p> <ul style="list-style-type: none"> Systematic review RCT Observational study Qualitative study NICE UK geographic Standard animal/non-English language exclusion <p>Limits:</p> <ul style="list-style-type: none"> Date from 2003
Identify if an update	Not applicable
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 1 database	For details please see appendix B.
Data collection process – forms/duplicate	A standardised evidence table format will be used, and published as appendix D (evidence tables) or H (economic evidence tables).
Data items – define all variables to be collected	For details please see evidence tables in appendix D (evidence tables) or H (economic evidence tables).
Methods for assessing bias at outcome/study level	<p>The following checklists will be used to assess risk of bias/quality of individual studies:</p> <ul style="list-style-type: none"> ROBIS for systematic reviews/meta-analyses of interventions studies Cochrane RoB tool v2 for (individual or cluster) RCTs; 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-after studies, (iii) interrupted time series studies, and JBI Checklist for cross-sectional studies

Field (based on PRISMA-P)	Content
	<ul style="list-style-type: none"> • 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 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	<p>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,</p> <ul style="list-style-type: none"> • Mean differences (MDs) or standardised mean differences (SMDs) for continuous outcomes, risk ratios (RRs) for dichotomous outcomes, and hazard ratios (HRs) for time to event outcomes, will be used for outcomes relevant to establishing the effectiveness of interventions. 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. <p>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.</p> <p>References Pearson, A., White, H., Bath-Hextall, F. (2015). A mixed-methods approach to systematic reviews. <i>International Journal of Evidence-based Healthcare</i>, 13: 121-131. Pluye, P., & Hong, Q. N. (2014). Combining the power of stories and the power of numbers: mixed methods research and mixed studies reviews. <i>Annual review of public health</i>, 35: 29-45.</p>
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. GRADEpro will be used to record (and assess) the quality of quantitative evidence for outcomes relevant to establishing the effectiveness of interventions. For assessing confidence in the qualitative evidence, GRADE-CERQual will be used.

Field (based on PRISMA-P)	Content
Rationale/context – Current management	For details please see the introduction to the evidence review.
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	Protocol is not registered with PROSPERO.

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

Appendix B – Literature search strategies

Literature search strategies for review question: What are the most effective, cost-effective and acceptable interventions, tools or approaches to support adult carers to enter, remain in, and/or return to (i) work, (ii) education, and (iii) training?

The search for this topic was last run on 9th January 2019.

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 psych or caregiver burden/ use psych
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 people/
14	12 or 13
15	14 use psych

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#	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 psych
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 cbct 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.
37	((communit* or family or social) adj (network* or support*)) or group conferencing or individualis?ed support).ti,ab.

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#	Searches
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 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

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#	Searches
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 individual* support or job centre or (vocat* adj2 employ*) or (work adj2 coach*).ti,ab.
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.

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#	Searches
93	((carer* or care giv* or caregiv*) adj3 (card* or employment or passport* or scheme* or work)) or paid employment or social security or social welfare).ti,ab.
94	(return adj to* adj (education or study or training or work*)).ti,ab.
95	(carer* allowance* or caregiv* allowance or flexible support or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging? or money or working rights) adj3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) adj7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) adj7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*))).ti,ab.
96	(signpost* or sign post*).ti,ab.
97	or/75,77,79,81,83,85-96
98	*day care/ or *respite care/
99	98 use emez
100	day care, medical/ or respite care/
101	100 use mesz, prem
102	adult day care/ use psyh or day care centers/ use psyh or respite care/ use psyh
103	(day care or daycare or day therap* or daytherap* or home help or short break or ((carer* or caregiv* or care giv*) adj3 support*).ti,ab.
104	((crisis or volunteer) adj support) or holiday* or homehelp* or home help* or housekeep* or house keep* or meal support or personal assistant or respite or ((activity or fund* or short) adj2 break*) or signpost*).ti,ab.
105	or/99,101-104
106	*assistive technology/ or *occupational therapy/ or *telehealth/ or *telemedicine/ or *telemetry/ or *telemonitoring/
107	106 use emez
108	assistive technology/ or occupational therapy/ or self-help devices/ or telemedicine/ or telemetry/ or telemonitoring/
109	108 use mesz, prem
110	assistive technology/ or occupational therapy/ or telemedicine/ or telemetry/
111	110 use psyh
112	((assistive adj2 (platform* or technolog*)) or interactive health communication).ti,ab.
113	(simulated presence or social robot* or telecare or telehealth or telematic* or telemonitor*).ti,ab.
114	(gps track* or location technology).ti,ab.
115	occupational therap*.ti,ab.
116	or/107,109,111-115
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 lu) 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.

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#	Searches
121	dyadic intervention*.ti,ab.
122	(reminiscence adj (group* or therap*)).ti,ab.
123	self disclosure/ use emez,mesz,psych 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 psych
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 psych
138	(interview* or action research or audiorecord* or ((audio or tape or video*) adj5 record*) or colaizzi* or (constant adj (comparative or comparison)) or content analy* or critical social* or (data adj1 saturat*) or discourse analys?s or emic or ethical enquiry or ethno* or etic or experiences or fieldnote* or (field adj (note* or record* or stud* or research)) or (focus adj4 (group* or sampl*)) or giorgi* or glaser or (grounded adj (theor* or study or studies or research)) or heidegger* or hermeneutic* or heuristic or human science or husserl* or ((life or lived) adj experience*) or maximum variation or merleau or narrat* or ((participant* or nonparticipant*) adj3 observ*) or ((philosophical or social) adj research*) or (pilot testing and survey) or purpos* sampl* or qualitative* or ricoeur or semiotics or shadowing or snowball or spiegelberg* or stories or story or storytell* or strauss or structured categor* or tape record* or taperecord* or testimon* or (thematic* adj3 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

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#	Searches
	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 psych
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 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 psych
158	or/152,154,156-157
159	meta-analysis/
160	meta-analysis as topic/ or systematic reviews as topic/
161	"systematic review"/
162	meta-analysis/
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 psychlit 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 psych or or/163-171 use psych

#	Searches
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 (follow-up study or longitudinal study or prospective study or retrospective study).md.
183	182 use psyh
184	((epidemiologic* or observational) adj (study or studies)).ti,ab.
185	(cohort*1 or cross section* or crosssection* or followup* or follow up* or followed or longitudinal* or prospective* or retrospective*).ti,ab.
186	(case adj2 (control or series or stud*)).ti,ab.
187	(nonequivalent control group or posttesting or pretesting or pretest posttest design or pretest posttest control group design or quasi experimental methods or quasi experimental study or time series or time series analysis).sh.
188	((nonequivalent or non equivalent) adj3 control*) or posttest* or post test* or pre test* or pretest* or quasi experiment* or quasiexperiment* or timeseries or time series).tw.
189	or/179,181,183-188
190	177 or 189
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

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#	Searches
	(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 (worchester not (massachusetts* or boston* or harvard*)) or ("worchester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,ad.
197	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,ad.
198	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,ad.
199	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,ad.
200	or/192-199 use emez
201	exp united kingdom/
202	(national health service* or nhs*).ti,ab,in.
203	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
204	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jw,in.
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 (worchester not (massachusetts* or boston* or harvard*)) or ("worchester'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.

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#	Searches
206	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in.
207	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in.
208	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in.
209	or/201-208
210	(exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp great britain/ or europe/)
211	209 not 210
212	211 use mesz, prem
213	(national health service* or nhs*).ti,ab,in,cq.
214	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
215	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,cq.
216	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "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 (worchester not (massachusetts* or boston* or harvard*)) or ("worchester'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 psych
221	or/200,212,220

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#	Searches
222	150 and 221
223	131 and or/191,222

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

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

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#	Searches
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 resilient* 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 mediat* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* adj (service* or system)))).ti,ab.
27	((network* or peer*) adj2 (discuss* or exchang* or interact* or meeting*)).ti,ab.
28	(carer* network* or support group*).ti,ab.
29	or/10-28
30	(helpline or help line or ((phone* or telephone*) adj3 (help* or instruct* or interact* or interven* or mediat* or learn* 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 individual* support or job centre or (vocat* adj2 employ*) or (work adj2 coach*)).ti,ab.
42	((individual placement adj2 support) or ips model).ti,ab.

DRAFT FOR CONSULTATION

Supporting adult carers to enter, remain in or return to work, education and training

#	Searches
43	((permitted or voluntary or rehab*) adj3 work*).ti,ab.
44	((psychosocial or psycho social or social) adj2 rehab*).ti,ab.
45	rehabilitation counsel*.ti,ab.
46	((prevocat* or vocat*) adj3 (advice* or advis* or assist* or casework* or case work* or counsel* or educat* or integrat* or interven* or liaison* or mentor* or network* or program* or rehab* or reintegrat* or service* or setting* or skill* or support* or retrain* or teach* or therap* or train* or treat* or specialist*).ti,ab.
47	(volunteering or (work adj2 placement*).ti,ab.
48	((carer* or care giv* or caregiv*) adj3 (card* or employment or passport* or scheme* or work)) or paid employment or social security or social welfare).ti,ab.
49	(return adj to* adj (education or study or training or work*).ti,ab.
50	(carer* allowance* or caregiv* allowance or flexible support or ((aid or benefit* or bills or budget* or financ* or flexible support fund or housing or income* or legal or lodging? or money or working rights) adj3 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*)) or ((carer* or caregiver*) adj7 (benefits* or bills or budget* or financ* or flexible support fund or housing or legal or money) adj7 (advice or assist* or brochure* or educat* or information or intervention* or program* or service* or support* or tool*))).ti,ab.
51	(signpost* or sign post*).ti,ab.
52	or/41-51
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 lu) 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,psych 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: CINAHL – EBSCO

- 1 (mh "caregivers")
- 2 tx (carer* or caregiv* or "care giv*")
- 3 #1 or #2
- 4 (mh "counseling+")
- 5 (mh "psychotherapy, group+")
- 6 (mh "cognitive therapy+")
- 7 (mh "mindfulness")
- 8 (mh "patient centered care")
- 9 (mh "problem solving")
- 10 (mh "reality therapy")
- 11 (mh "simple relaxation therapy (iowa nic)")
- 12 (mh "social support (iowa noc)") or (mh "support, psychosocial")
- 13 tx (psychotherap*)
- 14 (mh "case management")
- 15 (mh "crisis intervention")
- 16 (mh "crisis intervention (iowa nic)")
- 17 (mh "education, nonprofessional")
- 18 (mh "social networks")
- 19 (mh "group processes")
- 20 (mh "interpersonal relations")
- 21 (mh "professional-family relations")
- 22 (mh "support groups")
- 23 (mh "peer group")
- 24 (mh "psychotherapy, group")
- 25 (mh "social networking+")
- 26 (mh "computers and computerization")
- 27 (mh "computer assisted instruction")
- 28 (mh "computer communication networks")
- 29 (mh "online systems")
- 30 (mh "social media+")
- 31 (mh "therapy, computer assisted")
- 32 (mh "telecommunications")
- 33 (mh "telemedicine")
- 34 (mh "internet+")
- 35 (mh "social networking+")
- 36 tx (((psychological* or psychosocial or psychotherapeutic) n2 (intervention* or program* or support* or therap* or treat*)) or "brief intervention*" or psychotherap*)
- 37 tx (((behaviour* or behavior*) n2 cognitiv*) or cbt or cbct 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 (advise* 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 attituder* 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 metasyntes*) 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 (mh "case control studies+") or (mh "cross sectional studies") or (mh "epidemiological research") or (mh "prospective studies+")
 170 tx ((epidemiologic* or observational) adj (study or studies))
 171 tx (cohort* or cross section* or crosssection* or followup* or follow up* or followed or longitudinal* or prospective* or retrospective*)
 172 tx (case n2 (control or series or stud*))
 173 (mh "nonequivalent control group") or (mh "pretest-posttest control group design") or (mh "pretest-posttest design") or (mh "quasi-experimental studies") or (mh "time series")
 174 tx (((nonequivalent or "non equivalent") n3 control*) or posttest* or "post test*" or "pre test*" or pretest* or "quasi experiment*" or quasiexperiment* or timeseries or "time series")
 175 #169 or #170 or #171 or #172 or #173 or #174
 176 #155 or #156 or #168 or #175
 177 #148 and #176

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*)

DRAFT FOR CONSULTATION

Supporting adult carers to enter, remain in or return to work, education and training

#	Searches
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 (advic* 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 (advic* or advis* or counsel* or intervention* or program* or psychotherap* or support*) or "anticipatory grief")
S17	noft (((communit* or family or social) near/1 (network* or support**)) or "group conferencing" or "individualised support" or "individualized support")
S18	noft (((carer* or caregiv* or "care giv**") near/2 (mentor* or support**)) or (unpaid near/3 support*) or "mentoring scheme**")
S19	noft (((carer* or caregiv* or "care giv**") near/3 (communication or integrat* or relations* or relationship*) near/3 (practitioner* or professional* or worker**)) or (famil* near/3 (intervention* or program**)))
S20	noft (psychoeducat* or "psycho educat**")
S21	noft ((emotion* near/1 (disclosure or focus* or friend* or relation*)) or ((emotion* or network* or social or psychosocial) near/1 (adapt* or reintegrat* or support**)))
S22	noft ((dyadic or loneliness or psychosocial* or "psycho social**") near/2 (assist* or intervention* or program* or support* or therap* or treat**))
S23	noft ((emotion* or "one to one" or transition*) near/1 support*)
S24	noft (lay near/1 (led or run))
S25	noft ((crisis or crises or emergenc*) near/3 (advise or advice or assist* or help* or intervention* or network* or program* or service* or support**))
S26	noft ((coping or resilien* or "well being" or wellbeing) near/2 (intervention* or program* or therap* or skill* or strateg* or workshop**))
S27	noft (advocate or advocacy or ((support* near/3 (approach* or educat* or forum* or instruct* or interven* or learn* or module* or network* or program* or psychotherap* or strateg* or system* or technique* or therap* or train* or workshop* or work shop*)) or (support* near/1 (service* or system**)))
S28	noft ((network* or peer*) near/2 (discuss* or exchang* or interact* or meeting**))
S29	noft (carer* network* or "support group**")
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**)))

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

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

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#	Searches
	participat* or perceive* or perspective* or preferen* or prepar* or priorit* or satisf* or view* or voices or worry))
S76	noft ((consumer or patient) near/2 (focus* or centered or centred))
S77	S73 or S74 or S75 or S76
S78	noft (assign* or allocat* or crossover* or cross over* or ((doubl* or singl*) near/1 blind*) or factorial* or placebo* or random* or volunteer*)
S79	S78
S80	noft ("meta analy*" or metanaly* or metaanaly*)
S81	noft ((systematic or evidence) near/2 (review* or overview*))
S82	noft ("cross case analys*" or "eppi approach" or metaethno* or "meta ethno*" or metanarrative* or "meta narrative*" or "meta overview" or metaoverview or metastud* or "meta stud*" or metasummar* or "meta summar*" or "qualitative overview*" or ("critical interpretative" or evidence or meta or "mixed methods" or multilevel or "multi level" or narrative or parallel or realist) near/1 synthes*) or metasynthes*)
S83	S80 or S81 or S82
S84	noft ((epidemiologic* or observational) near/1 (study or studies))
S85	noft (cohort* or "cross section*" or crosssection* or followup* or "follow up*" or followed or longitudinal* or prospective* or retrospective*)
S86	noft (case near/2 (control or series or stud*))
S87	noft (((nonequivalent or non equivalent) near/3 control*) or posttest* or "post test*" or "pre test*" or pretest* or "quasi experiment*" or quasiexperiment* or timeseries or "time series")
S88	S84 or S85 or S86 or S87
S89	S77 or s79 or S83 or S88
S90	S72 and S89

Database: Cochrane Library - Wiley

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#	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 cbct 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

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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 resilient* or "well being" or wellbeing) near/2 (intervention* or program* or therap* or skill* or strateg* or workshop*)):ti,ab,kw

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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

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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

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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: 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.

DRAFT FOR CONSULTATION

Supporting adult carers to enter, remain in or return to work, education and training

#	Searches
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

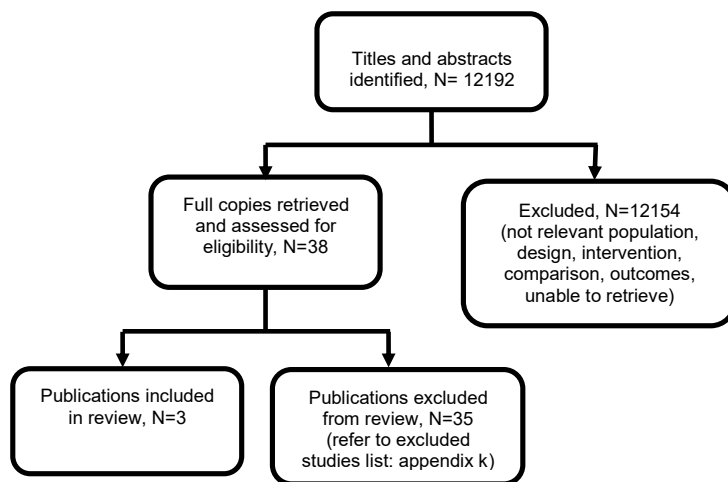
#	Searches
1	mesh descriptor: [caregivers] this term only
2	(carer* or caregiv* or "care giv*"):ti,ab,kw
3	#1 or #2

Appendix C – Evidence study selection

Study selection for review question: What are the most effective, cost-effective and acceptable interventions, tools or approaches to support adult carers to enter, remain in, and/or return to (i) work, (ii) education, and (iii) training?

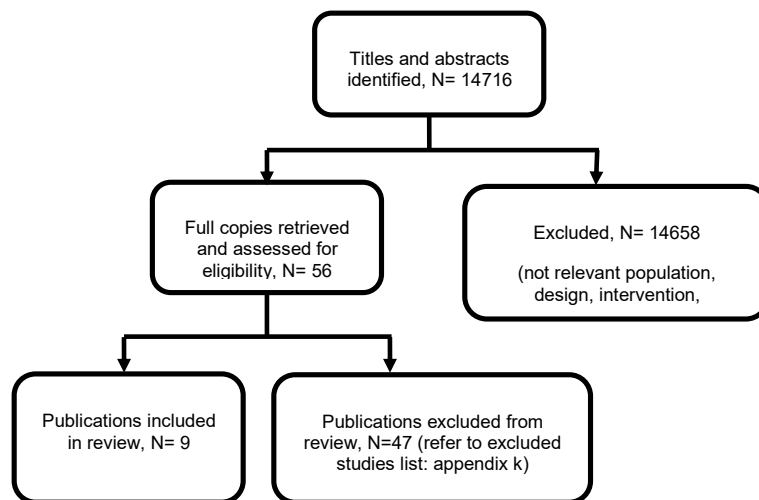
Quantitative component of the review

Figure 3: Study selection flow chart - quantitative component of the review



Qualitative component of the review

Figure 4: Study selection flow chart - qualitative component of the review



Appendix D – Evidence tables

Evidence tables for review question: What are the most effective, cost-effective and acceptable interventions, tools or approaches to support adult carers to enter, remain in, and/or return to (i) work, (ii) education, and (iii) training?

Quantitative component of the review

Table 5: Evidence tables for the quantitative component of the review

Study Details	Participants	Methods	Outcomes and Results	Comments															
<p>Full citation Boezeman, E. J., Nieuwenhuijsen, K., Sluiter, J. K., An intervention that reduces stress in people who combine work with informal care: randomized controlled trial results, European journal of public health, 28, 485-489, 2018</p> <p>Ref Id 959869</p> <p>Country/ies where the study was carried out The Netherlands</p> <p>Study type RCT</p> <p>Aim of the study The aims of this RCT was to compare the effectiveness of a</p>	<p>Sample size N = 128</p> <p>Characteristics Carer</p> <ul style="list-style-type: none"> • Carer (age)= mean age - SD (years): 51.3 - 7.1 (intervention); 50.9 - 7.3 (control) • Carer gender (n)-M/F= 8/57 (intervention); 5/58 (control) • Caring and working/Caring and not working (n): N/A (all included carers were working) • Number of work hours per week (mean [SD]): 29.1 [8.6] (intervention); 27.6 [7.8] (control) <p>Professionals</p> <ul style="list-style-type: none"> • N/A <p>Care recipient</p> <ul style="list-style-type: none"> • Care recipient (condition)= More than 1 condition <p>Inclusion criteria</p> <ul style="list-style-type: none"> • at least 23 years of age 	<ul style="list-style-type: none"> • Setting where intervention is provided: Online • Recruitment procedures: The study sample was identified via community organisations across the Netherlands that offer support to informal caregivers. These organisations spread the recruitment message digitally among the informal caregivers in their respective regions. The recruitment message was also spread via message boards in hospitals, and via patient organisations and labour unions. • Sample size statistical power: Achieved for 1 and 2 months follow-up • Randomization methods: The allocation sequence was performed by a statistician and the randomization was performed with using Arifin's (Arifin WN. EIMJ 2012; 	<p>Results</p> <ul style="list-style-type: none"> • 1 month follow-up <table border="1"> <thead> <tr> <th>Outcomes - Mean (SD)</th> <th>Intervention (n=46)</th> <th>Control (n=52)</th> </tr> </thead> <tbody> <tr> <td>Carer mental health (stress).</td> <td>12.4 (5.5)</td> <td>14.8 (5.7)</td> </tr> <tr> <td>Carer mental health (distress)</td> <td>14.6 (6.8)</td> <td>19.0 (7.9)</td> </tr> </tbody> </table> <ul style="list-style-type: none"> • 2 months follow-up <table border="1"> <thead> <tr> <th>Outcomes - Mean (SD)</th> <th>Intervention (n=46)</th> <th>Control (n=49)</th> </tr> </thead> <tbody> <tr> <td>Carer mental health (stress).</td> <td>10.9 (5.8)</td> <td>14.2 (5.4)</td> </tr> </tbody> </table>	Outcomes - Mean (SD)	Intervention (n=46)	Control (n=52)	Carer mental health (stress).	12.4 (5.5)	14.8 (5.7)	Carer mental health (distress)	14.6 (6.8)	19.0 (7.9)	Outcomes - Mean (SD)	Intervention (n=46)	Control (n=49)	Carer mental health (stress).	10.9 (5.8)	14.2 (5.4)	<p>Limitations (assessed using the Cochrane 'Risk of bias' tool for randomized trials)</p> <ul style="list-style-type: none"> • Random sequence generation: Low risk • Allocation concealment: Low risk • Blinding of participants/personnel high risk (no blinding of included carer - potential performance bias) • Blinding of outcome assessment: Unclear risk (Not described in sufficient detail, potential detection bias) • Incomplete outcome data: High risk (Attrition bias because amount of incomplete outcome data: high dropout)
Outcomes - Mean (SD)	Intervention (n=46)	Control (n=52)																	
Carer mental health (stress).	12.4 (5.5)	14.8 (5.7)																	
Carer mental health (distress)	14.6 (6.8)	19.0 (7.9)																	
Outcomes - Mean (SD)	Intervention (n=46)	Control (n=49)																	
Carer mental health (stress).	10.9 (5.8)	14.2 (5.4)																	

Study Details	Participants	Methods	Outcomes and Results	Comments			
<p>role-focused self-help intervention (to support carers who suffered stress because they combine paid work with informal caregiving) to a wait list control</p> <p>Study dates</p> <ul style="list-style-type: none"> • Publication date: 2018 • Data collection: 2015 to 2016 <p>Source of funding</p> <p>This study was funded by a grant awarded by the Instituut Gak, grant number 2014-513</p>	<ul style="list-style-type: none"> • informal carer for at least 2 h a week • involved in paid work for at least 12 h a week and • self-reported stress complaints due to the involvement in informal care <p>Exclusion criteria</p> <ul style="list-style-type: none"> • Not reported (Please look the inclusion criteria) 	<p>4:e129–43) randomization procedure.</p> <ul style="list-style-type: none"> • Blinding: Outcome assessors were blind, whilst carers were not blinded • Follow-up outcome measurement from baseline: 1 and 2 months • Intervention characteristics: role-focused self-help course (that is E-book plus a non-obligatory internet support module): <ul style="list-style-type: none"> ○ It contained exercises, texts and practical suggestions. ○ Its introduction text encouraged users to complete the self-help course at their own convenience ○ the selected materials are suitable for helping people who have paid work ○ to understand and shape their carer role ○ to combine the role of informal caregiver with other roles (that is the work role, social roles) • Control characteristics: waiting list control (Control group carers received the self-help course after follow-up measurements) 	<table border="1"> <tr> <td data-bbox="1066 405 1171 507">Carer mental health (distress)</td> <td data-bbox="1178 405 1294 507">11.3 (7.2)</td> <td data-bbox="1301 405 1397 507">18.7 (8.7)</td> </tr> </table>	Carer mental health (distress)	11.3 (7.2)	18.7 (8.7)	<p>rate both at 1 month follow-up and 2 months follow-up – with potential imbalances of dropouts in higher in the intervention group)</p> <ul style="list-style-type: none"> • Selective reporting: Low risk • Other bias: High risk (1 – intervention's adherence was not monitored; and 2 a waiting-list control condition was used). <p>Overall risk of bias: very serious</p> <p>Other information</p> <ul style="list-style-type: none"> • Main provider of the intervention: On-line self-help guided • Mode of intervention delivery: On-line (web-site with both synchronous and asynchronous information) • Is the intervention tailored to carer needs?: unclear
Carer mental health (distress)	11.3 (7.2)	18.7 (8.7)					

Study Details	Participants	Methods	Outcomes and Results	Comments																		
<p>Full citation Pickard, Linda, Brimblecombe, Nicola, King, Derek, Knapp, Martin, 'Replacement Care' for Working Carers? A Longitudinal Study in England, 2013–15, Social Policy and Administration, 44, 690-709, 2018</p> <p>Ref Id 959201</p> <p>Country/ies where the study was carried out UK</p> <p>Study type</p> <ul style="list-style-type: none"> Mixed-methods (quantitative plus qualitative) research study Longitudinal observational study <p>Aim of the study The aims of this mixed-methods research were to to evaluate causal association between 'replacement care' and carers' employment in carers who were employed in the public sector in England</p>	<p>Sample size N = 166</p> <p>Characteristics</p> <p>Carer</p> <ul style="list-style-type: none"> Carer (age)= mean age (years - % [95% CI]): 3.7 [1.7 to 7.8] (% <35); 14.2 [10.0 to 20.4] (% 35–44); 50.6 [43.0 to 58.2] (% 45–54); 31.5 [24.8 to 39.0] (% 55–64) Carer gender (n)-M/F= 27/139 Caring and working/Caring and not working (n): not reported <p>Professionals</p> <ul style="list-style-type: none"> N/A <p>Care recipient</p> <ul style="list-style-type: none"> Care recipient (condition)= More than 1 condition <p>Inclusion criteria</p> <ul style="list-style-type: none"> Working carers employed in the public sector in 2013 Aged less than 65 years old (men); and less than 62 years old (women) Carers caring for 10 or more hours a week for the main care recipient at baseline <p>Exclusion criteria Carers caring for someone in residential care (because national and international definitions of unpaid care do not necessarily include people caring for someone in those settings)</p>	<ul style="list-style-type: none"> Setting where intervention is provided: Community settings Recruitment procedures: The analysis includes the carers who took part in February – June 2013 to the 'Working Carers' Questionnaire' (Data collection began with an online survey, the 'Survey of Employees', to identify employees providing unpaid care: November 2012 to February 2013). Data collection & analysis: The analysis included a multivariate logistic regression analysis dependent variable: carers's employment independent variables: <ul style="list-style-type: none"> receipt of 'key services' by the care recipient (including home care, personal assistant, day care, meals-on-wheels or their equivalent and short-term breaks) characteristics of the carer (including age, gender, ethnicity, health, education) carer's work (including full or part time, use of 'carer-friendly' benefits, difficulties combining work and care); 	<p>Results Results of the multivariate analysis</p> <p>Regression results for factors associated with leaving work to care after two years: working carers providing care for ten or more hours a week to main care recipient at baseline</p> <table border="1"> <thead> <tr> <th>Covariates at baseline</th> <th>Odds Ratio**</th> <th>P value</th> </tr> </thead> <tbody> <tr> <td>Care-recipient's service receipt^A</td> <td>13.68</td> <td>< 0.01</td> </tr> <tr> <td>Age of carers^B</td> <td>4.30</td> <td>< 0.05</td> </tr> <tr> <td>Hours of care for main care recipient^C</td> <td>5.06</td> <td>< 0.05</td> </tr> <tr> <td>Number of people cared for^D</td> <td>3.76</td> <td>< 0.05</td> </tr> <tr> <td>Constant</td> <td>0.001</td> <td>< 0.01</td> </tr> </tbody> </table> <p>N=137</p> <p>A Care recipient did not use services... relative to care recipient used services B Carer aged 53 years and over ... relative to carer aged under 53 years C Care for 20 or more hours a week ... relative to care for less than 20 hours a week</p>	Covariates at baseline	Odds Ratio**	P value	Care-recipient's service receipt ^A	13.68	< 0.01	Age of carers ^B	4.30	< 0.05	Hours of care for main care recipient ^C	5.06	< 0.05	Number of people cared for ^D	3.76	< 0.05	Constant	0.001	< 0.01	<p>Limitations (Newcastle-Ottawa Scale (NOS) Checklist)</p> <ul style="list-style-type: none"> Selection: Low risk of bias Comparability: not applicable Outcome: Low risk of bias
Covariates at baseline	Odds Ratio**	P value																				
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Hours of care for main care recipient ^C	5.06	< 0.05																				
Number of people cared for ^D	3.76	< 0.05																				
Constant	0.001	< 0.01																				

Study Details	Participants	Methods	Outcomes and Results	Comments
<p>Study dates</p> <ul style="list-style-type: none"> • Publication date: 2018 • Data collection: 2012-2015 <p>Source of funding</p> <p>This paper is funded by the National Institute for Health Research (NIHR) School for Social Care Research</p>		<ul style="list-style-type: none"> o care provided (including hours of care, number of people cared for, locus of care); o and the care-recipient's characteristics (including care-recipient's age, relationship to carer) <p>The analyses examine potential connections between carers 'employment outcomes and receipt of 'key services 'by the care recipient. 'Key services' are those that were associated with carers 'employment in our earlier cross-sectional analysis: home care, personal assistant, day care, meals-on-wheels or their equivalent and short-term breaks (See Pickard 2015). 'Day care'refers to a day centre, lunch club, day activities or special school/college. 'Home care 'refers primarily to help with personal care. 'Personal assistants'are people employed by individuals with care needs, often in receipt of personal budgets. 'Meals-on-wheels 'are meals delivered to individuals at home. Short-term breaks refer to short stays in residential homes or short-break/respite centres.</p>	<p>D Care for two or more people ... relative to care for one person</p>	

Study Details	Participants	Methods	Outcomes and Results	Comments																																				
		All the analyses used a level of 0.05 as the criterion to determine significance.																																						
<p>Full citation Pickard, Linda, King, Derek, Brimblecombe, Nicola, Knapp, Martin, The Effectiveness of Paid Services in Supporting Unpaid Carers' Employment in England, Journal of Social Policy, 44, 567-590, 2015</p> <p>Ref Id 725325</p> <p>Country/ies where the study was carried out England</p> <p>Study type Cross-sectional observational study</p> <p>Aim of the study The aims of this quantitative observational research were to explore the effectiveness of paid services in supporting unpaid carers' employment in England</p> <p>Study dates</p>	<p>Sample size N = 6304</p> <p>Characteristics Carer</p> <ul style="list-style-type: none"> • Carer (age)= mean age - SD (years): 53,7 - 8,6 (men); 50,1 - 7,7 (women) • Carer gender (n)-M/F= 2198/4106 • Caring and working/Caring and not working (n): 2751/3553 <p>Professionals</p> <ul style="list-style-type: none"> • N/A <p>Care recipient</p> <ul style="list-style-type: none"> • Care recipient (condition)= More than 1 condition <p>Inclusion criteria</p> <ul style="list-style-type: none"> • Cares at working age • Providing intense care (10 or more hours a week) • Included in the 2009/10 PSS SACE survey (Personal Social Services Survey of Adult Carers in England) • And replying both questions on services and employment <p>Exclusion criteria Not reported (Please look the inclusion criteria)</p>	<p>Details</p> <ul style="list-style-type: none"> • Setting where intervention is provided: Community settings • Recruitment procedures: The analysis uses the 2009/10 Personal Social Services Survey of Adult Carers in England (PSS SACE) (Health and Social Care Information Centre (HSCIC), 2010a). The survey includes questions on both the employment of the carer and the services received by the cared-for person. The 2009/10 PSS SACE was administered through local authorities (Councils with Adult Social Services Responsibilities (CASSRs)) and was designed for adult carers in contact, either directly or via the person they cared for, with social services • Data collection & analysis: The analysis (STATA 12.1) included: 1) descriptive statistics of PSS SACE; 2) Bivariate regression analysis - to identify patterns that appear to be occurring in 	<p>Results Relationship between employment rates of unpaid carers and care-recipients' use of paid services, controlling for covariates</p> <table border="1"> <thead> <tr> <th colspan="4">Regression results for factors associated with employment status under state peion age providing unpaid care for ten or more hours a week, including use of individual services by the cared-for person</th> </tr> <tr> <th colspan="4">Women</th> </tr> <tr> <th></th> <th>Odds Ratio**</th> <th>95% CI</th> <th>P value</th> </tr> </thead> <tbody> <tr> <td>Use of home care only</td> <td>1.64</td> <td>1.29 to 2.07</td> <td>< 0.01</td> </tr> <tr> <td>Use of day care only</td> <td>1.26</td> <td>1.00 to 1.59</td> <td>< 0.05</td> </tr> <tr> <td>Use of personal assistant only</td> <td>1.74</td> <td>1.27 to 2.37</td> <td>< 0.01</td> </tr> <tr> <td>Use of care home only</td> <td>1.10</td> <td>0.74 to 1.65</td> <td>*</td> </tr> <tr> <td>Use of meals-on-wheels only</td> <td>2.85</td> <td>1.13 to 7.21</td> <td>< 0.05</td> </tr> <tr> <td>Use of home care and day care</td> <td>1.65</td> <td>1.10 to 2.48</td> <td>< 0.05</td> </tr> </tbody> </table>	Regression results for factors associated with employment status under state peion age providing unpaid care for ten or more hours a week, including use of individual services by the cared-for person				Women					Odds Ratio**	95% CI	P value	Use of home care only	1.64	1.29 to 2.07	< 0.01	Use of day care only	1.26	1.00 to 1.59	< 0.05	Use of personal assistant only	1.74	1.27 to 2.37	< 0.01	Use of care home only	1.10	0.74 to 1.65	*	Use of meals-on-wheels only	2.85	1.13 to 7.21	< 0.05	Use of home care and day care	1.65	1.10 to 2.48	< 0.05	<p>Limitations (Newcastle-Ottawa Scale (NOS) Checklist)</p> <ul style="list-style-type: none"> • Selection: Low risk of bias • Comparability: not applicable • Outcome: Low risk of bias
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Study Details	Participants	Methods	Outcomes and Results				Comments
<ul style="list-style-type: none"> • Publication date: 2015 • Data collection: 2009/10 <p>Source of funding This study was funded by the National Institute for Health Research (NIHR) School for Social Care Research</p>		<p>the data, before adjustment for relevant covariates</p> <p>3) Multivariate logistic regression analysis.</p> <p>A positive association between paid services for the cared-for person and carers' employment rates can be regarded as a necessary condition if services for the cared-for person are effective in supporting carers' employment. If the analysis finds no association between use of services by the cared-for person and carers' employment, it is unlikely that services would be effective in supporting carers' employment. All the analyses used a level of 0.05 as the criterion to determine significance.</p>	Use of home care and care home	1.16	0.78 to 1.74	*	
			Use of home care and personal assistant	1.26	0.78 to 2.03	*	
			Use of day care and care home	1.65	1.21 to 2.25	< 0.05	
			Use of day care and personal assistant	2.13	1.38 to 3.31	< 0.01	
			Use of meals-on-wheels and homecare	1.87	1.05 to 3.30	< 0.05	
			Use of home care, day care and care home	2.24	1.25 to 4.02	< 0.01	
			Use of home care, day care and personal assistant	2.26	1.44 to 3.57	< 0.01	
			Use of other combination of services	2.10	1.51 to 2.93	< 0.01	
			Men				
				Odds Ratio	95% CI	P value	

Study Details	Participants	Methods	Outcomes and Results				Comments
			Use of home care only	1.69	1.27 to 2.25	< 0.01	
			Use of day care only	1.29	0.87 to 1.91	*	
			Use of personal assistant only	2.45	1.55 to 3.89	< 0.01	
			Use of care home only	0.98	0.56 to 1.72	*	
			Use of meals-on-wheels only	1.98	0.59 to 6.65	*	
			Use of home care and day care	1.96	1.25 to 3.06	< 0.01	
			Use of home care and care home	1.96	1.22 to 3.16	< 0.01	
			Use of home care and personal assistant	1.68	0.98 to 2.86	*	
			Use of day care and care home	1.67	0.77 to 3.62	*	
			Use of day care and personal assistant	1.88	0.87 to 4.07	*	
			Use of meals-on-wheels	2.74	1.27 to 5.91	< 0.05	

Study Details	Participants	Methods	Outcomes and Results			Comments
			and homecare			
			Use of home care, day care and care home	1.30	0.55 to 3.09	*
			Use of home care, day care and personal assistant	1.052	0.73 to 3.18	*
			Use of other combination of services	1.68	1.04 to 2.71	< 0.05
			* no significant			
			** relative to not using services			

CI: confidence intervals; F: Female; M: Male; N: number; N/R: not reported; SD: Standard deviation; RCT: Randomised controlled trial

Qualitative component of the review

Table 6: Evidence tables for the qualitative component of the review

Study details	Participants	Methods	Outcomes and Themes	Comments
<p>Full citation Arksey, H., People into Employment: supporting people with disabilities and carers into work, Health & social care in the community, 11, 283-292, 2003</p> <p>Ref Id 716656</p>	<p>Sample size N = 28 adult carers</p> <p>Characteristics Carer</p> <ul style="list-style-type: none"> • Carer (age)= not reported • Carer gender (n)- M/F= not reported • Caring and working/Caring and 	<ul style="list-style-type: none"> • Recruitment methods: Carers were recruited in the study if they attended People into Employment (PIE), a pilot employment project • Data collection & analysis: Data were collected through (face-to-face and telephone) semi-structured interviews. All interviews were audio-taped, and comprehensive notes 	<ul style="list-style-type: none"> • Barriers to employment • Working with clients: job search activities • Employers' views 	<p>Limitations (assessed using the CASP checklist for qualitative studies)</p> <ul style="list-style-type: none"> • 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? - Can't tell

Study details	Participants	Methods	Outcomes and Themes	Comments
<p>Country/ies where the study was carried out UK</p> <p>Study type Qualitative research study</p> <p>Aim of the study The aims of this mixed-methods research were to evaluate People into Employment (PIE), a pilot employment project in the north-east of England designed to support people with disabilities, carers and former carers in gaining mainstream work.</p> <p>Study dates</p> <ul style="list-style-type: none"> • Publication date: 2003 • Data collection: 2001 <p>Source of funding Not reported</p>	<p>not working (n): not reported</p> <p>Professionals</p> <ul style="list-style-type: none"> • N/A <p>Care recipient</p> <ul style="list-style-type: none"> • Care recipient (condition)= People with disabilities <p>Inclusion criteria</p> <ul style="list-style-type: none"> • Not reported <p>Exclusion criteria</p> <ul style="list-style-type: none"> • Not reported 	<p>were made. The analysis used the a framework approach (Ritchie and Spencer 1994)</p>		<p>(there was no discussion about how the method was decided)</p> <ul style="list-style-type: none"> • Q4: Was the recruitment strategy appropriate to the aims of the research? – can't tell (Not sufficient detail on how included carers were selected) • Q5: Were the data collected in a way that addressed the research issue? - Can't tell (It was unclear whether saturation of data was reached) • Q6: Has the relationship between researcher and participants been adequately considered? - Can't tell (relationship between researcher and participants has not been adequately considered and reported in the paper) • Q7: Have ethical issues been taken into consideration? - Can't tell (No details on ethical issues - for example informed consent or confidentiality, or ethics committee approval) has been reported) • Q8: Was the data analysis sufficiently rigorous? – No (Insufficient data are presented to support the descriptive findings) • Q9: Is there a clear statement of findings? - Yes

Study details	Participants	Methods	Outcomes and Themes	Comments
				<ul style="list-style-type: none"> • Q10: Is the research valuable for the UK (1. Contribution to literature and 2. Transferability)? - Yes <p>Methodological Limitations: Major</p>
<p>Full citation Arksey, Hilary, Kemp, Peter, Glendinning, Caroline, Carers' aspirations and decisions around work and retirement *</p> <p>Ref Id 717210</p> <p>Country/ies where the study was carried out UK</p> <p>Study type Qualitative research study</p> <p>Aim of the study The aims of this qualitative research were to assess the effectiveness of financial (Carer's Allowance) and labour market support (Job Centre Plus) in England to encourage carers to work. This article is complementary to the evidence presented in Arksey (2007) and Arksey (2008)*</p>	<p>Sample size N = 80 adult carers</p> <p>Characteristics</p> <p>Carer</p> <ul style="list-style-type: none"> • Carer (age)= range (years): 25 to 64 • Carer gender (n)- M/F= 22/58 • Caring and working/Caring and not working (n): 43/37 <p>Professionals</p> <ul style="list-style-type: none"> • N = 59 <p>Care recipient</p> <ul style="list-style-type: none"> • Care recipient (condition)= More than 1 condition <p>Inclusion criteria Carers were eligible if they were</p> <ul style="list-style-type: none"> • carers in different employment situations, that is in full-time work; in part-time work; not in work; 	<ul style="list-style-type: none"> • Recruitment methods: Carers were selected purposively in four research sites (including an integrated Jobcentre Plus office; a carers centre run by the voluntary sector; and not be an existing DWP research area): 1) a high labour demand area; 2) an inner city area; 3) a rural area; 4) a declining industrial area. The recruitment of carers was mixed: DWP's CA database; databases held by the local Jobcentre Plus offices; the local social services departments; the local carers centres; local employers, in both the public and private sectors; snowballing. • Data collection & analysis: Data were collected through (face-to-face and telephone) semi-structured interviews and focus group. Interviews lasted one hour on average. All interviewees were asked questions about: the caring 	<ul style="list-style-type: none"> • Difficulties in accessing services (Difficulties in accessing social services support) • Information availability and appropriateness to carers' needs (Difficulties in accessing social services support) • Working hours and Flexibility • Unsupportive managers & colleagues • Financial difficulties • Distance, transport and travelling time • Commitment to care recipient (Barriers to remain work) • Wishes and/or needs of care recipients (Barriers to remain work) • Carers' physical health and emotional well-being • Carers' personal factors (for example identity, commitment to career) • Identity • Commitment to career 	<p>Limitations (assessed using the CASP checklist for qualitative studies)</p> <ul style="list-style-type: none"> • 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? - Can't tell (there was no discussion about how the method was decided) • Q4: Was the recruitment strategy appropriate to the aims of the research? - yes • Q5: Were the data collected in a way that addressed the research issue? - Yes • Q6: Has the relationship between researcher and participants been adequately considered? - Yes • Q7: Have ethical issues been taken into consideration? - Yes • Q8: Was the data analysis sufficiently rigorous? - Can't tell

Study details	Participants	Methods	Outcomes and Themes	Comments
<p>Study dates</p> <ul style="list-style-type: none"> • Publication date: 2005* • Data collection: 2004 <p>Source of funding This study was funded by the Department for Work and Pensions and carried out by the Social Policy Research Unit at the University of York</p>	<ul style="list-style-type: none"> • carers in receipt of CA, and carers not in receipt of this benefit; • carers who had attended a Work Focused Interview (WFI) at their local Jobcentre Plus office; • carers looking after disabled children, spouses/partners and older relatives; • carers from ethnic minority communities. <p>Exclusion criteria</p> <ul style="list-style-type: none"> • Not reported (Please look the inclusion criteria) 	<p>situation; past and current training and employment experiences; retirement planning and financial provisions; Jobcentre Plus and WFIs; social services provision; and CA. The interviews were all tape-recorded, and transcribed in full. The analysis used the a framework approach (Ritchie and Spencer 1994)</p>	<ul style="list-style-type: none"> • Carer's assessment (Support from social care services) • Limited opportunities to discuss carers' employment issues • Jobcentre Plus • Work Focused Interviews • Better Off Calculation • Financial support for carers (for example Carer's Allowance) • Formal workplace policies • Work-related flexibility and help • Supportive employers, managers and colleagues 	<p>(there is no discussion of whether saturation was achieved for discontinuing data collection and/or analysis)</p> <ul style="list-style-type: none"> • 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 <p>Methodological Limitations: Minor</p> <p>Other information This article is complementary to the evidence presented in Arksey (2007) and Arksey (2008):</p> <ul style="list-style-type: none"> • Arksey Hilary, Combining work and care: the reality of policy tensions for carers, <i>Benefits</i>, 15, 139-149, 2007 • Arksey Hilary, Glendinning Caroline, Combining work and care: carers' decision-making in the context of competing policy pressures, <i>Social Policy and Administration</i>, 42, 1-18, 2008 <p>These two articles (listed above) were considered for data collection but were not included in the review analysis</p>
<p>Full citation Bernard, Miriam, Phillips, Judith E., Working carers of</p>	<p>Sample size N = 48 adult carers</p> <p>Characteristics</p>	<ul style="list-style-type: none"> • Recruitment methods: A convenience sample of carers was recruited through 	<ul style="list-style-type: none"> • What helps and what hinders 	<p>Limitations (assessed using the CASP checklist for qualitative studies)</p>

Study details	Participants	Methods	Outcomes and Themes	Comments
<p>older adults: What helps and what hinders in juggling work and care?, Community, Work & Family, 10, 139-160, 2007</p> <p>Ref Id 714575</p> <p>Country/ies where the study was carried out UK</p> <p>Study type Qualitative research study</p> <p>Aim of the study The aims of this qualitative research were to explore how working carers and managers in two public sector organizations combined their work and caring responsibilities, and to explore to what extent existing family-friendly policies were being utilized</p> <p>Study dates</p> <ul style="list-style-type: none"> • Publication date: 2007 • Data collection: 2000/2002 <p>Source of funding Not reported</p>	<p>Carer</p> <ul style="list-style-type: none"> • Carer (age)= mean age - range (years): 51 - 32 to 70 • Carer gender (n)- M/F= 8/40 • Caring and working/Caring and not working (n): 48/0 <p>Professionals</p> <ul style="list-style-type: none"> • N/A <p>Care recipient</p> <ul style="list-style-type: none"> • Care recipient (condition)= Older people <p>Inclusion criteria</p> <ul style="list-style-type: none"> • Not reported <p>Exclusion criteria</p> <ul style="list-style-type: none"> • Not reported 	<p>two public sector organizations: a Social Services Department (SSD), and a National Health Service (NHS) Trust.</p> <ul style="list-style-type: none"> • Data collection & analysis: Data were collected through semi-structured interviews. No details are reported about the data analysis. 	<ul style="list-style-type: none"> o Work-related help versus workload pressures o Supportive or unsupportive managers and colleagues? o 'Being a professional' versus organizational pressures and culture o Distance dilemmas o Family and friends 	<ul style="list-style-type: none"> • 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? - Can't tell (there was no discussion about how the method was decided) • Q4: Was the recruitment strategy appropriate to the aims of the research? - can't tell (Insufficient detail on how included carers were selected) • Q5: Were the data collected in a way that addressed the research issue? - Can't tell (It was unclear whether saturation of data was reached) • Q6: Has the relationship between researcher and participants been adequately considered? - Can't tell (relationship between researcher and participants has not been adequately considered and reported in the paper) • Q7: Have ethical issues been taken into consideration? - Can't tell (No details on ethical issues - for example informed consent or confidentiality, or ethics committee approval) has been reported)

Study details	Participants	Methods	Outcomes and Themes	Comments
				<ul style="list-style-type: none"> • Q8: Was the data analysis sufficiently rigorous? - Can't tell (no details to assess the rigour of the data analysis) • 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 <p>Methodological Limitations: Major</p>
<p>Full citation Carmichael, Fiona, Hulme, Claire, Sheppard, Sally, Connell, Gemma, Work - life imbalance: Informal care and paid employment in the UK, Feminist Economics, 14, 3, 2008</p> <p>Ref Id 720311</p> <p>Country/ies where the study was carried out UK</p> <p>Study type Qualitative research study</p> <p>Aim of the study The aims of this qualitative research were to consider the impact that caring responsibilities have on</p>	<p>Sample size N = 30 adult carers</p> <p>Characteristics</p> <p>Carer</p> <ul style="list-style-type: none"> • Carer (age)= range (years): 45 to 65 • Carer gender (n)- M/F= 5/25 • Caring and working/Caring and not working (n): 30/0 <p>Professionals</p> <ul style="list-style-type: none"> • N/A <p>Care recipient</p> <ul style="list-style-type: none"> • Care recipient (condition)= More than 1 condition <p>Inclusion criteria Carers were eligible if :</p>	<ul style="list-style-type: none"> • Recruitment methods: Carers were recruited purposively through 8 carer support groups across northwestern England (organizations offering support to carers ranging from the organization of social events to the provision of formal services) • Data collection & analysis: Data were collected through a (self-administered) questionnaires (n=264) and semistructured interviews (n=26) - The questionnaires and the interviews included closed questions about the carer, their caring responsibilities, their current and previous employment, two 	<ul style="list-style-type: none"> • Giving up paid work to care • Difficulties returning to paid work • The longer-term effects of caring • Restricted opportunities in employment • Lack of flexibility in relation to carers' needs • Financial implications 	<p>Limitations (assessed using the CASP checklist for qualitative studies)</p> <ul style="list-style-type: none"> • 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? - can't tell (Insufficient detail on how included carers were selected) • Q5: Were the data collected in a way that addressed the research issue? - Yes

Study details	Participants	Methods	Outcomes and Themes	Comments
<p>carers's employment in England.</p> <p>Study dates</p> <ul style="list-style-type: none"> • Publication date: 2008 • Data collection: 2005 <p>Source of funding</p> <p>Not reported</p>	<ul style="list-style-type: none"> • 1) they where possible were below the state-pension age; • 2) no further criteria was used to select carers <p>Exclusion criteria</p> <ul style="list-style-type: none"> • Not reported (Please look the inclusion criteria) 	<p>questions asking whether working carers had changed either their hours of work or their job for the purpose of accommodating their caring responsibilities. The last question on the questionnaire was open-ended and asked about ways in which employers and the government could help carers combine work and caring. No details are reported about the data analysis.</p>		<ul style="list-style-type: none"> • Q6: Has the relationship between researcher and participants been adequately considered? - Can't tell (relationship between researcher and participants has not been adequately considered and reported in the paper) • Q7: Have ethical issues been taken into consideration? - Can't tell (No details on ethical issues - for example informed consent or confidentiality, or ethics committee approval) has been reported) • Q8: Was the data analysis sufficiently rigorous? - Can't tell (In the paper is not discussed if saturation was achieved for discontinuing data collection and/or analysis) • 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 <p>Methodological Limitations: Unclear</p>
<p>Full citation</p> <p>Pickard, Linda, Brimblecombe, Nicola, King, Derek, Knapp, Martin,</p>	<p>Sample size</p> <p>N = 40 adult carers</p> <p>Characteristics</p> <p>Carer</p>	<ul style="list-style-type: none"> • Recruitment methods: <p>Carers were recruited in May – July 2015 through a sub-</p>	<ul style="list-style-type: none"> • Reasons for leaving work: aspects of caring that led carers to leave work 	<p>Limitations (assessed using the CASP checklist for qualitative studies)</p>

Study details	Participants	Methods	Outcomes and Themes	Comments
<p>'Replacement Care' for Working Carers? A Longitudinal Study in England, 2013–15, Social Policy and Administration, 44, 690-709, 2018</p> <p>Ref Id 959201</p> <p>Country/ies where the study was carried out UK</p> <p>Study type</p> <ul style="list-style-type: none"> Mixed-methods (quantitative plus qualitative) research study Cross-sectional observational study <p>Aim of the study The aims of this mixed-methods research were to consider the qualitative experiences of working carers (working in the public sector) to improve the understanding of the mechanisms by which services for the care-recipient may help carers to combine care and work.</p> <p>Study dates</p> <ul style="list-style-type: none"> Publication date: 2018 Data collection: 2012-2015 	<ul style="list-style-type: none"> Carer = age (years - N): 15 (under 53 years); 25 (53 years and over) Carer gender (n)- M/F= 8/32 Caring and working/Caring and not working (n): all study sample <p>Professionals</p> <ul style="list-style-type: none"> N/A <p>Care recipient</p> <ul style="list-style-type: none"> Care recipient (condition)= More than 1 condition <p>Inclusion criteria</p> <ul style="list-style-type: none"> Working carers employed in the public sector Aged less than 65 years old (men); and less than 62 years old (women) caring for 10 or more hours a week for the main care recipient at baseline <p>Exclusion criteria Carers caring for someone in residential care (because national and international definitions of unpaid care do not necessarily</p>	<p>sample of carers who take part in February – June 2013 to the 'Working Carers ' Questionnaire' (Data collection began with an online survey, the 'Survey of Employees', to identify employees providing unpaid care: November 2012 to February 2013). Carers were selected purposively to reflect diverse age, gender, ethnicity and employment status.</p> <p>Data collection & analysis: Data were collected through telephone semi-structured interviews. The main analytical technique applied to this data was inductive thematic analysis.</p>	<ul style="list-style-type: none"> Other reasons for leaving work How services helped carers to remain in employment 	<ul style="list-style-type: none"> 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? - can't tell (Insufficient detail on how included carers were selected) Q5: Were the data collected in a way that addressed the research issue? - Can't tell (It was unclear whether saturation of data was reached) Q6: Has the relationship between researcher and participants been adequately considered? - Can't tell (relationship between researcher and participants has not been adequately considered and reported in the paper) Q7: Have ethical issues been taken into consideration? - Can't tell (No details on ethical issues - for example informed consent or confidentiality, or ethics committee approval) has been reported) Q8: Was the data analysis sufficiently rigorous? - No (Not

Study details	Participants	Methods	Outcomes and Themes	Comments
<p>Source of funding This paper is funded by the National Institute for Health Research (NIHR) School for Social Care Research</p>	include people caring for someone in those settings)			<p>enough data are presented to support the descriptive findings)</p> <ul style="list-style-type: none"> • 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 <p>Methodological Limitations: Moderate concerns</p>
<p>Full citation Seddon Diane, et al., Supporting carers in paid employment: developing a needs led approach, Quality in Ageing, 5, 14-23, 2004</p> <p>Ref Id 716095</p> <p>Country/ies where the study was carried out UK</p> <p>Study type Qualitative research study</p> <p>Aim of the study The aims of this qualitative research were to consider the qualitative experiences of family carers for older people who are in employment, paying particular attention to their support needs.</p>	<p>Sample size N = 46 adult carers</p> <p>Characteristics</p> <p>Carer</p> <ul style="list-style-type: none"> • Carer (age)= mean age - range (years): 51 - 26 to 63 • Carer gender (n)- M/F= Not reported • Caring and working/Caring and not working (n): 46/0 <p>Professionals</p> <ul style="list-style-type: none"> • N = 40 <p>Care recipient</p> <ul style="list-style-type: none"> • Care recipient (condition)= Older people <p>Inclusion criteria</p> <ul style="list-style-type: none"> • Not reported <p>Exclusion criteria</p> <ul style="list-style-type: none"> • Not reported 	<ul style="list-style-type: none"> • Recruitment methods: Carers were recruited purposively through six social services departments and key voluntary agencies in the study setting. The carer sample reflected a broad range of occupational experiences, with carers employed in various professional, managerial, administrative and skilled and unskilled manual occupations. • Data collection & analysis: Data were collected through semi-structured interviews. The main analytical technique applied to this data was latent content analysis. 	<ul style="list-style-type: none"> • Supporting carers in employment <ul style="list-style-type: none"> ○ Assessment ○ Services ○ Deficits in service provision • Difficulties in accessing services. • Flexibility • Reliability • Links with employers <ul style="list-style-type: none"> ○ Supporting carers in employment: examples of good practice • Identifying carers in employment • Flexible delivery of health and social care services • Forging links between service providers and employers 	<p>Limitations (assessed using the CASP checklist for qualitative studies)</p> <ul style="list-style-type: none"> • 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? - can't tell (Insufficient detail on how included carers were selected) • Q5: Were the data collected in a way that addressed the research issue? - Can't tell (It was unclear whether saturation of data was reached)

Study details	Participants	Methods	Outcomes and Themes	Comments
<p>Study dates</p> <ul style="list-style-type: none"> • Publication date: 2004 • Data collection: not reported <p>Source of funding Not reported</p>				<ul style="list-style-type: none"> • Q6: Has the relationship between researcher and participants been adequately considered? - Can't tell (relationship between researcher and participants has not been adequately considered and reported in the paper) • Q7: Have ethical issues been taken into consideration? - Can't tell (No details on ethical issues - for example informed consent or confidentiality, or ethics committee approval) has been reported) • Q8: Was the data analysis sufficiently rigorous? - No (Not enough data are presented to support the descriptive 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 <p>Methodological Limitations: Major concerns</p>
<p>Full citation Sempik Joe, Becker Saul, Young adult carers and employment, 25, 2014 Ref Id 720905</p>	<p>Sample size N = 77 young adult carers Characteristics Carer</p>	<ul style="list-style-type: none"> • Recruitment methods: Carers were recruited in the study if they were part of NEET survey (carers who are in employment, or not in employment, education or 	<ul style="list-style-type: none"> • Difficulties in balancing education/training and care • Working hours and Flexibility • Unsupportive managers & colleagues 	<p>Limitations (assessed using the CASP checklist for qualitative studies)</p>

Study details	Participants	Methods	Outcomes and Themes	Comments
<p>Country/ies where the study was carried out UK</p> <p>Study type Qualitative cross-sectional survey</p> <p>Aim of the study The aims of this qualitative research were to explore the experiences and perceptions of carers who are in employment, or not in employment, education or training (NEET)</p> <p>Study dates</p> <ul style="list-style-type: none"> • Publication date: 2014 • Data collection: 2013 <p>Source of funding This study was funded by Carers Trust</p>	<ul style="list-style-type: none"> • Carer (age)= mean age (years): 21 • Carer gender (n)- M/F= 15/62 • Caring and working/Caring and not working (n): 39/38 <p>Professionals</p> <ul style="list-style-type: none"> • N/A <p>Care recipient</p> <ul style="list-style-type: none"> • Care recipient (condition)= More than 1 condition <p>Inclusion criteria</p> <ul style="list-style-type: none"> • young adult carers • who were aged 16-24 years • left school • were either in work or NEET (not in employment, education or training) <p>Exclusion criteria</p> <ul style="list-style-type: none"> • Not reported (Please look the inclusion criteria) 	<p>training) - commissioned by Carers Trust to the University of Nottingham</p> <ul style="list-style-type: none"> • Data collection & analysis: Data were collected as part of an online survey questionnaire. No details are reported about the data analysis. 	<ul style="list-style-type: none"> • Transition from education to work 	<ul style="list-style-type: none"> • 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? - Can't tell (there was no discussion about how the method was decided). • 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? - Can't tell (It was unclear whether saturation of data was reached) • Q6: Has the relationship between researcher and participants been adequately considered? - Can't tell (relationship between researcher and participants has not been adequately considered and reported in the paper) • Q7: Have ethical issues been taken into consideration? - Can't tell (No details on ethical issues - for example informed consent or confidentiality, or ethics committee approval) has been reported) • Q8: Was the data analysis sufficiently rigorous? - Can't tell

Study details	Participants	Methods	Outcomes and Themes	Comments
				<p>(In the paper is not discussed if saturation was achieved for discontinuing data collection and/or analysis)</p> <ul style="list-style-type: none"> • 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 <p>Methodological Limitations: Unclear concerns</p>
<p>Full citation Vickerstaff, Sarah, et al., Employment support for carers (Research report no 597), 2009</p> <p>Ref Id 718938</p> <p>Country/ies where the study was carried out UK</p> <p>Study type Qualitative research study</p> <p>Aim of the study The aims of this qualitative research were to examine what employment supports are needed for carers currently in work or those who are currently caring or have recently ended a spell of caring and want to return to paid employment</p>	<p>Sample size N = 55 adult carers</p> <p>Characteristics</p> <p>Carer</p> <ul style="list-style-type: none"> • Carer (age)= Under 50/Over 50 years (n): 24/31 • Carer gender (n)- M/F= 13/42 • Caring and working/Caring and not working (n)/former carers: 26/16/13 <p>Professionals</p> <ul style="list-style-type: none"> • N/A <p>Care recipient</p> <ul style="list-style-type: none"> • Care recipient (condition)= More than 1 condition <p>Inclusion criteria</p>	<ul style="list-style-type: none"> • Recruitment methods: Carers were recruited purposively through a mixture of methods: 1) carers' information and nursing support groups; 2) local employers; 3) care homes; 4) adult training centres; 5) local newspapers and free local newspapers; and 6) participant referrals. • Data collection & analysis: Data were collected through semi-structured interviews that took place at the respondent's home. Before the start of the interview respondents were given a financial gift to thank them for taking part (£25 per individual respondent). To ensure consistency as far as possible, all interviewers were 	<ul style="list-style-type: none"> • Information availability and appropriateness to carers' needs • Unsupportive managers & colleagues • Financial difficulties • Distance, transport and travelling time • Unhelpful attitudes of family or friends • Commitment to care recipient (Barriers to obtain work or to return work) • Carers' physical health and emotional well-being • Carers' personal factors (for example identity, commitment to career) • Identity 	<p>Limitations (assessed using the CASP checklist for qualitative studies)</p> <ul style="list-style-type: none"> • Q1: Was there a clear statement of the aims of the research? - Yes • Q2: Was a qualitative methodology appropriate? - Yes • Q3: Was the research design appropriate to address the aims of the research? - Yes • Q4: Was the recruitment strategy appropriate to the aims of the research? - Yes • Q5: Were the data collected in a way that addressed the research issue? - Yes • Q6: Has the relationship between researcher and participants been adequately considered? - Yes

Study details	Participants	Methods	Outcomes and Themes	Comments
<p>Study dates</p> <ul style="list-style-type: none"> • Publication date: 2009 • Data collection: 2007 <p>Source of funding This study was funded by the Department for Work and Pensions</p>	<ul style="list-style-type: none"> • Not reported (The only information provided is that were selected carers based on their residency: they were recruited from a number of poorer towns, with higher than national average rates of unemployment) <p>Exclusion criteria</p> <ul style="list-style-type: none"> • Not reported (Please look the inclusion criteria) 	<p>trained by the lead researcher. All the interviews were transcribed and analysed using QSR NVivo 7. The interviews were coded interpretively for references to factors affecting continued working or ability to return to work and respondents' experience of the support and help they received from informal and formal sources.</p>	<ul style="list-style-type: none"> • Carers' personal factors (for example identity, commitment to career) • Commitment to career • Respite care (Support from social care services) • Paying for care • Voluntary organisations • NHS • Jobcentre Plus • Jobcentre Plus office • Provision of employment advice and support • Expertise about carers • The type of work being offered • Work Focused Interviews • Better Off Calculation • Financial support for carers (for example Carer's Allowance) • Complexity of benefits • Value of benefits • Inflexibility of benefit rules • Work-related flexibility and help • Self-employment • Working from home • Time off • Agency work • Supportive employers, managers and colleagues • Employer support 	<ul style="list-style-type: none"> • Q7: Have ethical issues been taken into consideration? - Yes • Q8: Was the data analysis sufficiently rigorous? - Can't tell (In the paper is not discussed if saturation was achieved for discontinuing data collection and/or analysis) • 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 <p>Methodological Limitations: Minor concerns</p>

Study details	Participants	Methods	Outcomes and Themes	Comments
			<ul style="list-style-type: none"> Line managers Support from colleagues Culture of the organisation Support from family and friends 	
<p>Full citation Yeandle, Sue, et al., Managing caring and employment (Carers, employment and services report series), 2007</p> <p>Ref Id 714021</p> <p>Country/ies where the study was carried out UK</p> <p>Study type Qualitative cross-sectional survey</p> <p>Aim of the study The aims of this qualitative research were to explore how services are used by carers of working age to support them in managing caring alongside paid employment, and to explore the situation and perspectives of those who have given up work to care, or who, as carers, are finding it difficult to enter or return to work.</p> <p>Study dates</p> <ul style="list-style-type: none"> Publication date: 2007 	<p>Sample size N = 143 adult carers</p> <p>Characteristics Carer</p> <ul style="list-style-type: none"> Carer (age)= not reported Carer gender (n)- M/F= not reported Caring and working/Caring and not working (n): 93/50 <p>Professionals</p> <ul style="list-style-type: none"> N/A <p>Care recipient</p> <ul style="list-style-type: none"> Care recipient (condition)= More than 1 condition <p>Inclusion criteria</p> <ul style="list-style-type: none"> Carers involved in the Carers, Employment and Services (CES) survey (2006-7) Who had given consent to further involvement in the study <p>Exclusion criteria</p>	<ul style="list-style-type: none"> Recruitment methods: Carers were recruited in the study if they were part of the Carers, Employment and Services (CES) survey conducted in 2006-7 at the University of Leeds, and commissioned by Carers UK. Contact was made with carers who had given consent to further involvement in the study, and an appointment booked by telephone. Data collection & analysis: Data were collected through semi-structured interviews that took place either in the interviewee's home or at their workplace. The interview schedule was structured to capture the carer's experience of social and other services in relation to their employment situation, including the strengths and weaknesses of the existing system, their employer's attitude to working carers, and perceptions of ideal services. The interview material was transcribed by 	<ul style="list-style-type: none"> Information availability and appropriateness to carers' needs (Difficulties in accessing social services support) Limited flexibility to the carers' needs (Difficulties in accessing social services support) Limited flexibility to the carers' needs (Difficulties in accessing social services support) Working hours and Flexibility Commitment to care recipient (Barriers to obtain work or to return work) Wishes of care recipients (Barriers to obtain work or to return work) Carers' personal factors (for example identity, commitment to career) Respite care Financial support for carers (for example Carer's Allowance) Supportive employers, managers and colleagues Support from family and friends 	<p>Limitations (CASP- checklist for qualitative studies)</p> <ul style="list-style-type: none"> 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? - Can't tell (there was no discussion about how the method was decided). Q4: Was the recruitment strategy appropriate to the aims of the research? - can't tell (Insufficient detail on how included carers were selected) 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? - Can't tell (relationship between researcher and participants has not been adequately considered and reported in the paper)

Study details	Participants	Methods	Outcomes and Themes	Comments
<ul style="list-style-type: none"> • Data collection: 2006/7 <p>Source of funding This study was funded by Carers UK</p>	<ul style="list-style-type: none"> • Not reported (Please look the inclusion criteria) 	<p>the interviewer. Field-notes were included as well as verbatim quotations to capture interviewees' direct experiences of caring, and the completed templates were then subjected to a thematic analysis.</p>		<ul style="list-style-type: none"> • Q7: Have ethical issues been taken into consideration? - Yes • Q8: Was the data analysis sufficiently rigorous? - Can't tell (no details to assess whether the data analysis approach) • 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 <p>Methodological Limitations: Unclear concerns</p>

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

Appendix E – Forest plots

Forest plots for review question: What are the most effective, cost-effective and acceptable interventions, tools or approaches to support adult carers to enter, remain in, and/or return to (i) work, (ii) education, and (iii) training?

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

Appendix F – GRADE tables

GRADE tables for review question: What are the most effective, cost-effective and acceptable interventions, tools or approaches to support adult carers to enter, remain in, and/or return to (i) work, (ii) education, and (iii) training?

Individualised support

Table 7: Summary of evidence (GRADE): relationship between employment rates of carers and care-recipients' use of individually identified health and social care services or combinations of health and social care services.

Quality assessment							Number of people	Effect ²	Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations				
Employment rates of women carers										
1 (Pickard 2015)	observational studies ¹	no serious	no serious	no serious	no serious	none	4106	<p>There were a significant association between the employment rate of women carers and:</p> <ul style="list-style-type: none"> • Use of home care only OR³ = 1.64 (95% CI, 1.29-2.07) • Use of day care only OR³ = 1.26 (95% CI, 1.00-1.59) • Use of personal assistant only OR³ = 1.74 (95% CI, 1.27-2.37) • Use of meals-on-wheels only OR³ = 2.85 (95% CI, 1.13-7.21) • Use of home care and day care OR³ = 1.65 (95% CI, 1.10-2.48) • Use of day care and care home OR³ = 1.65 (95% CI, 1.21-2.25) • Use of day care and personal assistant OR³ = 2.13 (95% CI, 1.38-3.31) • Use of meals-on-wheels and homecare OR³ = 1.87 (95% CI, 1.05-3.30) • Use of home care, day care and care home OR³ = 2.24 (95% CI, 1.25-4.02) 	LOW	CRITICAL

Quality assessment							Number of people	Effect ²	Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations				
								<ul style="list-style-type: none"> • Use of home care, day care and personal assistant OR³ = 2.26 (95% CI, 1.44-3.57) • Use of other combination of services OR³ = 2.10 (95% CI, 1.51-2.93) <p>There were not a significant association between the employment rate of women carers and:</p> <ul style="list-style-type: none"> • Use of care home only OR³ = 1.10 (95% CI, 0.74-1.65) • Use of home care and care home OR³ = 1.16 (95% CI, 0.78-1.74) • Use of home care and personal assistant OR³ = 1.26 (95% CI, 0.78-2.03) 		
Employment rates of men carers										
1 (Pickard 2015)	observational studies ¹	no serious	no serious	no serious	no serious	none	2198	<p>There were a significant association between the employment rate of men carers and:[*]</p> <ul style="list-style-type: none"> • Use of home care only OR³ = 1.69 (95% CI, 1.27-2.25) • Use of personal assistant only OR³ = 2.45 (95% CI, 1.55-3.89) • Use of home care and day care OR³ = 1.96 (95% CI, 1.25-3.06) • Use of home care and care home OR³ = 1.96 (95% CI, 1.22-3.16) • Use of meals-on-wheels and homecare OR³ = 2.74 (95% CI, 1.27-5.91) • Use of other combination of services OR³ = 1.68 (95% CI, 1.04-2.71) <p>There were a significant association between the employment rate of men carers and:</p> <ul style="list-style-type: none"> • Use of care home only OR³ = 0.98 (95% CI, 0.56-1.72) 	LOW	CRITICAL

Quality assessment							Number of people	Effect ²	Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations				
								<ul style="list-style-type: none"> • Use of meals-on-wheels only OR³ = 1.98 (95% CI, 0.59-6.65) • Use of home care and personal assistant OR³ = 1.68 (95% CI, 0.98-2.86) • Use of day care and care home OR³ = 1.67 (95% CI, 0.77-3.62) • Use of day care and personal assistant OR³ = 1.88 (95% CI, 0.87-4.07) • Use of home care, day care and care home OR³ = 1.30 (95% CI, 0.55-3.09) • Use of home care, day care and personal assistant OR³ = 1.52 (95% CI, 0.73-3.18) 		

CI: confidence intervals; OR: odd ratio

1 Correlational cross-sectional study (non-comparative)

2 The odd ratios were adjusted for a number of variables: including the characteristics of the carer, the cared-for person and the nature of the care provided (the specific variable are not reported in the paper)

3 relative to not using paid services

Table 8: Summary of evidence (GRADE): relationship between service receipt by the care recipient and carers leaving work because of caring

Quality assessment							Number of people	Effect ²	Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations				
Employment rates of women carers										
1 (Pickard 2018)	observational studies ¹	no serious	no serious	no serious	no serious	none	166	Carers were more likely to leave work because of: <ul style="list-style-type: none"> • Their care recipients did not use services (relative to care recipients using services) OR = 13.68 (p = 0.016) • They aged 53 years and over (relative to to carers aged under 53 years) 	LOW	CRITICAL

Quality assessment							Number of people	Effect ²	Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations				
								OR = 4.30 ($\rho = 0.032$) • They cared for 20 or more hours a week (relative to carers caring for less) OR = 0.05 ($\rho = 0.026$) • They cared for two or more people (relative to carers caring for one person) OR = 3.76 ($\rho = 0.040$)		

OR: odd ratio; ρ : p value

1 Correlational longitudinal study (non-comparative)

2 The odd ratios were adjusted for a number of variables: including the characteristics of the carer, the cared-for person and the nature of the care provided (the specific variables are not reported in the paper)

Interventions, tools or approaches for improving carers' ability to enter, remain or return to education or training

Table 9: Summary of evidence (GRADE): Role-focused self-help course for supporting carers to remain to work

Quality assessment							Number of people		Effect		Quality	Importance
Number of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Role-focused self-help E-course	WLC Control	Relative (95% CI)	Absolute		
Carer mental health (stress) at 1 and 2 months follow-up - 1 month follow-up (Better indicated by lower values)												
1 ¹	randomised trials	very serious ²	no serious inconsistency	no serious indirectness	no serious imprecision	none	56	59	-	MD 2.4 lower (4.45 to 0.35 lower)	LOW	IMPORTANT
Carer mental health (stress) at 1 and 2 months follow-up - 2 months follow-up (Better indicated by lower values)												
1 ¹	randomised trials	very serious ²	no serious inconsistency	no serious indirectness	no serious imprecision	none	46	52	-	MD 3.3 lower (5.53)	LOW	IMPORTANT

											to 1.07 lower)	
Carer mental health (distress) at 1 and 2 months follow-up - 1 month follow-up (Better indicated by lower values)												
1 ¹	randomised trials	very serious ²	no serious inconsistency	no serious indirectness	no serious imprecision	none	56	59	-	MD 4.4 lower (7.09 to 1.71 lower)	LOW	IMPORTANT
Carer mental health (distress) at 1 and 2 months follow-up - 2 months follow-up (Better indicated by lower values)												
1 ¹	randomised trials	very serious ²	no serious inconsistency	no serious indirectness	no serious imprecision	none	46	52	-	MD 7.4 lower (10.39 to 4.41 lower)	LOW	IMPORTANT

MD: mean difference

1 Boezeman 2018

2 The quality of the evidence was downgraded by two levels because of the high risk of attrition bias (due to amount of incomplete outcome data: high dropout rate both at 1 and 2 months follow-up, in the 2-month analysis assessments were much lower [70.0%] in the intervention group than those in the control group [82.1%]), and high risk of other bias, as reported in the report itself (1: high risk of self-selection bias [carers had self-applied for participation in the study and some of them discontinued their participation on their own initiative]; and 2: intervention adherence was not monitored and a waiting-list control condition was used [high risk of contamination bias])

GRADE - CERQual tables for review question: What are the most effective, cost-effective and acceptable interventions, tools or approaches to support adult carers to enter, remain in, and/or return to (i) work, (ii) education, and (iii) training?

Workplace support

Table 10: Summary of evidence (GRADE-CERQual), Theme 1: Supporting a carer to enter, remain in, or return to work

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
Support from formal workplace policies							
1 (Arksey 2005)	Semi-structured interviews and focus groups	Some carers described how their organisation had invited them to register their caring role with their manager so it could be taken into account	Minor 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
		should a problem ever arise. In some carers' and employers' view, this was useful because it helped ensure that carers were identified as a specific group, it recognised their existence and it prevented them from remaining invisible.					
Support from work-related flexibilities							
3 (Arksey 2005; Bernard 2007; Vickerstaff 2009)	1: Semi-structured interviews and focus groups; 2: Semi-structured interviews	Carers' suggested some workplace-related actions would help carers to work while caring. Carers felt that flexibility in relation to days/hours worked, and working at home, would help them deal with emergencies and planned appointments.	Minor concerns ³	No or very minor concerns	No or very minor concerns	Minor concerns ⁴	MODERATE
Support from employers, managers and colleagues							
4 (Arksey 2005; Bernard 2007; Yeandle 2007; Vickerstaff 2009)	1: Semi-structured interviews and focus groups; 3: Semi-structured interviews	Many adult carers valued supportive and understanding managers and colleagues; this could lead to good working relationships and meant the carer knew where they stood in terms of formal and informal flexibility.	Moderate concerns ⁵	No or very minor concerns	No or very minor concerns	No or very minor concerns	MODERATE

¹ Evidence was downgraded due to substantial methodological limitations (In the paper is not discussed if saturation was achieved for discontinuing data collection and/or analysis)

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

³ Evidence was downgraded due to substantial methodological limitations (Bernard 2007: not clearly reporting the sampling method, or the relationship between the researcher and participants; furthermore, this study did not report whether saturation was achieved in terms of data collection or data analysis. Furthermore, all papers did not discuss if saturation was achieved for discontinuing data collection and/or analysis)

⁴ Evidence was downgraded due to minor concerns with the adequacy of data, as only 3 studies supported the review's findings (offering thin data)

5 Evidence was downgraded due to potential methodological limitations in two studies that contributed to the findings (Bernard 2007; Yeandle 2007: not clearly reporting the sampling method, or the relationship between the researcher and participants; furthermore, this study did not report whether saturation was achieved in terms of data collection or data analysis)

Table 11: Summary of evidence (GRADE-CERQual), Theme 2: Barriers to remain to work

STUDY information		Description of Theme or Finding	CERQUAL Quality Assessment				Overall Confidence
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	
Lack of flexibility							
5 (Carmichael 2008; Arksey 2005; Yeandle 2007; Sempik 2014; Vickerstaff 2009)	1: Semi-structured interviews and focus groups; 1: Semi-structured interviews and questionnaires; 1: Online survey questionnaire; 2: Semi-structured interviews	Many adult carers felt that the lack of flexibility in work hours and practices was a particular problem. Several carers emphasised the importance of working part-time to allow them to combine working and caring. In addition, some carers expressed specific needs within the workplace that, although relatively simple for employers to administer, were not always met and this made their lives difficult (like having a mobile phone). Also, many adult carers working in private sector organisations had difficulty managing time boundaries at work (this is in contrast to public or voluntary organisations).	Minor concerns ¹	No or very minor concerns	No or very minor concerns	No or very minor concerns	MODERATE
Unsupportive managers and colleagues							
3 (Arksey 2005; Sempik 2014; Vickerstaff 2009)	1: Semi-structured interviews and focus groups; 1: Online survey questionnaire;	Many adult carers perceived, often based on experience, that employers would view their caring responsibilities as an unwelcome intrusion. The result of this situation, and	Minor concerns ²	No or very minor concerns	No or very minor concerns	Minor concerns ^x	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
	1: Semi-structured interviews	often hiding their true circumstances from employers was stress, often accompanied by feelings of guilt.					

1 Evidence was downgraded due to potential methodological limitations (All studies did not report whether saturation was achieved in terms of data collection or data analysis)

2 Evidence was downgraded due to potential methodological limitations (All studies did not report whether saturation was achieved in terms of data collection or data analysis)

Individualised support

Table 12: Summary of evidence (GRADE-CERQual), Theme 3: Support from social care services

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
Carer's assessment							
2 (Arksey 2005; Seddon 2004)	1: Semi-structured interviews and focus groups; 1: Semi-structured interviews	Many adult carers reported the limited opportunities to discuss carers' employment issues during the course of the carers' assessment and to the fact that the timing and setting for assessments should be flexible to accommodate the needs of carers in employment.	Moderate concerns ¹	No or very minor concerns	No or very minor concerns	Serious concerns ²	VERY LOW
Respite care and replacement services							
2 (Pickard 2018; Yeandle 2007; Vickerstaff 2009)	2: Semi-structured interviews	Many adult carers felt that the services and support they had in place (including respite care and replacement care services) were very beneficial to improve their ability to remain in, or return to, work.	Moderate concerns ³	No or very minor concerns	No or very minor concerns	Minor concerns ⁴	LOW
Paying for care							

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 (Yeandle 2007; Vickerstaff 2009)	Semi-structured interviews	Many adult carers opted to pay privately for care services, other used vouchers for carers (provided by socials service department) to buy in their own care, whilst others used direct payments or welfare benefits to help with service costs.	Moderate concerns ³	No or very minor concerns	No or very minor concerns	Serious concerns ²	VERY LOW

¹ Evidence was downgraded due to substantial methodological limitations in 1 study that contributed to the findings (Seddon 2004: no details on the recruitment strategy, data collection and analysis methods, and whether saturation was achieved in terms of data collection or data analysis)

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

³ Evidence was downgraded due to potential methodological limitations in 1 study that contributed to the findings (Yeandle 2007: not sufficient details on how included carers were selected, and whether saturation was achieved in terms of data collection or data analysis)

⁴ Evidence was downgraded due to minor concerns with the adequacy of data, as only 3 studies supported the review's findings (offering thin data)

Table 13: Summary of evidence (GRADE-CERQual), Theme 4: Support from Jobcentre Plus and DWP

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
Jobcentre Plus							
2 (Arksey 2005; Vickerstaff 2009)	1: Semi-structured interviews and focus groups; 1: Semi-structured interviews	Many adult carers have mixed views about their experiences with Jobcentre Plus. On one hand, they reported that advisers gave carers useful advice in relation to, say, claiming benefits such as Carer's Allowance or Jobseeker's Allowance (JSA). In contrast carers expressed a need for someone in Jobcentre Plus with specific expertise on carers, and who are able to	Minor concerns ¹	No or very minor concerns	No or very minor concerns	Moderate 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
		understand or offer the kind of flexible jobs that carers need.					
Work Focused Interviews (WFI)							
2 (Arksey 2005; Vickerstaff 2009)	1: Semi-structured interviews and focus groups; 1: Semi-structured interviews	Those carers who had experienced a WFI did not find them particularly useful; carers reported that WFIs tended to be short and the discussions with a personal adviser were unlikely to influence carers' decisions about obtaining paid work.	Minor concerns ¹	No or very minor concerns	No or very minor concerns	Moderate concerns ²	LOW
Better Off Calculation							
2 (Arksey 2005; Vickerstaff 2009)	1: Semi-structured interviews and focus groups; 1: Semi-structured interviews	Some adult carer felt slightly affronted by the experience of having a 'Better Off Calculation', as they had not gone back to work for the money.	Minor concerns ¹	No or very minor concerns	No or very minor concerns	Moderate concerns ²	LOW

¹ Evidence was downgraded due to substantial methodological limitations (In both papers is not discussed if saturation was achieved for discontinuing data collection and/or analysis)

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

Table 14: Summary of evidence (GRADE-CERQual), Theme 5: Barriers to remain to work

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
Difficulties in accessing care services							
2 (Arksey 2005; Pickard 2018)	Semi-structured interviews and focus groups	Adult carers' perceptions on the availability of services, together with the way in which they were provided, influenced their decisions about whether, when and how much to work.	Minor concerns ¹	No or very minor concerns	No or very minor concerns	Moderate 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
		In addition, paperwork, bureaucracy and red tape emerged as key obstacles that inhibited carers' use of services.					
Information availability and appropriateness to carers' needs							
5 (Arksey 2005; Pickard 2018; Seddon 2004; Yeandle 2007; Vickerstaff 2009)	1: Semi-structured interviews and focus groups; 3: Semi-structured interviews	Carers experienced difficulties in accessing services. These difficulties were associated with the limited information on support services, carer problems in understanding and assimilating this information and carers' limited time and energies to identify sources of support. Additionally, many adult carers identified the fragmented nature of the 'support system' and the fact that they have to go to a number of different agencies to get information as factors inhibiting their use of services.	Moderate concerns ³	No or very minor concerns	No or very minor concerns	No or very minor concerns	MODERATE
Limited flexibility to the carers' needs							
2 (Arksey 2003; Yeandle 2007)	2: Semi-structured interviews	Many adult carers believe the number and timing of appointments they were required to attend hindered or disrupted their work routines. Some carers experienced this as a conflict between work and care or a barrier to employment and felt appointments could be arranged to be more sensitive to their needs at work.	Moderate concerns ⁴	No or very minor concerns	No or very minor concerns	Serious concerns ⁵	VERY LOW

- 1 Evidence was downgraded due to minor methodological limitations (In the paper is not discussed if saturation was achieved for discontinuing data collection and/or analysis)
 2 Evidence was downgraded due to substantial concerns with the adequacy of data, as only 2 studies supported the review's findings (offering poor data)
 3 Evidence was downgraded due to substantial methodological limitations
 4 Evidence was downgraded due to substantial methodological limitations in one study that contributed to the findings (not clearly reporting the sampling method, or the relationship between the researcher and participants. Furthermore, both studies did not report whether saturation was achieved in terms of data collection or data analysis)
 5 Evidence was downgraded due to substantial concerns with the adequacy of data, as only 2 studies supported the review's findings (offering thin data)

Financial assistance

Table 15: Summary of evidence (GRADE-CERQual), Theme 6: Financial support for 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
Carer's Allowance							
4 (Arksey 2005; Carmichael 2008; Yeandle 2007; Vickerstaff 2009)	1: Semi-structured interviews and focus groups; 1: Semi-structured interviews and questionnaires; 2: Semi-structured interviews	Many adult carers who experienced 'Carer's Allowance' sometimes found this benefit complex to access and use, inflexible in terms of application rules, and of relatively low monetary value.	Minor concerns ¹	No or very minor concerns	No or very minor concerns	No or very minor concerns	MODERATE

- 1 Evidence was downgraded due to potential methodological limitations (In all papers is not discussed if saturation was achieved for discontinuing data collection and/or analysis)
 2 Evidence was downgraded due to major concerns with the adequacy of data, as only 1 study supported the review's findings (offering poor data)

Table 16: Summary of evidence (GRADE-CERQual), Theme 7: Financial difficulties - barriers to remain to work

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
4 (Arksey 2005; Carmichael 2008; Yeandle 2007;	1: Semi-structured interviews and focus groups; 1: Semi-structured interviews and	The decisions made by many carers centred on finances (to balancing caring responsibilities and financial hardship), in particular the necessity to earn 'good'	Minor concerns ¹	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
Vickerstaff 2009)	questionnaires; 2: Semi-structured interviews	salaries and about retirement. The decision to give up work to care is not an easy one, since it puts carers under considerable financial pressure.					

¹ Evidence was downgraded due to minor methodological limitations (All studies did not report whether saturation was achieved in terms of data collection or data analysis)

Other qualitative themes

Table 17: Summary of evidence (GRADE-CERQual), Theme 8: Predisposing factors to seeking 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
Carers' physical health and emotional well-being							
1 (Arksey 2005)	1: Semi-structured interviews and focus groups	Many adult carers felt paid work contributed to their sense of self-esteem, physical health and emotional well-being. This could be a predisposing factor to seeking support to enter or remain in work.	Minor concerns ¹	No or very minor concerns	No or very minor concerns	Serious concerns ²	VERY LOW
Carers' personal factors: identity							
2 (Arksey 2005; Vickerstaff 2009)	1: Semi-structured interviews and focus groups; 1: Semi-structured interviews	Many adult carers felt that their decision about whether to take on a caring role, was influenced by the extent to which they identified themselves as primarily a worker or a carer.	Minor concerns ³	No or very minor concerns	No or very minor concerns	Moderate concerns ⁴	LOW
Carers' personal factors: commitment to career							

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
4 (Arksey 2005; Carmichael 2008; Yeandle 2007; Vickerstaff 2009)	1: Semi-structured interviews and focus groups; 1: Semi-structured interviews and questionnaires; 2: Semi-structured interviews	Many adult carers felt their opportunities for career development were restricted because of their caring responsibilities.	Moderate concerns ⁵	No or very minor concerns	No or very minor concerns	No or very minor concerns	MODERATE

¹ Evidence was downgraded due to potential methodological limitations (In the paper is not discussed if saturation was achieved for discontinuing data collection and/or analysis)

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

³ Evidence was downgraded due to potential methodological limitations (In both papers is not discussed if saturation was achieved for discontinuing data collection and/or analysis)

⁴ Evidence was downgraded due to substantial concerns with the adequacy of data, as only 2 studies supported the review's findings (offering thin data)

⁵ Evidence was downgraded due to substantial methodological limitations (In all papers is not discussed if saturation was achieved for discontinuing data collection and/or analysis. Furthermore, in Yeandle 2007 there were insufficient details on how included carers were selected)

Table 18: Summary of evidence (GRADE-CERQual), Theme 7: Support from family and friends

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 (Bernard 2007; Yeandle 2007; Vickerstaff 2009)	3: Semi-structured interviews	Many adult carers praised the majority of relatives and friends for providing practical support, for relieving them so they can go out to work or help out in emergencies.	Moderate concerns ¹	No or very minor concerns	No or very minor concerns	Minor concerns ²	LOW

¹ Evidence was downgraded due to potential methodological limitations in two studies that contributed to the findings (Bernard 2007; Yeandle 2007: not clearly reporting the sampling method, or the relationship between the researcher and participants. Furthermore, all studies did not report whether saturation was achieved in terms of data collection or data analysis)

² Evidence was downgraded due to major concerns with the adequacy of data, as only 3 studies supported the review findings (offering thin data)

Table 19: Summary of evidence (GRADE-CERQual), Theme 9: Barriers to remain in education or training

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 (Sempik 2014)	Online survey questionnaire	Many young adult carers felt that they would like more support from their teachers and schools in order to balancing education/training needs and caring duties.	Serious concerns ¹	No or very minor concerns	No or very minor concerns	Serious concerns ²	VERY LOW

¹ Evidence was downgraded due to serious methodological limitations in the study that contributed to the review findings (no details on the recruitment strategy, data collection and analysis methods, and whether saturation was achieved in terms of data collection or data analysis)

Table 20: Summary of evidence (GRADE-CERQual), Theme 10: Barriers to remain to work

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
Distance, transport and travelling time							
3 (Arksey 2005; Bernard 2007; Vickerstaff 2009)	1: Semi-structured interviews and focus groups; 2: Semi-structured interviews	Carers gave serious consideration to the practicalities of getting to the workplace and back in decisions about paid work. Distances between work and home and lengthy travel times raised real challenges.	Moderate concerns ¹	No or very minor concerns	No or very minor concerns	Minor concerns ²	MODERATE
Commitment to care recipient							
2 (Arksey 2005; Carmichael 2008)	1: Semi-structured interviews and focus groups; 1: Semi-structured interviews and questionnaires	Carers often give up paid work because they didn't believe that it was compatible with their caring role or because combining caring and employment would be too difficult or stressful.	Minor concerns ³	No or very minor concerns	No or very minor concerns	Serious concerns ⁴	VERY LOW
Wishes and/or needs of care recipients							

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 (Arksey 2005; Carmichael 2008)	1: Semi-structured interviews and focus groups; 1: Semi-structured interviews and questionnaires	Many adult carers reported that the wishes and/or needs of care recipients influenced their decisions about working and caring.	Minor concerns ³	No or very minor concerns	No or very minor concerns	Serious concerns ⁴	VERY LOW
Unhelpful attitudes of family							
2 (Bernard 2007; Vickerstaff 2009)	2: Semi-structured interviews	Some carers perceived a lack of interest of negative attitudes among their family.	Moderate concerns ⁵	No or very minor concerns	No or very minor concerns	Serious concerns ⁶	VERY LOW
Commitment to career							
3 (Yeandle 2007; Carmichael 2008; Vickerstaff 2009)	1: Semi-structured interviews and questionnaires ; 2: Semi-structured interviews	Many adult carers' opportunities for career development were restricted because of their caring responsibilities. Many adult carers in professional jobs were committed to their careers; and as a consequence, they were unwilling to lose the investment they had built up over their working life.	Minor concerns ⁷	No or very minor concerns	No or very minor concerns	Minor concerns ²	MODERATE

¹Evidence was downgraded due to potential methodological limitations (All studies did not report whether saturation was achieved in terms of data collection or data analysis)

²Evidence was downgraded due to minor concerns with the adequacy of data, as only 3 studies supported the review's findings (offering thin data)

³Evidence was downgraded due to unclear methodological limitations in one study that contributed to the findings (Carmichael 2008: no enough details on the recruitment strategy, data collection and analysis methods)

⁴Evidence was downgraded due to substantial concerns with the adequacy of data, as only 2 studies supported the review's findings (offering poor data)

⁵Evidence was downgraded due to potential methodological limitations in one study that contributed to the findings (Bernard 2007: not clearly reporting the sampling method, or the relationship between the researcher and participants; furthermore, this study did not report whether saturation was achieved in terms of data collection or data analysis)

⁶Evidence was downgraded due to substantial concerns with the adequacy of data, as only 2 studies supported the review's findings (offering thin data)

⁷Evidence was downgraded due to potential methodological limitations in the study that contributed to the findings (Yeandle 2007: not sufficient details on how included carers were selected, and whether saturation was achieved in terms of data collection or data analysis. Furthermore, all studies did not report whether saturation was achieved in terms of data collection or data analysis)

Table 21: Summary of evidence (GRADE-CERQual), Theme 11: Lack of confidence and self-esteem - barriers to enter and/or to return to work

STUDY information		Description of Theme or Finding	CERQUAL Quality Assessment				Overall Confidence
Number of studies	Design		Methodological Limitations	Coherence of findings	Applicability of evidence	Adequacy of Data	
Lack of confidence and self-esteem							
1 (Seddon 2004)	Semi-structured interviews	Some carers and agency staff felt that the lack of confidence and self-esteem among carers was a potential barrier to attending job interviews.	Serious concerns ¹	No or very minor concerns	No or very minor concerns	Serious concerns ²	VERY LOW
Limited link with employers							
1 (Seddon 2004)	Semi-structured interviews	Local authority staff reported that developments in employment practice for carers occur in isolation from health and social care initiatives. Links between statutory service providers and employers were deemed to be limited and appear to be forged on an ad hoc basis.	Serious concerns ¹	No or very minor concerns	No or very minor concerns	Serious concerns ²	VERY LOW
Transition from education to work							
1 (Sempik 2014)	Online survey questionnaire	Many young adult carers felt that they had not received good career advice at school; and that the advice did not consider their caring role. This could be an impeding factor to enter work or training from school.	Serious concerns ¹	No or very minor concerns	No or very minor concerns	Serious concerns ²	VERY LOW

¹ Evidence was downgraded due to serious methodological limitations in the study that contributed to the review findings (no details on the recruitment strategy, data collection and analysis methods, and whether saturation was achieved in terms of data collection or data analysis)

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

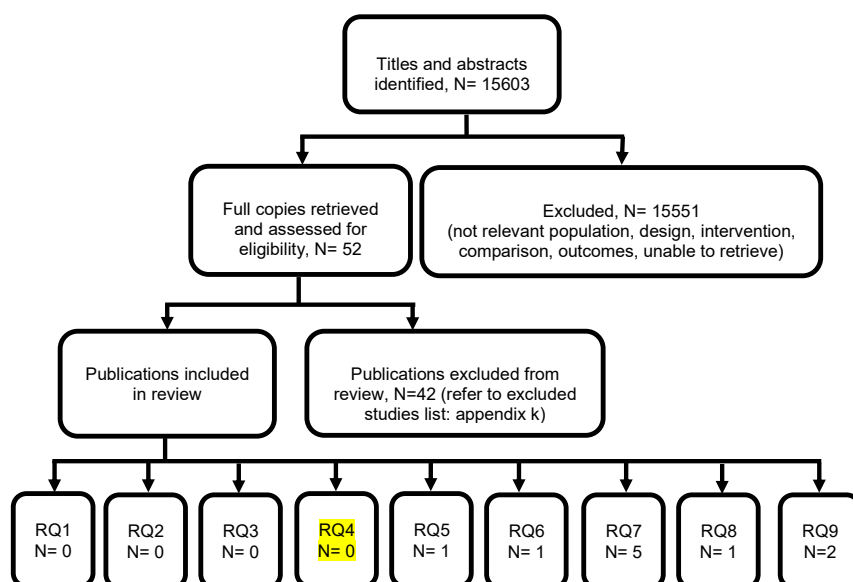
1 Appendix G – Economic evidence study selection

2 Economic evidence study selection for review question: What are the most 3 effective, cost-effective and acceptable interventions, tools or approaches to 4 support adult carers to enter, remain in, and/or return to (i) work, (ii) education, 5 and (iii) training?

6 A global economic literature search was undertaken for supporting adult carers. This covered
7 all 9 review questions (RQs) in this guideline. As shown in Figure 5 below, no economic
8 study was identified which was applicable to this review question.

9 **Figure 5: Study selection flow chart**

10
11



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- 1
- 2

1 **Appendix H – Economic evidence tables**

2 **Economic evidence tables for review question: What are the most effective, cost-**
3 **effective and acceptable interventions, tools or approaches to support adult**
4 **carers to enter, remain in, and/or return to (i) work, (ii) education, and (iii)**
5 **training?**

6 No economic evidence was identified for this review

7

8

1 **Appendix I – Economic evidence profiles**

2 **Economic evidence profiles for review question: What are the most effective,**
3 **cost-effective and acceptable interventions, tools or approaches to support**
4 **adult carers to enter, remain in, and/or return to (i) work, (ii) education, and (iii)**
5 **training?**

6 No economic evidence was identified for this review

7

8

1 **Appendix J – An economic model to evaluate the costs and** 2 **cost-utility of replacement care to support adult carers to** 3 **enter, remain in or return to work**

4

5 **Introduction**

6 It has been estimated that the value of unpaid carer's contribution to the UK economy is
7 £132 billion (Valuing Carers 2015 - the rising value of carers' support) and this value is rising
8 in the context of an ageing population. Many carers find it difficult to juggle the competing
9 pressures of paid work with their caring responsibilities and may suffer financial loss and a
10 reduction in well-being as a result.

11 The Care Act (2014) requires that local authorities promote the individual "well-being" of
12 carers. It is noted in the Act that participation in work, training and education is part of
13 individual well-being and replacement care, alongside other practices that promote flexible
14 working, is considered as a means to achieving the objectives of participation in work,
15 education and training.

16 Adult carers can face a number of challenges in the workplace such as a lack of support,
17 poor attitudes and a lack of flexibility which can make it difficult to co-ordinate work and
18 caring. These challenges can ultimately cause carers to leave the labour market. A recent
19 study (Pickard 2017) has estimated that 345,000 carers have left employment because their
20 caring responsibilities with an estimated public expenditure cost of £2.9 billion per year
21 arising because increased payment of social security benefits and reduced tax receipts. The
22 authors contend that if there was "greater public investment in social care, such as
23 'replacement care' to support carers in employment, and fewer carers then left employment,
24 public spending on benefits would be lower and revenues from taxation would be higher".

25 Adult carers often are experienced employees and have acquired many skills. Not only may
26 that human capital depreciate when carers are out of the labour market for any length of time
27 but employers also need to replace those lost skills. It has been estimated that the cost of an
28 employee leaving work could be 50%-150% of their salary (HM Government, Employers for
29 Carers and Carers UK, 2013).

30 **Aim**

31 An economic model was developed to assess the costs and cost-utility of replacement care
32 provided to adult carers to support them to return to work.

33 **Methods**

34 **Setting and population**

35 In line with the NICE reference case (<https://www.nice.org.uk/process/pmg20>) for an
36 intervention with health and non-health outcomes, the evaluation was undertaken from a
37 societal perspective and, for the purposes of this analysis, the intervention of replacement
38 care was offered to all adult carers not in employment as a result of caring. A time horizon of
39 1-year was chosen primarily for ease of exposition. The model treats the number of carers
40 out of work as a result of caring as a "stock. It does not model "flows" into and out of a caring
41 role other than as a function of the number of hours caring. As the intervention would be on-
42 going the relationship between costs and outcomes over time would be a linear one.

43 Labour force participation, broken down by age and gender, is shown in Table 22. This
44 labour force data was used to make an estimate of adult carers who would work if adult carer

1 employment rates were representative of the general population. This was undertaken using
 2 the proportion employed of the total population in each age category in conjunction with an
 3 estimate of the total number of carers in each age category, estimated from the population
 4 data in Table 22 and the data on proportion caring by age in Table 23.

5 **Table 22: Labour force by age and gender**

Category	Age 18-24 ^a	Age 25-49	Aged 50-64	Age 65+
All	5,906,900	18,433,400	10,403,600	9,836,100
Employed	3,167,400	15,540,500	7,469,900	1,029,600
Male proportion	0.511	0.498	0.492	0.463
Female proportion	0.489	0.502	0.508	0.537

6 Data from the 2011 census (ONS, 2011) reported in "Walking the tightrope". (Carers UK,
 7 2016) was used in the model to estimate the baseline hours of unpaid caring by age and
 8 gender, as described in Table 23.

9 **Table 23: Proportion of population caring by hours per week caring by age and gender**

Category	Age 18-24			Age 25-49			Age 50-64			Age 65+		
	1-19	20-49	50+	1-19	20-49	50+	1-19	20-49	50+	1-19	20-49	50+
Male	1.6%	0.3%	0.2%	5.4%	1.1%	1.3%	11.9%	1.7%	2.9%	7.4%	1.8%	5.8%
Female	2.1%	0.4%	0.2%	7.6%	1.6%	3.0%	16.1%	3.0%	4.5%	6.5%	1.6%	5.0%
Combined	1.9%	0.3%	0.2%	6.5%	1.4%	2.2%	14.0%	2.4%	3.7%	6.9%	1.7%	5.4%
Total	2.4%			10.0%			20.1%			14.0%		

10

11 In order to derive greater granularity, with an estimate of the distribution of the percentage
 12 caring for each additional hour, the combined percentages in Table 23 were plotted, for the
 13 mid-point of the hours range, and a best fit line estimated (using the method of least squares)
 14 for this relationship in order to give an approximate probability density function. This is shown
 15 for the 4 age bands in Table 23 in Figure 6, Figure 7, Figure 8 and Figure 9 respectively.

Figure 6: Estimated distribution of hours per week caring, age 18-24

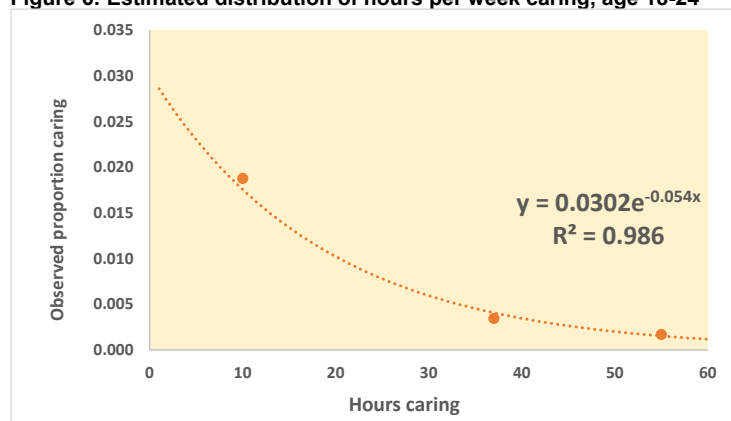
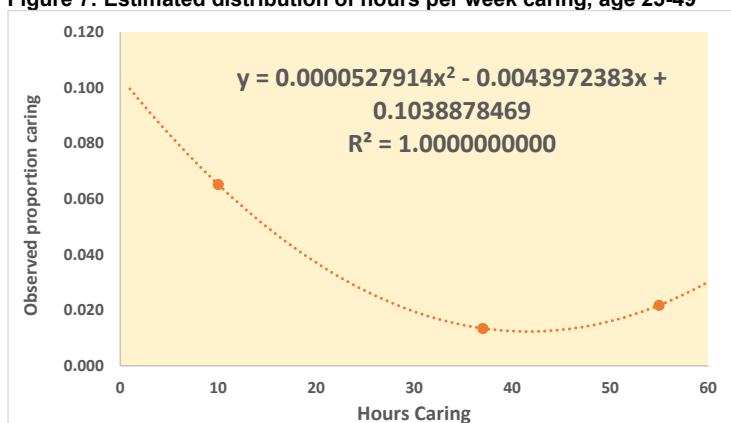


Figure 7: Estimated distribution of hours per week caring, age 25-49



1
2

Figure 8: Estimated distribution of hours per week caring, age 50-64

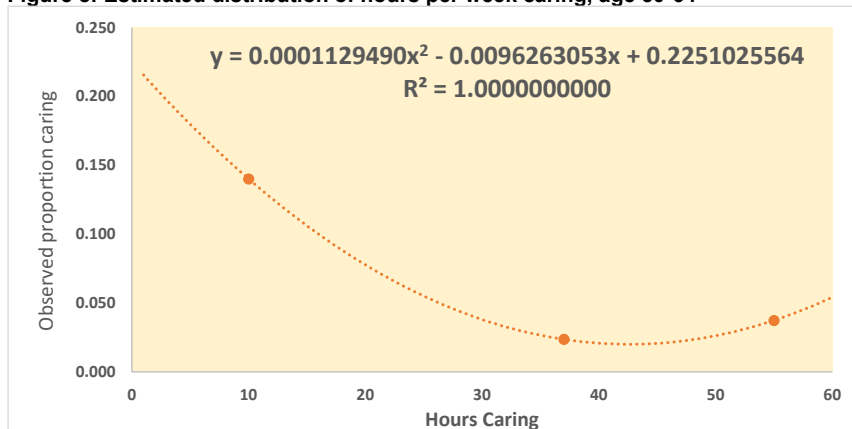
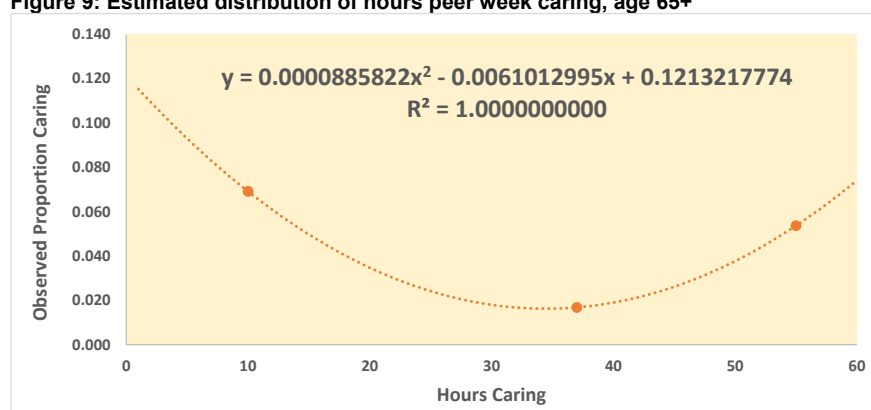


Figure 9: Estimated distribution of hours peer week caring, age 65+



- 1 The fitted values derived from these relationships for each age band are shown in Table 24.
- 2 It should be noted that each of the 3 observed points plotted in Figure 6, Figure 7, Figure 8
- 3 and Figure 9 are the actual proportions for a range of hours and therefore, the vertical axes
- 4 in the figures do not give an estimate of the proportion caring at each hour but to estimate
- 5 the relative frequency distribution for each hour caring per week. To estimate the proportion
- 6 caring for each of the equations shown in Figure 6, Figure 7, Figure 8 and Figure 9 above, y
- 7 is calculated for each hour (x) in the range 1-60 hours. These 60 values are then summed
- 8 which enables a weight to be calculated for each hour, which for a given hour x is given by:

9 $Weight w_i = y_i \div (\sum_i^{60} y_i)$

- 10 The bottom row of Table 23 gives the total proportion of the age band that are carers and for
- 11 each hour the estimated proportion caring is given by:

- 12 Estimated proportion caring for x_i hours = weight w_i x total proportion of age band that are
- 13 carers.

14 **Table 24: Proportion of age band involved in caring by hours of caring**

Hours per week caring	Age 18-24	Age 25-49	Age 50-64	Age 65+
1	0.001309	0.004798	0.010253	0.006075
2	0.001241	0.004593	0.009811	0.005767
3	0.001175	0.004394	0.009380	0.005469
4	0.001114	0.004200	0.008960	0.005180
5	0.001055	0.004011	0.008551	0.004901
6	0.001000	0.003827	0.008152	0.004631
7	0.000947	0.003648	0.007764	0.004370
8	0.000897	0.003475	0.007387	0.004119
9	0.000850	0.003306	0.007020	0.003877
10	0.000805	0.003142	0.006665	0.003644
11	0.000763	0.002984	0.006320	0.003420
12	0.000723	0.002830	0.005985	0.003206

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Hours per week caring	Age 18-24	Age 25-49	Age 50-64	Age 65+
13	0.000685	0.002682	0.005662	0.003002
14	0.000649	0.002539	0.005349	0.002806
15	0.000615	0.002401	0.005047	0.002620
16	0.000583	0.002268	0.004756	0.002443
17	0.000552	0.002140	0.004475	0.002276
18	0.000523	0.002017	0.004205	0.002118
19	0.000495	0.001899	0.003946	0.001969
20	0.000469	0.001786	0.003698	0.001830
21	0.000445	0.001679	0.003460	0.001699
22	0.000421	0.001576	0.003234	0.001579
23	0.000399	0.001479	0.003017	0.001467
24	0.000378	0.001386	0.002812	0.001365
25	0.000358	0.001299	0.002617	0.001272
26	0.000339	0.001217	0.002434	0.001189
27	0.000322	0.001140	0.002261	0.001115
28	0.000305	0.001068	0.002098	0.001050
29	0.000289	0.001001	0.001947	0.000995
30	0.000274	0.000939	0.001806	0.000949
31	0.000259	0.000882	0.001676	0.000912
32	0.000246	0.000831	0.001556	0.000884
33	0.000233	0.000784	0.001447	0.000866
34	0.000220	0.000743	0.001350	0.000858
35	0.000209	0.000706	0.001262	0.000858
36	0.000198	0.000675	0.001186	0.000868
37	0.000187	0.000649	0.001120	0.000887
38	0.000178	0.000628	0.001065	0.000916
39	0.000168	0.000612	0.001021	0.000954
40	0.000159	0.000601	0.000988	0.001001
41	0.000151	0.000595	0.000965	0.001058
42	0.000143	0.000594	0.000953	0.001123
43	0.000136	0.000599	0.000952	0.001199
44	0.000128	0.000608	0.000961	0.001283
45	0.000122	0.000622	0.000982	0.001377
46	0.000115	0.000642	0.001013	0.001480
47	0.000109	0.000667	0.001054	0.001593
48	0.000103	0.000697	0.001107	0.001715
49	0.000098	0.000731	0.001170	0.001846
50	0.000093	0.000771	0.001244	0.001987
51	0.000088	0.000816	0.001329	0.002137
52	0.000083	0.000867	0.001424	0.002296
53	0.000079	0.000922	0.001531	0.002464
54	0.000075	0.000982	0.001647	0.002642
55	0.000071	0.001048	0.001775	0.002830
56	0.000067	0.001118	0.001914	0.003026
57	0.000064	0.001194	0.002063	0.003232

Hours per week caring	Age 18-24	Age 25-49	Age 50-64	Age 65+
58	0.000060	0.001274	0.002223	0.003447
59	0.000057	0.001360	0.002393	0.003672
60	0.000054	0.001451	0.002575	0.003906
Total ^a	0.0239	0.1004	0.2010	0.1397

1 (a) The totals for each age category sum to the the same value as the last row in Table 23

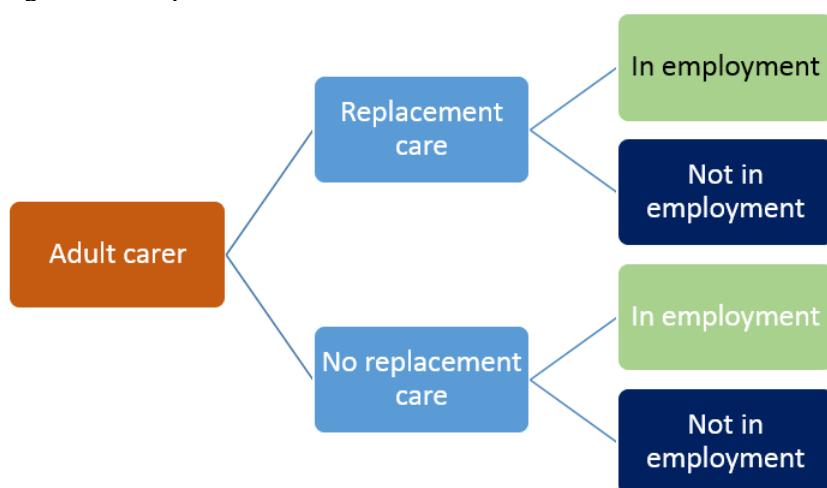
2 By multiplying the proportions in Table 24 by the population data in Table 22 an estimate of
 3 the total number of carers in a given age band caring for a certain number of hours per week
 4 was made. For example, carers aged 18-24 caring for 2 hours per week was given by:

5 $0.001241 \times 5,906,900 = 7,328$ carers

6 Model structure

7 A simple decision analytic framework was used to model the impact of replacement care on
 8 employment. This is illustrated in Figure 10.

Figure 10: Replacement care decision tree



9 Effectiveness

10 In order to estimate how the provision of replacement care could lead to an increase in hours
 11 worked we used an analysis from Age UK reported in "Walking the tightrope". (Carers UK,
 12 2016) which gave the likelihood of being in paid work according to the number of hours per
 13 week caring. These probabilities are reported in Table 25.

14 **Table 25: Carer's likelihood of being in paid work compared to general population**
 15 **according to the hours of caring per week**

Hours of caring per week	Likelihood of being in paid work
0 hours	100%
1-4 hours	98.6%

Hours of caring per week	Likelihood of being in paid work
5-9 hours	88.6%
10-19 hours	78.3%
20-34 hours	62.6%
35-49 hours	58.3%
50-99 hours	45.3%

1

2 Earlier, it was noted that the model estimated that there were 7,328 adult carers aged 18-24
3 years who were providing care for 2 hours per week. From Table 22, the model estimates
4 that if these carers were representative of the general population then the number employed
5 would be given by:

$$6 \quad 7,328 \times (3,167,400 \div 5,906,900) = 3,929$$

7 The model then uses the data in Table 25 to estimate that the actual number of 18-24 year
8 olds in work who provide 2 hours care per week would be:

$$9 \quad 3,929 \times 0.986 = 3,874$$

10 To assess the impact of replacement care the model then subtracted the hours of
11 replacement care provided per week from the baseline hours of care. So, in the example
12 above if 2 hours of replacement care per week were offered to 18-24 year olds, then those
13 previously providing 2 hours of care per week would now not be providing any hours of care
14 and from Table 25 the change in their likelihood of being in paid work would be 100% and
15 therefore the number returning to work would be derived as follows:

$$16 \quad 3,929 - 3,874 = 55$$

17 **Costs**

18 Costs are presented in 2017/18 prices and reflect a societal perspective. The impact on
19 productivity was included in this societal perspective which represents a departure from the
20 NICE Reference Case (NICE Guidelines Manual). This exception to the NICE Reference
21 Case was deemed appropriate in this case as the intervention was assessed in terms of its
22 effectiveness in supporting carers to return to work. Other published literature also considers
23 productivity when addressing the provision of replacement care (Yeandle 2015; Pickard
24 2017).

25 The costing of replacement care had 2 components:

26 i. Cost of providing replacement care

27 The cost of providing replacement care was made up of the number of replacement care
28 hours given to adult carers and the unit cost of an hour of replacement care. The guideline
29 recommendations are not prescriptive with respect to the amount of care that should be
30 provided and focuses rather on the fact that replacement care should be available and be
31 flexible to the circumstances of the carer. However, for modelling purposes the quantity of
32 replacement care allocated to each adult carer could be determined by the following
33 methods:

- 34 a) Fixed maximum hours per week – for exposition purposes only, the model
35 default was 1 hour of replacement care per week per carer
36 b) A sliding scale according to the number of hours of care provided per week –
37 the default for this is shown in Table 26

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Table 26: Allocation of replacement hours of care per week by amount of care undertaken by carers per week

Hours of caring per week	Hours of replacement care per week
1-4 hours	1 hour
5-9 hours	2 hours
10-19 hours	4 hours
20-34 hours	6 hours
35-49 hours	8 hours
50+ hours	10 hours

The unit cost of an hour of replacement care is shown in Table 27. It was additionally assumed that replacement care would be provided for 47 weeks per year to reflect that carers would not work 52 weeks in paid employment and that this would have no reduced effect on return to work.

Table 27: Unit cost of replacement care

Variable	Value	Source
Hourly cost of replacement care	£22.00 ^a	PSSRU (2018)

(a) Based on the unit cost of a home care worker for a weekday hour

ii. Benefits of return to work

The model inputs used to estimate the monetary benefit to society from return to work are shown in Table 28.

Table 28: Model inputs used to estimate the monetary benefit of a carer returning to work

Variable	Value	Source
Carers leaving employment because of caring	345,000	Pickard (2017)
Public cost of carers leaving employment per annum	£2.9 billion ^a	Pickard (2017)
Lost earnings from leaving employment	£6.9 billion ^b	Annual Survey of Hours and Earnings (ONS 2018)
Average tax rate	17.2% ^c	Pickard (2017)

(a) Calculated from an estimate of increased benefit payments and reduced tax receipts

(b) Calculated from carers leaving employment and annual median earnings of £24,006 net of tax
 $345,000 \times 24,006 \times (1-0.172)$

(c) The average UK tax rate for 2015/2016 (HMRC 2016)

The benefits of a return to employment were estimated from national statistics on median earnings and the estimated cost to public expenditure arising from adult carers leaving employment because caring. The aggregate societal benefit was calculated as the sum of the benefit to the public sector arising from increased tax receipts and reduced welfare payments and the benefits to the carer/employer, as earnings net of taxation.

24 Quality Adjusted Life Years

It has been reported that those with considerable caring responsibilities are 2-3 times more likely to be in poor health when compared to non-carers ("Who Cares Wins", Carers UK, 2006). This would suggest that replacement care, by reducing the caring workload, could have benefits to health related quality of life over and above the benefits achieved from greater labour market participation. As far as we are aware there are no data that map the relationship between health state utility and caring and therefore this aspect of the analysis was done on a "what-if" basis.

1 The model allowed the health state utility loss associated with caring to be modelled as a
 2 linear loss with increasing hours of care. In the default case it was assumed that there would
 3 be a 0.01 health state utility decrement for each additional hour of caring per week with this
 4 varied in sensitivity analysis (see Table 29 below).

5

6 Sensitivity analysis

7 In order to address uncertainty in model inputs a number of one-way sensitivity analyses
 8 were undertaken. For sensitivity analysis addressing parameter uncertainty, the results were
 9 presented in a Tornado diagram to illustrate where model conclusions may be more sensitive
 10 to the uncertainty in model inputs and to provide insights into the key parameters driving the
 11 model output. The ranges used in these sensitivity analysis are given in Table 29.

12 Probabilistic sensitivity analysis was not undertaken as probability distributions could not
 13 readily be estimated for the model's parameter input values.

14 **Table 29: Range of values used in one-way sensitivity analysis**

Variable	Low Value	High Value
Health state utility from each hour of caring	0.005	0.015
Lost earnings from leaving employment	£5 billion	£10 billion
Cost of replacement care per hour	£10	£30

15

16 Results

17 Base case analysis

18 Table 30 shows the impact of replacement care at the population level, assuming that all
 19 carers not working because caring receive 1 hour of replacement care per week for 47
 20 weeks of the year. Table 31 depicts this information per recipient of care.

21 **Table 30: Cost analysis of replacement care at the aggregate level**

	Age in years				Total
	18-24	25-49	50-64	65+	
Return to work	958	18,763	18,610	1,582	39,914
Replacement care hours per week	16,541	387,565	353,481	41,672	799,260
Replacement care cost per annum	£17 million	£401 million	£365 million	£43 million	£826 million
Benefit of return to employment	£27 million	£531 million	£526 million	£45 million	£1,129 million
Net cost					-£302 million

22

23

24

1

2 **Table 31: Cost analysis of replacement care per recipient**

	Age in years				Total
	18-24	25-49	50-64	65+	
Return to work	0.007	0.010	0.009	0.001	0.007
Replacement care hours per week	1.00	1.00	1.00	1.00	1.00
Replacement care cost per annum	£1,034	£1,034	£1,0134	£1,034	£1,034
Benefit of return to employment	£1,639	£1,369	£1,489	£1,074	£1,412
Net cost					-£378

3

4 The results of a “what-if” cost-utility analysis are presented for the model parameter’s default
5 values in Table 32 and are presented per recipient of replacement care. It was assumed that
6 each carer who received replacement care would experience a 0.01 QALY gain. The net
7 monetary benefit (NMB) was calculated for a cost-effectiveness threshold of £20,000 per
8 QALY. The results show that, a societal level, replacement care dominates no replacement
9 care, producing net savings and small improvements in health related quality of life.

10 **Table 32: Results of a cost-utility analysis for the model parameter’s default values**

	Age in years				Total
	18-24	25-49	50-64	65+	
Net cost	-£605	-£335	-£455	-£40	-£378
QALYs	0.01	0.01	0.01	0.01	0.01
NMB					£578
ICER					Dominates

11 *ICER = Incremental cost-effectiveness ratio; NMB = Net Monetary Benefit; QALYs = Quality adjusted life years*

12

13 Sensitivity analysis

14 i. Allocation of hours of replacement care by hours of caring per week using the default
15 values given in Table 26.

16 In this analysis the hours of replacement care per week were allocated according to the
17 hours of caring per week with the default values given in Table 26. The results are
18 presented per recipient of replacement care in Table 33 **Error! Reference source not**
19 **found..**

20 **Table 33: Results of a cost-utility analysis for the model parameter’s default values**
21 **with replacement care allocated by hours of caring per week**

	Age in years				Total
	18-24	25-49	50-64	65+	
Net cost	£26	£1,007	£535	£2,314	£846
QALYs	0.057	0.065	0.063	0.075	0.065
NMB					£447

	Age in years				Total
	18-24	25-49	50-64	65+	
ICER					£13,085

1 ICER = Incremental cost-effectiveness ratio; NMB = Net Monetary Benefit; QALYs = Quality adjusted life years

2

3 ii. Allocation of hours of replacement care by hours of caring per week using the values
4 given in Table 34.

5

6 In this analysis the hours of replacement care per week were allocated according to the
7 hours of caring per week with the values given in Table 34. The results are presented per
8 recipient of replacement care in Table 35.

9 **Table 34: Allocation of replacement hours of care per week by amount of care**
10 **undertaken by carers per week for sensitivity analysis**

Hours of caring per week	Hours of replacement care per week
1-4 hours	0 hour
5-9 hours	5 hours
10-19 hours	10 hours
20-34 hours	30 hours
35-49 hours	30 hours
50+ hours	30 hours

11 **Table 35: Results of a cost-utility analysis with replacement care allocated by hours of**
12 **caring per week but varied from the model parameter's default values**

	Age in years				Total
	18-24	24-49	50-64	65+	
Net cost	-£1,166	£3,668	£2,203	£9,299	£3,214
QALYs	0.201	0.220	0.212	0.245	0.217
NMB					£1,134
ICER					£14,784

13 ICER = Incremental cost-effectiveness ratio; NMB = Net Monetary Benefit; QALYs = Quality adjusted life years

14

15 iii. Allocation of a fixed number of replacement care hours per week but varying the
16 amount

17

18 This analysis is as per the default analysis presented in **Error! Reference source**
19 **not found.** but the fixed number of replacement hours of caring per week available to
20 each adult carer not in work because caring is varied. The results are presented as
21 the NMB per recipient of replacement care in Table 36.

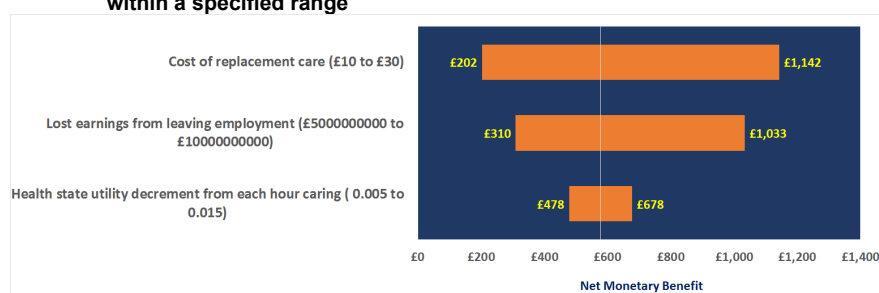
22 **Table 36: Net monetary benefit of replacement care varying the amount of hours of**
23 **replacement care available**

	Replacement care (hours)								
	1	2	5	10	15	20	30	40	50
Net monetary benefit	£578	£1,098	£2,338	£3,734	£3,829	£3,366	£2,352	£2,352	£2,227

1 Tornado diagram

2 Figure 11 shows the Tornado diagram for a one-way sensitivity analysis where input
3 parameters for 3 model variables were varied between the low and high values specified in
4 Table 29.

Figure 11: Tornado diagram showing the impact on NMB from varying model inputs within a specified range



5 Discussion

6 Under the modelling assumptions, the annual cost of providing 1 hour of replacement care
7 per week for 47 weeks would be £1,034 per recipient, Table 31. The model suggests that as
8 a result of that replacement care there will be a societal benefit of £1,412 per recipient as a
9 result of carers returning to work, facilitated by a reduction in their number of hours a week
10 caring. Approximately £420 of the societal benefit would be to public expenditure as a result
11 of increased tax receipts and reduced welfare payments. The cost analysis indicated that
12 replacement care would be cost saving from a societal perspective with the benefits of
13 increased labour market participation in excess of the costs of replacement care provision .

14 The "what-if" cost-utility analysis suggested that 1 hour of replacement care per adult carer
15 not working because caring dominated no replacement care **Error! Reference source not
16 found.**, with reduced societal costs alongside an assumed QALY gain from reduced hours of
17 caring. Reflecting the cost-effectiveness of replacement care provision the overall net
18 monetary benefits of replacement care was £578 per recipient.

19 Sensitivity analysis suggested that overall the provision of greater levels of replacement care
20 could be cost-effective with the NMB per recipient rising up to a level of approximately 15
21 hours of replacement care per adult carer per week, Table 36. Falling NMB for provision of
22 replacement care above 15 hours per week suggests that replacement care above 15 hours
23 may not be cost-effective with the incremental costs of additional hours in excess of the
24 additional costs. The Tornado diagram in Figure 11 suggested that the cost of replacement
25 care was a particularly important determinant of the cost-effectiveness of replacement care.
26 Conversely changes in assumptions about the health state utility decrement from each hour
27 caring had a rather limited impact on cost-effectiveness. This reflects that the monetised
28 benefit of improvements in health state utility are small in comparison to the monetary
29 benefits from the additional earnings and savings to public expenditure arising from a return
30 to work.

31 However, it is important to understand these model results in the context of the model
32 assumptions and potentially serious limitations. The effectiveness of replacement care in the
33 model, at facilitating a return to work, was estimated from data which showed a relationship
34 between hours of caring per week and likelihood of employment. The model assumed that an
35 adult carer who moved to a lower level of caring per week would then have the same rate of

1 labour market participation as those currently caring that number of hours per week.
2 Therefore, the modelled effectiveness of replacement care is not based on a randomised
3 intervention study and therefore may not accurately predict changes in employment because
4 of various biases. For example, there may be systematic differences between adult carers
5 providing more hours of care per week than those providing less hours of care which means
6 that those providing more hours of care would not necessarily have the same labour market
7 participation rates as those currently providing less hours of care even if their caring hours
8 were reduced to the levels of those currently providing less hours of care.

9 The model made an estimate of the distribution of the hours caring per week based on a very
10 small number of data points (Figure 6, Figure 7, Figure 8 and Figure 9) and therefore there is
11 some uncertainty with respect to the actual distribution. Nevertheless, the distributions do
12 seem reasonable in terms of what would be expected, with a much smaller proportion of
13 young carers undertaking long hours of caring for example. Sensitivity analysis was not
14 undertaken on the fitted relationship as any alternative would not result in marked differences
15 in the proportions caring at a given number of hours (Table 24) and therefore would not
16 produce a markedly different result.

17 The guideline recommended that replacement care should be made available, should take
18 account of employed carers and should be flexible, so that it can respond to changes in
19 people's working patterns and career development. The recommendations did not stipulate
20 that replacement care provision should be provided in the manner adopted in the model. It is
21 difficult to model the real world utilisation and uptake of replacement care services which in
22 practice will depend on a multitude of factors that pertain to the circumstances and
23 preferences of individual carers. Based on the available data, on the number of hours caring
24 per week and the likelihood of being in paid work, the model estimated the number of adult
25 carers who were not working because caring. This produced a higher estimate of carers not
26 working because of caring than the 345,000 estimated in a recent study (Pickard, 2017).
27 Furthermore, the model treated employment as a binary state where the carer was either not
28 working because of caring or had returned to full-time working. However, for many adult
29 carers the response to juggling care and work would be to reduce working hours rather than
30 leave the labour market completely. It is estimated that 675,000 adult carers are in part-time
31 work ("Who Cares Wins", Carers UK, 2006)

32 In using the median earnings of employment the model may not capture some of the longer
33 term career impacts of increased labour market participation. For example, it has been
34 commented in "Walking the tightrope". (Carers UK, 2016) that caring responsibilities can lead
35 to early retirement, a carer passing up opportunities for promotion and taking a less skilled
36 job than for what they are qualified. Therefore, the model may underestimate the societal
37 benefit of an adult carer returning to work.

38 Whilst providing replacement care to adult carers can have a number of objectives this
39 analysis focused predominantly on carers returning to work although the cost utility analysis
40 did address potential improvement in health related quality of life that adult carers in
41 employment might derive from replacement care.

42 However, the guideline recommendations cover a much larger population than the subset of
43 adult carers not working because caring, such as those in part-time or full-time work or
44 carers who wish remain or return to full-time education or training. The model focused on a
45 more limited sub-set because of the available data which allowed a return to work to be
46 readily estimated and quantified in monetary terms. Some of the benefits to the wider
47 population of adult carers are less easy to quantify. However, to the extent that replacement
48 care facilitates labour market participation, education and training then there are human
49 capital benefits to the wider population of adult carers. It is recognised that education and
50 training are important to the development of human capital and there is empirical evidence
51 that human capital depreciates as a result of non-labour market participation (Edin, 2008).

1 Although the model makes a crude attempt to estimate the impact on well-being through a
2 “what-if” cost-utility analysis it does not directly capture any benefits from employment that
3 relate to a sense of identity or social connectivity. Nor does the model capture the wider
4 context where replacement care can be part of a package to improve opportunities to remain
5 in or return to work, training or education by enhancing flexible working.

6 Replacement care can be provided from local authority and independent sectors and funded
7 from different sources, including personal budgets, but it is important to acknowledge in
8 practice that there be labour market and budgetary constraints that limit the availability of
9 replacement care to the millions of adult carers in England. For example, the model
10 suggested that 11 million hours of replacement care would be needed to provide
11 replacement care of 15 hours per week to the entire population of adult carers not in work
12 because caring. This would amount to approximately 250,000 additional paid carers.

13 Conclusion

14 There are resource constraints in terms of the replacement care that can be provided but it
15 should also be recognised that many adult carers would not necessarily want such
16 replacement care or utilise services available at the levels suggested in this analysis.
17 Replacement care does carry opportunity cost and it cannot automatically be assumed to be
18 cost-effective just because there are potentially large gains from increasing labour market
19 participation amongst carers. Ultimately, the cost-effectiveness of replacement care is likely
20 to depend on the effectiveness of replacement care in facilitating employment, training,
21 education and carer well-being

22 The analysis presented does have serious limitations and is underpinned by the assumption
23 that the probability of being in work is determined solely by the number of hours caring.
24 However, subject to these limitations, this analysis suggested that the provision of
25 replacement care to adult carers not working because caring was cost-effective from a
26 societal perspective. It additionally suggested that replacement care would be cost-effective
27 up to a maximum of approximately 15 hours of care per carer per week. Whilst the analysis
28 focused on adult carers not working because caring, replacement care would be likely to also
29 provide benefits to all adult carers by mitigating the impact of caring on health related quality
30 of life and by promoting improvements in human capital.

31 References

32 The Care Act 2014

33 The Care Act 2014, c.23. Available at:
34 <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted> (Accessed: 3 June 2019),
35 2014

36 Carers UK 2013

37 Carers UK, Supporting Working Carers: The Benefits to Families, Business and the
38 Economy. Available at:
39 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/232303/Supporting_Working_Carers_Final_Report_accessible.pdf (Accessed: 3
40 June 2019), 2013

42 Carers UK 2016

43 Carers UK., Age UK., Walking the tightrope: The challenges of combining work and care in
44 later life. Available at: <https://www.carersuk.org/for-professionals/policy/policy-library/walking-the-tightrope-the-challenges-of-combining-work-and-care-in-later-life> (Accessed: 3 June
45 2019), 2016

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- 2 Edin, P.A., Gustavsson, M. , Time Out of Work and Skill Depreciation , Industrial Labor
3 Relations (ILR) Review, 61, 163-180, 2008
- 4 **Pickard 2017**
- 5 Pickard, L. King, D. Brimblecombe, N. Knapp, M., Public expenditure costs of carers leaving
6 employment in England, 2015/2016. , Health and Social Care in the Community, 26 , e132-
7 e142, 2017
- 8 **Yeandle 2015**
- 9 Yeandle, S., Buckner, L., Valuing Carers 2015 – the rising value of carers' support. Available
10 at: <https://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015>
11 (Accessed: 3 June 2019)., Carers UK., 2015
- 12 **Yeandle 2006**
- 13 Yeandle, S., Bennett, C., Buckner, L., Shipton, L., Suokas, A., Who Cares Wins: The Social
14 and Business Benefits of Supporting Working Carers. Available at:
15 [https://www.employersforcarers.org/resources/research/item/225-who-cares-wins-the-social-
16 and-business-benefits-of-supporting-working-carers](https://www.employersforcarers.org/resources/research/item/225-who-cares-wins-the-social-and-business-benefits-of-supporting-working-carers) (Accessed: 3 June 2019)., 2006
17

1 Appendix K – Excluded studies

2 Excluded studies for review question: What are the most effective and cost-effective interventions, tools or approaches to support adult carers to enter, remain in, and/or return to (i) work, (ii) education, and (iii) training?

5 Quantitative component of the review

6 Table 37: Excluded studies from the quantitative component of the review

Study	Reason for Exclusion
Ang, Shannon, Malhotra, Rahul, Expressive social support buffers the impact of care-related work interruptions on caregivers' depressive symptoms, <i>Aging & mental health</i> , 22, 755-763, 2018	No comparative study design.
Banks, Pauline, Jahoda, Andrew, Dagnan, Dave, Kemp, John, Williams, Victoria, Supported employment for people with intellectual disability: The effects of job breakdown on psychological well-being, <i>Journal of Applied Research in Intellectual Disabilities</i> , 23, 344-354, 2010	This study does not focus on carers.
Bauer, J. C., The fourth factor of production. Helping caregivers work smarter instead of harder, <i>Journal of healthcare information management : JHIM</i> , 21, 4-5, 2007	Not data have been reported in this commentary.
Beauchamp, N., Irvine, A. B., Seeley, J., Johnson, B., Worksite-based internet multimedia program for family caregivers of persons with dementia, <i>Gerontologist</i> , 45, 793-801, 2005	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Brown, Melissa, Pitt-Catsoupes, Marcie, A mediational model of workplace flexibility, work-family conflict, and perceived stress among caregivers of older adults, <i>Community, Work & Family</i> , 19, 379-395, 2016	No study design: this review has been excluded. Its references have been handsearched for relevant studies.
Brown, Melissa, Pitt-Catsoupes, Marcie, Workplace Characteristics and Work-to-Family Conflict: Does Caregiving Frequency Matter, <i>Journal of gerontological social work</i> , 56, 452-460, 2013	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Carmichael, F., Ercolani, M. G., Unpaid caregiving and paid work over life-courses: Different pathways, diverging outcomes, <i>Social Science & Medicine</i> , 156, 1-11, 2016	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Curry, L. C., Walker, C., Hogstel, M. O., Educational Needs of Employed Family Caregivers of Older Adults: Evaluation of a Workplace Project, <i>Geriatric Nursing</i> , 27, 166-173, 2006	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Ewing, G., Austin, L., Jones, D., Grande, G., Who cares for the carers at hospital discharge at the end of life? A qualitative study of current practice in discharge planning and the potential value of using The Carer Support Needs Assessment Tool (CSNAT) Approach, <i>Palliative Medicine</i> , 32, 939-949, 2018	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.

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Fine, Michael D., Employment and Informal Care: Sustaining Paid Work and Caregiving in Community and Home-based Care, Ageing International, 37, 57-68, 2012	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Goeman, D., Renehan, E., Koch, S., What is the effectiveness of the support worker role for people with dementia and their carers? A systematic review, BMC Health Services Research, 16, 285, 2016	No study design: this review has been excluded. Its references have been handsearched for relevant studies.
Gordon, Judith R., Pruchno, Rachel A., Wilson-Genderson, Maureen, Murphy, Wendy Marcinkus, Rose, Miriam, Balancing caregiving and work: Role conflict and role strain dynamics, Journal of Family Issues, 33, 662-689, 2012	No study design: this review has been excluded. Its references have been handsearched for relevant studies.
Gordon, Judith R., Rouse, Elizabeth D., The Relationship of Job and Elder Caregiving Involvement to Work-Caregiving Conflict and Work Costs, Research on Aging, 35, 96-117, 2013	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Heitmueller, A., The chicken or the egg? Endogeneity in labour market participation of informal carers in England, Journal of Health Economics, 26, 536-59, 2007	Using panel data techniques and employing data from the British Household Panel Study from 1991 to 2002, this paper studies how care responsibilities affect the labour market participation decision. The focus is not on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Henz, Ursula, Informal Caregiving at Working Age: Effects of Job Characteristics and Family Configuration, Journal of Marriage and Family, 68, 411-429, 2006	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Henz, Ursula, The effects of informal care on paid-work participation in Great Britain: a lifecourse perspective, Ageing and Society, 24, 851-880, 2004	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Iacobucci, G., Employers need to commit to flexible working for carers, says report, BMJ (Clinical research ed.), 347 (no pagination), 2013	No qualitative-quantitative data on unpaid carers.
Ireson, R., Sethi, B., Williams, A., Availability of caregiver-friendly workplace policies (CFWPs): an international scoping review, Health & Social Care in the Community, 26, e1-e14, 2018	No study design: this review has been excluded. Its references have been hand-searched for relevant studies.
Klemm, P. R., Hayes, E. R., Diefenbeck, C. A., Milcarek, B., Online support for employed informal caregivers: psychosocial outcomes, Computers, informatics, nursing : CIN, 32, 10-20, 2014	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Kuhn, D., Edelman, P., Fulton, B., Hollinger-Smith, L., AN ONLINE INTERVENTION FOR EMPLOYED FAMILY CAREGIVERS, The Gerontologist, 44, 207-208, 2004	Abstract: not enough information provided on results and methods.
Kuhn, Daniel, Hollinger-Smith, Linda, Presser, Judith, Civian, Jan, Batsch, Nicole, Powerful Tools for Caregivers Online: An Innovative Approach to Support Employees, Journal of Workplace Behavioral Health, 23, 51-69, 2008	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.

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Lilly, M. B., Laporte, A., Coyte, P. C., Labor market work and home care's unpaid caregivers: A systematic review of labor force participation rates, predictors of labor market withdrawal, and hours of work, <i>Milbank Quarterly</i> , 85, 641-690, 2007	No study design: this review has been excluded. Its references have been hand-searched for relevant studies.
Mahoney, D. F., Tarlow, B., Workplace response to virtual caregiver support and remote home monitoring of elders: The WIN project, <i>Studies in Health Technology & Informatics</i> , 122, 676-80, 2006	This study does not focus on carers.
Mahoney, D. M. F., Mutschler, P. H., Tarlow, B., Liss, E., Real world implementation lessons and outcomes from the Worker Interactive Networking (WIN) project: Workplace-based online caregiver support and remote monitoring of elders at home, <i>Telemedicine and e-Health</i> , 14, 224-234, 2008	No focus on the interventions of interest.
Martire, Lynn M., Stephens, Mary Ann Parris, Juggling parent care and employment responsibilities: The dilemmas of adult daughter caregivers in the workforce, <i>Sex Roles</i> , 48, 167-173, 2003	No study design: this review has been excluded (Its references have been handsearched for relevant studies).
Mortensen, J., Dich, N., Lange, T., Alexanderson, K., Goldberg, M., Head, J., Kivimaki, M., Madsen, I. E., Rugulies, R., Vahtera, J., Zins, M., Rod, N. H., Job strain and informal caregiving as predictors of long-term sickness absence: A longitudinal multi-cohort study, <i>Scandinavian Journal of Work, Environment & Health</i> , 43, 5-14, 2017	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Moscarola, Flavia Coda, Informal Caregiving and Women's Work Choices: Lessons from the Netherlands, <i>Labour</i> , 24, 93-105, 2010	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Paulson, Daniel PhD, Bassett, Rachel M. A., Kitsmiller, Emily B. A., Luther, Kandace B. S., Conner, Norma PhD R. N., When Employment and Caregiving Collide: Predictors of Labor Force Participation in Prospective and Current Caregivers, <i>Clinical Gerontologist</i> , 40, 401-412, 2017	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Payne-Harker, C., Industrial focus. Respecting caregivers and their work, <i>Nursing New Zealand (Wellington, N.Z., : 1995)</i> . 14, 23, 2008	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Sacco, L. B., Leineweber, C., Platts, L. G., Informal care and sleep disturbance among caregivers in paid work: Longitudinal analyses from a large community-based swedish cohort study, <i>Sleep</i> , 41, 2018	No comparative study design.
Singleton, Judy, Employed Elder Caregivers: The Use of Company-Sponsored Benefits, <i>Michigan Sociological Review</i> , 18, 82-107, 2004	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Taylor, J., Carers. Why the NHS must look after its hidden workers, <i>Health Service Journal</i> , 119, 18, 2009	Not intervention of interest.
Tonarelli, A., Cosentino, C., Artioli, D., Borciani, S., Camurri, E., Colombo, B., D'Errico, A., Lelli, L., Lodini, L., Artioli, G., Expressive writing. A	This study does not focus on carers.

tool to help health workers. Research project on the benefits of expressive writing, <i>Acta Biomedica</i> , 88, 13-21, 2017	
Walsh, E., Murphy, A., Investigating the causal relationship between employment and informal caregiving of the elderly, <i>BMC Research Notes</i> , 11, 570, 2018	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Williams, A. M., Tompa, E., Lero, D. S., Fast, J., Yazdani, A., Zeytinoglu, I. U., Evaluation of caregiver-friendly workplace policy (CFWPs) interventions on the health of full-time caregiver employees (CEs): implementation and cost-benefit analysis, <i>BMC public health</i> , 17, 728, 2017	Study protocol.

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4 Qualitative component of the review

5 Table 38: Excluded studies from the qualitative component of the review

Study	Reason for Exclusion
Adams Kathryn Betts, The transition to caregiving: the experience of family members embarking on the dementia caregiving career, <i>Journal of Gerontological Social Work</i> , 47, 3-29, 2006	Issue of interest: no data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Aldridge Hannah, Hughes Ceri, Informal carers & poverty in the UK: an analysis of the Family Resources Survey, 30, 2016	General focus on carers support with no specific focusing on on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Anonymous., Unpaid care, <i>Working With Older People</i> , 10, 6, 2006	General focus on carers support with no specific focusing on on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Arksey Hilary, Moree Marjolein, Supporting working carers: do policies in England and The Netherlands reflect 'doulia rights?', <i>Health and Social Care in the Community</i> , 16, 649-657, 2008	The Results section of this paper compares key English and Dutch policy measures for carers, and assesses their impact using empirical evidence from two primary studies of working carers (Morée 2002 and Arksey 2005).
Banks, Pauline, Jahoda, Andrew, Dagnan, Dave, Kemp, John, Williams, Victoria, Beyer, Beyer Brooke Chadsey-Rusch Collmann Cummins Dagnan Fabian Forrester-Jones Greenspan Hanley-Maxwell Jahoda Jenkins Kiernan Kilsby Kober Martin Parent Reid Smyth Taanila Verdugo Wistow, Supported employment for people with intellectual disability: The effects of job breakdown on psychological well-being, <i>Journal of Applied Research in Intellectual Disabilities</i> , 23, 344-354, 2010	The focus of this paper was not on carers.
Berkman, Lisa F., Cannuscio, Carolyn C., Colditz, Graham A., Jones, Camara P., Kawachi, Ichiro, Rimm, Eric B., Employment	Issue of interest: no data on interventions/approaches to support adult carers

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status, social ties, and caregivers' mental health, <i>Social Science and Medicine</i> , 58, 1247-1256, 2004	to enter/remain in/return to work/education/training.
Bittman, Michael, Hill, Trish, Thomson, Cathy, <i>The Impact of Caring on Informal Carers' Employment, Income and Earnings: a Longitudinal Approach</i> , <i>Australian Journal of Social Issues</i> , 42, 255-272, 136, 2007	This study was potentially eligible for the qualitative component of the question, but was excused as it was not placed in the UK.
Brimblecombe, N., Pickard, L., King, D., Knapp, M., <i>Perceptions of unmet needs for community social care services in England. A comparison of working carers and the people they care for</i> , <i>Health & Social Care in the Community</i> , 25, 435-446, 2017	No qualitative study design.
Brown, Melissa, Pitt-Catsoupes, Marcie, <i>A mediational model of workplace flexibility, work-family conflict, and perceived stress among caregivers of older adults</i> , <i>Community, Work & Family</i> , 19, 379-395, 2016	This study was potentially eligible for the qualitative component of the question, but was excused as it was not placed in the UK.
Callaby Pilar L.M, <i>Recognising the key predictors of caregiver burnout in dementia through facilitated mediation</i> , <i>Generations Review</i> , 17, 2007	Issue of interest: no data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Carers, U. K., <i>Caring and Family Finances Inquiry: UK report</i> , 156, 2014	General focus on carers support with no specific focusing on on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Carers, U. K., <i>Quality of care and carers: how quality affects families, employers and the economy</i> , 20, 2014	General focus on carers support with no specific focusing on on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Carpentier, Normand, Ducharme, Francine, Kergoat, Marie-Jeanne, Bergman, Howard, <i>Social Representations of Barriers to Care Early in the Careers of Caregivers of Persons With Alzheimer's Disease</i> , <i>Research on Aging</i> , 30, 344, 2008	This study was potentially eligible for the qualitative component of the question, but was excused as it was not placed in the UK.
Cascino, Nadine, Melan, Claudine, Galy, Edith, <i>Variability of job perceptions across the shift in shift-workers: arguments for a subjective and temporally located assessment of workload</i> , <i>Travail humain</i> , 79, 97-124, 2016	This study was potentially eligible for the qualitative component of the question, but was excused as it was not placed in the UK.
Caspar, Sienna M. A., O'Rourke, Norm PhD R. <i>Psych, Measurement of Workplace Empowerment Across Caregivers</i> , <i>Geriatric Nursing</i> , 32, 156, 2011	This study was potentially eligible for the qualitative component of the question, but was excused as it was not placed in the UK.
Courtin, E., Jemai, N., Mossialos, E., <i>Mapping support policies for informal carers across the European Union</i> , <i>Health Policy</i> , 118, 84-94, 2014	General focus on carers support with no specific focusing on on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Crooks Valorie A, et al., <i>Family caregivers' ideal expectations of Canada's Compassionate Care Benefit, Health and Social Care in the Community</i> , 20, 172-180, 2012	This study was potentially eligible for the qualitative component of the question, but was excused as it was not placed in the UK.
Daverth, Gwen, Cassell, Catherine, Hyde, Paula, Adams, Allen Allen Anderson Appelbaum Bearegard Behson Berk Bernas Bernerth Blair	Non UK evidence.

Bond Brandl Braun Byrne Casper Crompton Crompton Cropanzano Currie De Cieri Den Dulk Den Dulk Deutsch El-Sawad Emslie Ford Frone Frye Fuchs Gatrell Grandey Grandey Green Greenhaus Greenstein Greenstein Gregory Grover Grzywacz Hegtvedt Hegtvedt Hochschild Homans Howard Jespen Kawamura King Kossek Kroska Lapierre Lewis Lewis McCarthy McDonald McGuire Nadin Nomaguchi Ozbilgin Parasuraman Poelmans Redmond Reeve Ruppanner Russell Schwinger Smithson Swanberg Teasdale Theodorakopoulos Thompson Todd Warren Warren West Young, The subjectivity of fairness: Managerial discretion and work-life balance, <i>Gender, Work and Organization</i> , 23, 89-107, 2016	
Flackman, Birgitta, Haggstrom, Elisabeth, Kihlgren, Annika L., Kihlgren, Mona, Skovdahl, Kirsti, Work satisfaction and dissatisfaction - caregivers' experiences after a two-year intervention in a newly opened nursing home, <i>Journal of clinical nursing</i> , 14, 9-19, 2005	Non UK evidence.
Gazso, Amber, Balancing Expectations for Employability and Family Responsibilities While on Social Assistance: Low-Income Mothers' Experiences in Three Canadian Provinces*, <i>Family Relations</i> , 56, 454-466, 2007	Non UK evidence.
Liang, Phyllis, Fleming, Jennifer, Gustafsson, Louise, Little, Jacki, Occupational experience of caregiving during driving disruption following an acquired brain injury, <i>The British Journal of Occupational Therapy</i> , 80, 30-38, 2017	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Mc, Cartney Claire, Creating an enabling future for carers in the workplace, 30, 2016	General focus on carers support with no specific focusing on on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
McCabe, L., Robertson, J., Kelly, F., Scaffolding and working together: A qualitative exploration of strategies for everyday life with dementia, <i>Age and Ageing</i> , 47, 303-310, 2018	No data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Principi, Andrea, Lamura, Giovanni, Sirolla, Cristina, Mestheneos, Liz, Bien, Barbara, Brown, Jayne, Krevers, Barbro, Melchiorre, Maria Gabriella, Dohner, Hanneli, Work restrictions experienced by midlife family care-givers of older people: Evidence from six European countries, <i>Ageing & Society</i> , 34, 209-231, 2014	Issue of interest: no data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Rivera Hernandez, Norma I., Fernandez Garcia- Menocal, Rosy Edition date, Experiences of family caregivers of people with Alzheimer's condition: Implications for career counseling, AAI3610396	Non UK evidence.
Rosenthal, Carolyn J., Martin-Matthews, Anne, Keefe, Janice M., Care management and care provision for older relatives amongst employed informal care-givers, <i>Ageing and Society</i> , 27, 2007	Issue of interest: no data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.

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Scharlach, Andrew E., Gustavson, Kristen, Dal Santo, Teresa S., Assistance Received by Employed Caregivers and Their Care Recipients: Who Helps Care Recipients when Caregivers Work Full Time?, <i>Gerontologist</i> , 47, 752-762, 2007	Non UK evidence.
Schroeder, Bonnie, MacDonald, Jane, Shamian, Judith, Older Workers with Caregiving Responsibilities: A Canadian Perspective on Corporate Caring, <i>Ageing International</i> , 37, 39-56, 2012	Non UK evidence.
Seddon Diane, Robinson Catherine, Supporting carers in paid work, <i>Working With Older People</i> , 8, 13-18, 2004	Duplicate: this study has been already included in the review (Seddon 2004).
Snyder, Jason, The role of coworker and supervisor social support in alleviating the experience of burnout for caregivers in the human-services industry, <i>Southern Communication Journal</i> , 74, 373-389, 2009	Issue of interest: no data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training
Stewart, Lisa M., Family Care Responsibilities and Employment: Exploring the Impact of Type of Family Care on Work-Family and Family-Work Conflict, <i>Journal of Family Issues</i> , 34, 113-138, 2013	Non UK evidence.
Stewart, Lisa Maureen, Dependent care and work-life outcomes: Comparing exceptional care and typical care responsibilities, AAI3368180, 2732	No study design: dissertation.
Supporting working carers	Not enough data have been reported in this report to be included in the review
Swanberg, Jennifer E., Kanatzar, Terri, Mendiondo, Marta, McCoskey, Margaret, Caring for Our Elders: A Contemporary Conundrum for Working People, <i>Families in Society</i> , 87, 417-426, 2006	Non UK evidence.
Sweet, Stephen, Pitt-Catsoupes, Marcie, James, Jacquelyn Boone, Manager attitudes concerning flexible work arrangements: fixed or changeable?, <i>Community, Work & Family</i> , 20, 50-71, 2017	Non UK evidence.
Taylor, C., Supporting the carers of individuals affected by colorectal cancer, <i>British Journal of Nursing</i> , 17, 2008	General focus on carers support with no specific focusing on interventions/approaches to support adult carers to enter/remain in/return to work/education/training.
Vuksan Mirjana, Williams Allison M, Crooks Valorie A, The workplace perspective on supporting family caregivers at end of life: evaluating a new Canadian social program, <i>Community Work and Family</i> , 15, 317-333, 2012	Non UK evidence.
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, <i>Ageing & Society</i> , 23, 411-428, 2003	Issue of interest: no data on interventions/approaches to support adult carers to enter/remain in/return to work/education/training
Wenz-Gross, Melodie, Irsfeld, Toni DuBrino, Twomey, Tammy, Perez, Ana, Thompson, Judith, Wally, Martha, Colleton, Barbara, Kroell,	Non UK evidence.

Christine, McKeown, Steven K., Metz, Peter, Changing the System by Changing the Workforce: Employing Consumers to Increase Access, Cultural Diversity, and Engagement, <i>American Journal of Community Psychology</i> , 49, 546-555, 2012	
Winfield, Idee, Rushing, Beth, Bridging the Border between Work and Family: The Effects of Supervisor-Employee Similarity, <i>Sociological Inquiry</i> , 75, 55-80, 2005	Non UK evidence.
Yeandle Sue, Starr Madeleine, Action for carers and employment: impact of the ACE partnership 2002-7, 34p., 2007	This report does not provide enough data to be included in the review.
Yeandle, S., Bennette, C., Buckner, L., Shipton, L., and Suokas, A., Carers UK, Who Cares Wins: the social and business benefits of supporting working carers., 2006	This study includes carers of children with disabilities.
Yeandle, Sue, et al., Diversity in caring: towards equality for carers (Carers, employment and services report series), 2007	This report does not provide enough data to be included in the review.
Yeandle, Sue, Starr, Madeleine, University of Leeds Carers, U. K., Action for Carers and Employment, 34 pp, 2007	This report does not provide enough data to be included in the review.
Yedidia, Michael J., Tiedemann, Amy, How Do Family Caregivers Describe Their Needs for Professional Help?, <i>Journal of Social Work Education</i> , 44, 43-47, 2008	Non UK evidence.
Yu, L. B., Lu, Aisia J. B., Tsui, Man C. M., Li, D., Zhang, G. F., Tsang, Hector W. H., Impact of Integrated Supported Employment Program on People with Schizophrenia: Perspectives of Participants and Caregivers, <i>Journal of Rehabilitation</i> , 82, 11-17, 2016	Non UK evidence.
Zacher, Hannes, Winter, Gabriele, Eldercare Demands, Strain, and Work Engagement: The Moderating Role of Perceived Organizational Support, <i>Journal of Vocational Behavior</i> , 79, 667-680, 2011	Non UK evidence.

1 Economic component of the review

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

5 Table 39: Excludes 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-	Population of interest: the study focus is primarily on people.

Study	Reason for Exclusion
year follow-up, <i>Journal of advanced nursing</i> , 68, 1224-34, 2012	
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, <i>Stroke; a journal of cerebral circulation</i> , 46, 2212-2219, 2015	Population of interest: the study focus is primarily on people.
Forster, A., Young, J., Green, J., Patterson, C., Wanklyn, P., Smith, J., Murray, J., Wild, H., Bogle, S., Lawson, K., Structured re-assessment system at 6 months after a disabling stroke: a randomised controlled trial with resource use and cost study, <i>Age & Ageing</i> , 38, 2009	This cost analysis is focused primarily on people.
Gardiner, Clare, Brereton, Louise, Frey, Rosemary, Wilkinson-Meyers, Laura, Gott, Meryn, Approaches to capturing the financial cost of family care-giving within a palliative care context: A systematic review, <i>Health & Social Care in the Community</i> , 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. <i>Am J Geriatr Psychiatry</i> 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, <i>Cochrane Database of Systematic Reviews</i> , 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 people with advanced illness and their family caregivers, <i>JAMA: Journal of the American Medical Association</i> , 311, 1060-1061, 2014	Study design - this review of HE studies has been excluded for this guideline - but its references have been hand-searched for any relevant HE studies.
Heslin, M., Forster, A., Healey, A., Patel, A., A systematic review of the economic evidence for interventions for family carers of stroke people, <i>Clinical Rehabilitation</i> , 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, <i>Pharmacoeconomics</i> , 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, <i>BMC Health Services Research</i> , 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, Hounsborne Barry, A systematic review of the cost-effectiveness of interventions for supporting informal caregivers of people living with dementia residing in the community, <i>International Psychogeriatrics</i> , 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., Hounsborne, B., Health economics research into supporting carers of people living with dementia: A systematic review of outcome measures, <i>Health and Quality of Life Outcomes</i> , 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.

Study	Reason for Exclusion
Jutkowitz, E., Gitlin, L. N., Pizzi, L. T., Evaluating willingness-to-pay thresholds for dementia caregiving interventions: application to the tailored activity program, <i>Value in Health</i> , 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, <i>PLoS ONE [Electronic Resource]</i> , 10, e0116188, 2015	Population of interest: the study focus is primarily on people.
Kenrik Duru, O., Ettner, S. L., Vassar, S. D., Chodosh, J., Vickrey, B. G., Cost evaluation of a coordinated care management intervention for dementia, <i>American Journal of Managed Care</i> , 15, 521-528, 2009	Population of interest: the study focus is primarily on people.
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), <i>Bmj</i> , 347, f6342, 2013	Study finding updated by a more recent HE study (Livingston 2014).
Lauret, G. J., Gijssbers, 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 people with intermittent claudication, <i>Vascular Health & Risk Management</i> , 8, 495-503, 2012	Research protocol.
Li, C., Zeliadt, S. B., Hall, I. J., Smith, J. L., Ekwueme, D. U., Moynour, C. M., Penson, D. F., Thompson, I. M., Keane, T. E., Ramsey, S. D., Burden among partner caregivers of people diagnosed with localized prostate cancer within 1 year after diagnosis: an economic perspective, <i>Supportive Care in Cancer</i> , 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 people 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 people with tele-monitoring of pacemakers: the PONIENTE study, <i>Clinical Research in Cardiology</i> , 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 people 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, <i>Journal of advanced nursing</i> , 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 people.
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, <i>Health Technology Assessment (Winchester, England)</i> , 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, <i>Journal of the American Geriatrics Society</i> , 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	Population of interest: no primary focus on carers.

Study	Reason for Exclusion
on the effectiveness and cost impact of three management strategies. Value Health. 2012 Sep-Oct;15(6):851-9	
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 people.
Nichols LO, Chang C, Lummus A, Burns R, Martindale-Adams J, The cost-effectiveness of a behavior intervention with caregivers of people with Alzheimer's disease. J Am Geriatr Soc. 2008 Mar;56(3):413-20	This economic evaluation was conducted in the USA.
Nichols LO, Martindale-Adams J, Zhu CW, Kaplan EK, Zuber JK, Impact of the REACH II and REACH VA Dementia Caregiver Interventions on Healthcare Costs. J Am Geriatr Soc. 2017 May;65(5):931-936	This economic evaluation was conducted in the USA.
Orgeta, V., Leung, P., Yates, L., Kang, S., Hoare, Z., Henderson, C., Whitaker, C., Burns, A., Knapp, M., Leroi, I., Moniz-Cook, E. D., Pearson, S., Simpson, S., Spector, A., Roberts, S., Russell, I. T., de Waal, H., Woods, R. T., Orrell, M., Individual cognitive stimulation therapy for dementia: a clinical effectiveness and cost-effectiveness pragmatic, multicentre, randomised controlled trial, Health Technology Assessment (Winchester, England), 19, 1-108, 2015	Population of interest: the study focus is primarily on people.
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., Simoons, 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-	Population of interest: no primary focus on carers.

Study	Reason for Exclusion
utility evaluation alongside the Danish Alzheimer's Intervention Study (DAISY). BMJ Open. 2014 Jan 15;4(1):e004105	
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 (Sogaard 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 people, Stroke, 34, 528-36, 2003	Population of interest: the study focus is primarily on people.
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.

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1 Appendix L – Research recommendations

2 **Research recommendations for review question: What are the most effective,**
3 **cost-effective and acceptable interventions, tools or approaches to support**
4 **adult carers to enter, remain in and/ or return to (i) work, (ii) education and (iii)**
5 **training?**

6 **Why this is important**

7 In this review there was a paucity of evidence about the effectiveness of tools or approaches
8 for supporting carers to return to or enter work, education or training. The qualitative
9 evidence did however identify a range of factors perceived by carers to help or hinder them
10 in this context, including the resources needed to fund replacement care and practical
11 difficulties connected with getting to work such as transport and parking. In the absence of
12 research evidence, the committee discussed possible tools or approaches for addressing
13 these difficulties and informed by expert witness testimony agreed that personal budgets
14 either for the person receiving care or the carer in their own right might have positive
15 outcomes for the carer. Suggested examples included using a carer’s personal budget to fund
16 driving lessons or life coaching or for the care recipient’s personal budget to fund
17 replacement care. In the absence of data demonstrating the effectiveness of these examples
18 the committee agreed about the need for a randomised controlled trial to provide definitive
19 evidence about their potential role in supporting carers.

20 **Research recommendation in question format:** What is the effectiveness of personal
21 health and social care budgets in supporting carers to return to work, education or training?
22

Research question	What is the effectiveness of personal health and social care budgets in supporting carers to return to work, education or training?
Importance to people or the population	There are a range of barriers preventing carers from entering, returning to or remaining in employment. Being excluded from or feeling forced out of employment can have a significant impact on the quality of life, emotional and psychological well-being and career prospects of carers. The impact is also felt at a societal level with a loss of productivity, taxation and an increase in welfare payments.
Relevance to NICE guidance	NICE guidance provides advice on effective, good value health and social care, which covers care and support for adult carers.
Relevance to NHS/ social care	The Care Act (2014) places a duty on local authorities to promote individual well-being through participation in work or education. The development of evidence based approaches to supporting adult carers to enter, remain in or return to work, education or training will therefore help local authorities to make the best use of resources and achieve this objective, with relevance at both the individual and wider societal levels.
National priorities	As above, the Care Act (2014) places a duty on local authorities to promote individual well-being through participation in work or education. Determining the effectiveness of these interventions will contribute towards this objective.
Current evidence base	There is currently no published evidence about the effectiveness of personal health and social care budgets in supporting carers to return to work, education or training.
Equalities	N/A

23 *N/A: not applicable*

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Supporting adult carers to enter, remain in or return to work, education and training

Criterion	Explanation
Population	<ul style="list-style-type: none">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 and who are in or aiming to enter or return to work, education or training.
Intervention	<ul style="list-style-type: none">personal health budgetspersonal social care budgets.
Comparator	<ul style="list-style-type: none">no interventioneach intervention compared with the other.
Outcomes	<ul style="list-style-type: none">short and long-term employment or course attendance (relative to level of education/training) as measure for sustainability of, or ability to remain in work etc.short and long-term carer quality of life, including carer satisfaction/experienceproductivityhousehold income/financial issues or burdencarer mental health (include only measures that assess anxiety, depression, or stress/emotional wellbeing).
Study design	Randomised controlled trial
Timeframe	Two years from randomisation

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1 Appendix M – Quotes extracted from the included papers, 2 which support the qualitative review findings

3 Arksey 2003

- 4 • “I think it is extremely hard for a carer to obtain employment that fits in with caring duties. I
5 have now become resigned to being only a carer. It is just too complicated to work around
6 a life governed by a disabled (profoundly) person, especially when I have no other support
7 apart from day care”. (Adult carer, in full-time employment)
- 8 • “[The project development officer - PDO] believed that carers faced different types of
9 obstacles in their attempts to obtain work. For example, she found that carers lacked
10 confidence and self-esteem, and had emotional problems, which had not been
11 anticipated. (Author quote)

12 Arksey 2005

- 13 • “Yeah, you’re tied, the transport [to take my son to the day centre] comes at nine o’clock
14 so I couldn’t start a job at nine o’clock for a start. It would have to be later. I’ve got to be
15 here for four o’clock when he comes back. So you’re restricted there”. (Adult carer, in part-
16 time employment); “Social services were absolutely marvellous, I can’t praise them
17 enough. I mean they provided far more than I ever expected”. (Adult carer, employed);
18 “[home care staff] are very reliable. They come in every day ... they’re only off when
19 they’re sick”. (Adult carer, employed); “There’s no point [in requesting help]. They don’t
20 deliver. I’m sorry, they’re just absolutely useless in my book”. (Adult carer, not in
21 employment); “The service for the elderly, it really was appalling...You know, for anybody
22 who didn’t know their way around the system, or anybody who didn’t have sufficient
23 confidence to ask, I mean well you despair really for how they would manage”. (Former
24 adult carer); “Now if we get involved with these people, with medical assessments and
25 one thing and another, I’m afraid as where it might lead to...we really and truly are
26 frightened of them for the simple reason that we don’t know the outcome in the future”.
27 (Adult carer, not in employment);
- 28 • “carers did not know about available services, what they were entitled to or the right
29 questions to ask”. (Author quote)
- 30 • “If there was an employer at the moment that wasn’t flexible, I wouldn’t be able to work for
31 them, I wouldn’t be able to”. (Adult carer, employed); “It was sorted out between the
32 chappies, you know, the management wasn’t involved, that was the nature of the way
33 things used to be done...We’d done the job long enough to basically make our own
34 arrangements. If extra production was needed, we’d sort it out among ourselves what
35 extra hours we’d work”. (Adult carer, not in employment); “The trouble with market trading
36 is unfortunately you cannot cut your hours down, you have to be there and set up for nine
37 o’clock-ish and if you were travelling from here say to ‘x’ you’re talking three-quarters of
38 an hour to an hour’s drive...and you’re then talking quite a bit of time in setting up your
39 stall and everything”. (Adult carer, not in employment); “I’d looked for a long time for a job
40 that I felt...I could perhaps manage...I needed something where I didn’t have to work
41 nights, I couldn’t work nights, it had to be reasonably near, it couldn’t really be any more
42 than two days a week and it had to be sort of hours that I could sort of work around, fairly
43 flexible, you know”. (Adult carer, short part-time employed)
- 44 • “I did ask at one stage if I could do less...that was when my son wasn’t doing his
45 homework and I asked if I could do maybe two nights: just a Saturday and Sunday, and
46 make up the rest of the hours in the daytime. And my boss, who’s retired now...she said
47 ‘No, because it’s all changed and you have to sign a new contract’. When a job comes up
48 now, anybody that applies has to sign a contract to say that they’re willing to do evenings,
49 weekends, mornings, afternoons, any hours asked of them...which is stupid because
50 Social Services are sort of biting their noses off to spite their faces really”. (Adult carer, in
51 part-time employment); “I’ve found her not, at the moment, not very approachable. That’s

- 1 probably because I don't know her very well but she is the sort of manager who goes in
2 her office and she is in her den and you don't go. But until I know her better I will have to
3 wait and see how it goes before I sort of approach these personal issues". (Adult carer, in
4 full-time employment)
- 5 • "I just now work to be able to pay the mortgage really and, and pay bills...I wouldn't work if
6 I didn't have to". (Adult carer, in full-time employment); "My main drive really to be in work
7 is to get money under our belt because I don't just think we'll need it for our own lifestyle.
8 Once we do have to finish work, I then look at the worse case scenario of if [my child]
9 can't go off and be independent. Despite Disability Living Allowance, etc., Carer's
10 Allowance, it's amazing how much of a financial drain a disability can have on you". (Adult
11 carer, in short part-time employment)
- 12 • "I think you've got that muzziness...I think you live in this constant state of not being able
13 to plan anything because you don't know...I think you basically live one day at a time".
14 (Adult carer, in short part-time employment); "I'm fifty-eight now and say if I wanted to
15 retire at sixty, two years, now what can I make in two years? If I needed to retrain, it would
16 take me two years to retrain so that's out the window. I need to make fast bucks in a way,
17 right, so that is what I am trying to achieve by...investing in the property, maybe I could
18 even sell it over. I've already done that once". (Adult carer, not in employment)
- 19 • "You see [I'd] take a job stacking shelves at [the local supermarket] but if they only want
20 you for say three hours a day, by the time you've done three hours' work andyou've
21 taken out the petrol expenses and running expenses of your vehicle, there's not an awful
22 lot left". (Adult carer, not in employment rural carer);
- 23 • "I was certain that I wanted to look after my mum, my husband was supportive of that...he
24 encouraged me. we just took it on the chin and decided, you know, we had to do it. So we
25 just had to fund it ourselves somehow and if the pension suffers, it suffers". (Former carer
26 – non working); "As long as I'm physically able to do it, I will and I know that [my wife]
27 wouldn't want somebody else coming. I mean there are personal things which she needs
28 which she wouldn't want a stranger doing. All right, fair enough, if I wasn't here she'd have
29 no choice but she has got a choice and we have got a choice". (Adult carer, not in
30 employment); "Yeah, I've got the contact [with SS] and I know what is on offer...but I do
31 know we'd have to pay for it and I know my mum wouldn't like it. So to be fair on my mum,
32 I do try to abide by her wishes and not spend her money that quickly". (Adult carer, not in
33 employment)
- 34 • "I don't regret the decision [to leave work] and actually, if I'm totally honest, I suppose in
35 some ways I feel happier that I haven't got this great stressful position, taking phone calls
36 all the time and having to go to work. I actually feel I go and do my little job [at the office],
37 come home at night, and I may not have much money in the bank but I feel a lot better for
38 it". (Adult carer, not working); "What's really got me through [15 years' caring for a
39 husband with mental health problems] is being at work. It's been something that belongs
40 to me...It's the only thing that's kept me sane really...the only thing that really I have to
41 look forward is going to work". (Adult carer, employed); "[I worked for next to nothing]
42 because it was a change from [caregiving] all the time. I could go to work, I could socialize
43 with other people, I could talk about everyday things other than, you know, what I do at
44 home". (Adult carer, not in employment)
- 45 • "I didn't see my working life as having finished [when I started looking after my mother]. I
46 mean I've worked since I was twenty-two, you know...I wouldn't have wanted to have
47 gone without [my salary] and also I define myself to some extent by what I do and I
48 suppose, you know, I define myself as a professional person, an academic, a teacher, I
49 don't justify myself as a carer". (Adult carer, employed); "What's really got me through it is
50 being at work. It's been something that belongs to me. Nobody can take that away from
51 me...it's the only thing that's kept me sane really.the only thing that really I have to look
52 forward to is going to work". (Adult carer, employed); "No job, no money. No freedom. You
53 need money to buy freedom, to go places. I enjoy travelling. My job comes first. I've got to
54 go out to work, regardless of the caring for my mother". (Adult carer, employed)

- 1 • "Some carers in professional jobs were committed to their careers; they were unwilling to
2 lose the investment they had built up over their working life, especially those who also
3 enjoyed work". (Author quote)
- 4 • "I always get the response, "We're not here to help you go to work"; it's a kind of mantra.
5 Well, why not? "That's not our job, if you want to go to work that's up to you". (Adult carer,
6 in full-time employment); "This may sound very hard-faced, but they're carers and they're
7 a solution to our problem aren't they? 'Cos if we didn't have the carers, then the local
8 authority would be stuck, wouldn't it?". (Social worker)
- 9 • "The form was that thick and, and nothing simple on it...You've got to know what this is all
10 about.people that fill them regularly every day, they know, they've been trained to do this".
11 (Adult carer, not in employment); "I think it's incredibly sad that, that we're restricted in the
12 amount of income we can earn. In my situation, I've got a whole day while [my daughter]
13 is at school, like any able-bodied child would be at school, but I can't go out and get a job
14 that gives me my own sense of worth, mental stimulation, choices...I can't because there's
15 a financial restriction...in my case, the restriction of Carer's Allowance". (Adult carer, in
16 short part-time employment); "I worked at [a local supermarket] for nearly two years. I
17 used to earn £67.91 a week, out of that the Social Security used to take £47 off me, so
18 that meant...I was earning £20 a week. Out of the £20 a week, I used to pay £10 to £12 a
19 week in petrol so I was actually earning £8 a week". (Adult carer, not in employment)
- 20 • "It brought everybody out into the open and you began to realise of course that you
21 weren't the only person, which is always a feeling sometimes, if you have a problem
22 you're the only person with it. But actually you're not". (Adult carer, employed); "They've
23 been brilliant and I know that if I need that time, I could have that time. I mean it's
24 reciprocated.you know, there's been times when I've had to work a twenty-four hour shift
25 because somebody's not come to take over and it's my responsibility to make sure the
26 ward is covered...So they know that I will work twenty-four hours a day if I have to but
27 likewise if I need time off, then I can have it. My managers are very supportive of me
28 because they know they get 100 per cent of me when I'm at work. (Adult carer,
29 employed); "It was sorted out between the chappies, you know, the management wasn't
30 involved, that was the nature of the way things used to be done...We'd done the job long
31 enough to basically make our own arrangements. If extra production was needed, we'd
32 sort it out amongst ourselves what extra hours we'd work". (Adult carer, in full-time
33 employment)
- 34

35 Bernard 2007

- 36 • "I need to be in work at eight in a morning and I finish about five. I was going from (home)
37 to (m-in-l) in a morning to get her washed and changed...I was going back after work...it is
38 an hour's journey from here (work) to her house and then another hour back home. So, it
39 was adding another six hours on to my working day." (Adult carer, in full-time
40 employment); "At the time...I was based (in the south of the county), I lived (10 miles
41 away) then with my husband, and I used to go to work and finish work at about 10.30 am,
42 whiz off up there, look after her and come back about 9, 10 o'clock at night, go to work the
43 next morning...Get up about 5.30: uniform for school; one off to work; sandwiches for
44 school; make sure that if it was football the kit was washed and ready; everybody's
45 sandwiches; general wash up and tidy up before I went to work. If I knew she wanted
46 anything I picked it up on my way. The car was always full of petrol, I just had a morbid
47 fear of conking out somewhere in the middle of nowhere...I don't even remember some of
48 the journeys and that is frightening. I have sometimes turned up at that house, on the
49 drive, not even thinking I've left 10 minutes ago and that is frightening you know" (Adult
50 carer, in part-time employment)
- 51 • "I've got a mother-in-law that's 87...She's from a big family, there's six of them (but) we do
52 the caring...Have I got brothers and sisters? Yes. Has my husband? Yes. Do we (share
53 the caring responsibilities with anyone else)? No...They (her sister-in-law and husband)

- 1 took my mother and father-in-law...to (near Bristol) because she lives round the corner, to
 2 care for them, but they don't...she's not a carer. I mean, she does what she can but...I've
 3 only got one brother and he actually lives at home. I think he would do a lot more but like
 4 most men you have to ask and, like most people, my parents are very proud and they
 5 won't ask...I would love for one of the people in the family to take responsibility. It would
 6 be lovely not to have to have to do it, but it doesn't happen." (Adult carer, in full-time
 7 employment)
- 8 • "say she was going in somewhere, or going in like for an operation or something like
 9 that...I'd have to take annual leave". (Adult carer, in full time-employment); "I've took a
 10 week and two weeks and periods like that of annual leave to cater for various things".
 11 (Adult carer, in full time-employment); "I do sometimes accumulate some time owing
 12 where if I work late and things. I tend to use that perhaps with my mum: I was sort of
 13 going in late and then juggling my hours. Rather than starting work at 9, I was starting at
 14 11 and then finishing later in the day." (Adult carer, in full time-employment); "It (TOIL)
 15 would work if, the trouble is if I've always got time off in lieu: I'm never ever going to get to
 16 the bottom of it...I can take TOIL but TOIL is not always easy to do because TOIL is one
 17 of those things that if there's a crisis you have to give your TOIL back and come back and
 18 do your TOIL again another time. (It's) not easy to do if you're working, if you're trying to
 19 organize something with (mother-in-law): it's all the stress levels on that because it's
 20 juggling: it's throwing all the balls up in the air and whichever one happens to drop first is
 21 the one you deal with and then hopefully you throw it back up before the next one drops
 22 otherwise you end up with them all on the floor at the same time and you haven't got
 23 anywhere." (Adult carer, in full time-employment)
- 24 • "He had a terrible pain behind one eye; he lost his sight and everything, all within half an
 25 hour. And they just said we're sending Graham home, he needs to go straight round the
 26 doctors and she (the manager) just said, 'Go. Sort it'. She said, 'Have carers' leave. Don't
 27 bother about being here tomorrow or the next day, take two or three days carers' leave
 28 and let me know what's going on'. And that's what I did." (Adult carer, in full-time
 29 employment); "My colleagues were absolutely wonderful. You know, they'd listen to me
 30 sometimes you know and they'd say, 'Are you OK?' And maybe I needed to offload and
 31 they were very supportive you know...if I was panicking about something...they would be
 32 very willing to help (and)...there were times when I did become really quite upset. It was
 33 affecting me...I wasn't an easy person I don't think during that time...(and) I'll never forget
 34 how lovely they all were" (Adult carer, in part-time employment); "I suppose it's
 35 conversation with some of my friends and different colleagues and certainly when I'm on
 36 secondment to the department (of health), a colleague there has just gone through exactly
 37 the same. So, it's almost every week we're comparing notes and, you know, supporting
 38 one another and letting off steam." (Adult carer, in full-time employment)
- 39 • "I had to go away for one week and it was my friend who looked after my mother here. He
 40 said, 'Oh, don't get her admitted into any home at all, we'll look after her'. And for seven
 41 days they kept my Mum at their house...And it's the same thing: it's that when their
 42 parents are here or anything like that, if they need any help, I'll be willing to help them"
 43 (Adult carer, in full-time employment); "I've got some very good friends at (work) and they
 44 know me personally and my family. I know them personally and their family and what's
 45 gone on and the problems that they've had. The problems I've had. And if we're working
 46 together we'll sort of discuss things very, very quietly and that helps...there's about six
 47 nurses that I could trust my life with and I can say anything to them... (and) there's two
 48 very good friends that I've got: we help each other a lot in that way and we meet and we'll
 49 have lunch...and we'll air our views sort of thing in inverted commas, and it helps." (Adult
 50 carer, in part-time employment)

51 Carmichael 2008

- 52 • "If I needed time off for hospital appointments and doctors' appointments for Joan and
 53 anything like that all I had to do was let them know the day before and I would be written
 54 out for the work schedule for the following day. I didn't get paid for it but they would allow

- 1 me that time". (Adult carer, employed); "For example one carer said it was "imperative" to
 2 have a mobile phone in case the person he cared for needed to contact him urgently.
 3 However, his workplace did not allow mobile phones, and his employer refused to make
 4 an exception to the rule". (Author quote); "You're being paid to do a job at work I mean
 5 you can't just suddenly say in the middle of that job right whoever I care for needs me
 6 bye-bye can you...you're caring or you're working I can't see myself how that can be
 7 worked round really, I really can't". (Adult carer, employed)
- 8 • "I was...bringing home a thousand pounds a month which is good money and now I get
 9 forty-three pounds a week which is a bit of a difference so the caravan had to go, the car
 10 had to go and so financially it's a completely different world". (Adult carer, employed);
 11 "Well it's been quite devastating really. I mean I've basically lost everything. I lost my job,
 12 the career I was aiming for and most of what I had really...I had a very good job and it's all
 13 gone, it's all been lost". (Adult carer, employed); "Either you're caring for somebody or
 14 you're working aren't you...I mean it's difficult to juggle the two." (Adult carer, employed);
 15 "We found it very, very difficult, my husband and I, because my mother lived with us. I
 16 gave up a full time job to have my mum." (Adult carer, employed); "I thought well she's
 17 done a lot for me, and it's time to give back.....She was put on a lot of medication so
 18 because she lived alone, and I didn't like her...in the house...by herself, I packed in the job
 19 and went caring for her all the time." (Adult carer, employed); "I tried to take a job a while
 20 back: I managed to do it for three months. Chris's fits became worse and I think it was
 21 because I was out of the house and it was only four hours a day...so I gave it up". (Adult
 22 carer, not in employment);
- 23 • "The people I used to work with...are now two or three levels above me and I've had to
 24 stay where I am because there are no opportunities for people who work part time like
 25 me."; "I was the breadwinner in my house (before I became a carer)...I was earning more
 26 than Andrew, I had a company car and everything and that was just to nothing."; "I had to
 27 move back north to be with my father this coincided with a chance to take redundancy
 28 from my job in Suffolk. I eventually got a job in Dundee but it was a step down in my
 29 career."
- 30 • "I got a rise under the minimum wage, my wage rose from £23 to £27, but that meant that
 31 I came over the allowed allowance – not by much – only by about well a pound really. And
 32 that meant that I lost the £25 income support so I gained £3 and lost £25". (Adult carer,
 33 not in employment); "If I was working for the voluntary sector I would earn a lot less and
 34 so therefore I would be entitled to more benefits. I know it sounds stupid but because I'm
 35 on that threshold it prohibits us from some things...it's the housing benefit we don't get any
 36 of that we don't get any help with our rent we don't get any help with the house". (Adult
 37 carer, employed)

38 Pickard 2018

- 39 • "Well, a lot of it was to do with the caring because I wasn't well me self, I was caring for
 40 me husband, me dad was dead, I was looking after mum. ... It was getting to the stage, I
 41 was absolutely shattered". (56-year old woman, left work to care, no services)
- 42 • "If somebody had been there, like a carer, somebody to come in of a morning, dinner
 43 [lunch] time ... I'd have felt a lot ... better within myself at work". (56-year old woman, left
 44 work to care, no services)
- 45 • "... just purely from a time factor, I could not have carried on going before and after work
 46 ... And also from a peace of mind factor, because I know they will contact me if they have
 47 any concerns". (50-year old woman, working carer, with services)
- 48 • "Without the day-centre, I'd never have been able to work". (59-year old woman, working
 49 carer, with services)
- 50 • "It's like a weight off my mind...I know that [my father] is going to be fed and looked after
 51 while I'm at work...I know he's being taken to the toilet". (39-year old man, working carer,
 52 with services)

1

2 Seddon 2004

- 3 • “These difficulties are associated with the limited information on local services, carer
4 problems in understanding and assimilating this information and carers’ limited time and
5 energies to identify sources of support”. (Author quote)
- 6 • “Employers have not been brought round the table. It’s high time they were”. (Team
7 Leader, Social Services Department)
- 8 • “Employment should be high on the list of concerns when the assessment is being done
9 but in practice it isn’t. The focus is very much on how they manage the caring and it’s up
10 to the carer whether or not they want to discuss things that go on outside of that”. (Service
11 Manager for Older People, Social Service Development); “They only seemed interested in
12 what I could do for Dad and they didn’t seem too concerned that I was trying to hold down
13 a job as well”. (Adult carer, employed)
- 14 • “He was assessed when he was in the hospital, but I wasn’t very satisfied with the way
15 things were organised [...] I had to have a day off [...] No one asked me how I would cope
16 or whether I worked. They just assumed I’d get my head down and get on with it”. (Adult
17 carer, employed)

18 Sempik 2014

- 19 • “[Many young adult carers]... felt that they would have got better grades at school if it was
20 not for their caring role”. (Author quote); “[Many young adult carers]... who had been to
21 college or university dropped out because of their caring role. This is four times greater
22 than the national average for degree courses”. (Author quote)
- 23 • “[Many young adult carers] felt that they had not received good career advice at school;
24 and that the advice did not take into account their caring role”. (Author quote)

25 Vickerstaff 2009

- 26 • “One thing I feel, particularly in the dementia field, there are lots of organisations out there
27 but they’re not very well integrated together and finding out what you need, what is
28 available and whether it would suit you is a big task for a carer and there’s not an easy
29 way through. Getting it all from one place would be great”. (Adult [former] carer, not
30 working)
- 31 • “I’ve managed to keep everything going and I try not to let what’s happening to me at
32 home infringe on work because, well for two reasons. One is I’m working in a tough,
33 competitive environment, they can’t afford to carry dead wood, you know. I need to be
34 able to do my job properly. I can’t expect them to, you know, carry me, so that means...I
35 mean luckily I’m good at it, so you know I can do my job OK. But the other thing is I need
36 to keep the worst of what’s happening out of work so that I don’t even think about it
37 because then I don’t get upset at work. So that’s why I never discuss anything that’s bad
38 at work, because I don’t want to get upset”. (Adult carer, in employment)
- 39 • “No. But it was just...Like by the time I’d paid it I had to have a uniform, I had to wear...I
40 think it was all black. I didn’t have anything so I had to buy all that. ...it’s just ridiculous
41 and Housing Benefit of course that all gets stopped until they re-do it all and everything
42 and I was just working for nothing. Even the Housing Benefit people agreed with me and
43 the jobcentre. It was working for nothing so....” (Adult carer, not in paid employment)
- 44 • “We have family who’ve sort of run away from us...we’ve never been invited to a wedding
45 at all, my brother’s wedding because it’s too much for them...they don’t advertise that
46 we’ve got children with a disability. In Asian families it’s a taboo thing. ...So they kind
47 of sideline us so we are isolated”. (Adult carer, not working); “...you tend to lose a lot of
48 friends when you’re a carer and you feel very isolated and unless you’ve got, like, good
49 neighbours or other relatives you can become a bit of a recluse which is what I am

- 1 becoming. And I can't really see any other way...to help that type of problem to be honest.
2 ". (Adult carer, not working)
- 3 • "Unfortunately my sister's basically accused my husband and I because of financial
4 matters. She considers herself to be the one who should be dealing with things. But I've
5 always dealt with mum's financial matters and she's basically accused us of taking money
6 and had us investigated. Which is now in the hands of the public guardians". (Adult carer,
7 not working)
- 8 • "My ex-husband doesn't live far away and he does come although I can't leave them
9 alone together, he just winds [name] up and gets him really upset so I can't leave them
10 alone together for long". (Adult carer, not working)
- 11 • "You know, if I've got to work on a Monday morning, for example, and mum's got an
12 appointment with the consultant at the hospital and those kind of appointments are very
13 hard to shift. And some employers, you know, are brilliant, they are flexible but obviously
14 you can understand from their point of view maybe they can't be flexible so I'm aware that
15 when I go back to work there may...there may well be issues". (Adult carer, not in
16 employment)
- 17 • "I used to walk in in the morning, I could laugh about it in the morning. You know I'd walk
18 in and someone would say "what was he like when you got home" or perhaps there'd
19 been travel in the afternoon, "did you find him?" and I'd say "oh yes, I found him up the
20 road here", or that kind of thing". (Adult carer, ceased caring - employed); "I used to walk
21 in in the morning, I could laugh about it in the morning. You know I'd walk in and someone
22 would say "what was he like when you got home" or perhaps there'd been travel in the
23 afternoon, "did you find him?" and I'd say "oh yes, I found him up the road here", or that
24 kind of thing". (Adult carer, ceased caring - employed)
- 25 • 'It is that but even though I can stay in work and I can do those hours I've lost out on
26 promotion prospects a hell of a lot because most of the girls who qualified with me are
27 Sisters and that now but I can't maintain the work record and it costs...You just cannot get
28 a permanent job because your priority at the end of the day has to be the family and as
29 soon as you take that stance you're penalised for it.' (Adult carer, employed)
- 30 • "It restricts the...the sort of the career opportunities that you're going to go for because as
31 you become more and more of a carer then obviously there are certain things that you just
32 won't even consider you won't go for them because you realise that right from the start
33 that they're...they're out. So in a way you kind of frame your career increasingly, including
34 the caring aspect in it. How will the caring fit in amongst it?". (Adult carer, employed)
- 35 • "So it puts you off thinking about other jobs.' 'It does. Yeah. It does because then you've
36 got to explain everything, that you're a carer, you know, home has to come first in a way
37 and...I don't know how employers would be. Would they not employ me if I needed to take
38 time off with a week's notice or something?". (Adult carer, employed)
- 39 • "Respite care...it was really a sitting service and I had carers in for two occasions during
40 the week for about 2.5 hours. This allowed me just to take some time to go out and do
41 things such as going to the dentist and the other session allows me to play in an amateur
42 orchestra every Monday evening". (Adult carer, not working)
- 43 • "...and I got to a point when I was just so low and I thought I've just got to do something
44 about this. And I phoned my husband and said "I've blanked out three weeks in October",
45 I said "I'm phoning social services and I'm going to see if I can get respite care", which I've
46 done. He's going to go for three weeks to Sampson Court and they are lovely there and I
47 have booked to go to Italy. Because we've not had a holiday since I can't remember...".
48 (Adult carer, employed)
- 49 • "She [daughter] went in for two weeks respite. Well maybe it was naïve, I guess I thought
50 originally that we would maybe get respite every weekend or something like that. The
51 social worker came round and said you're entitled to four to six weeks of respite a year
52 and it has to be in blocks of a week minimum at a time". (Adult carer, employed)

- 1 • “We get respite vouchers to be used at the Lothian Autistic Society that produce a list of
2 carers that have worked with children with autism. We’ve got a carer called Ben who takes
3 them [two autistic sons] every fortnight because that’s all I can pay him...the vouchers
4 [cover] the number of hours he’s working with the children, extras we have to pay
5 for...around about £10-£20 depending on what activities they’re up to. “. (Adult carer, not
6 working); “I paid for most of it [sitting service] out of my own pocket. I managed to spread
7 the direct payments out to cover some of it and I made up the rest myself. “. (Adult carer,
8 not working); “For the Independent Living Fund [ILF] you are financially assessed and you
9 contribute towards the home care and we contribute towards the respite care. The money
10 from the ILF is to pay for a personal carer to come in”. (Adult carer, not working)
- 11 • “Sheila’s been great, she attended meetings with us, she’s taken up a role to give us extra
12 back up and advice on everything we need. The problems we’ve been having with mum’s
13 care...she’s been a godsend. [She also has] a case worker from Perennial, the Gardeners
14 Benevolence Society, through dad...whose been very, very good as well. Lots of advice
15 and financial advice. Sheila’s our guardian angel really”. (Adult carer, employed)
- 16 • “Myself I got involved with Vocal, the carers organisation. They were a great help in terms
17 of, you know, they run evening things and good clubs and you get together with other
18 carers and chat things over and that was...that was a support to me personally”. (Former
19 carer, not working); “[Name of town] Parent Support Forum is made up of a large majority
20 of parents like me who have got children with special needs or who are trying to work and
21 look after them and are juggling things. So when we have a meeting we make sure we
22 have like a half hour networking slot where we can just all talk or moan or whatever we
23 want to do”. (Adult carer, employed)
- 24 • “Mum’s doctors, her GP especially, has been wonderful”. (Adult carer, not working); “My
25 GP, she’s very good. And I see a counsellor at the practice as well. And there’s an
26 Admiral Nurse that I’m going to be seeing and Ann the CPN comes around quite
27 frequently and always goes with us when we go to see Dr Smith who is the psychiatrist”.
28 (Adult carer, employed); “we also have an Admiral Nurse...she is brilliant.’ (Adult carer,
29 not working); “...My carers group, that’s run by Admiral Nurses. And that’s been very
30 good, very useful indeed.’ (Adult carer, not working)
- 31 • “I’ve always been treated with a great deal of respect and...and the people have tried to
32 put themselves in my position. But the fact is they have to have a number on their form”.
33 (Adult carer, employed)
- 34 • “Because I asked whether or not they had somebody, an adviser to deal with people who
35 have been out of work as carers for some time and needed help to get back into the work
36 situation and they said they don’t have people to do that specifically, just general, you
37 know, search facilities and advisers...Have somebody specifically trained to help carers
38 get back into the swing of things, either full-time or part-time, either into voluntary work...”.
39 (Adult carer, not working)
- 40 • “And very rarely in jobcentres will you find part-time work or temporary work. Obviously it’s
41 going to be the 30 hours a week stuff”. (Adult carer, not working); ‘I’m used to being a
42 manager and I also find that the staff, generally speaking, haven’t got a clue about
43 anything beyond their own level of employment. So unless I want to go to Jobcentre Plus
44 and be employed as a civil servant in some, whatever grade they are, it’s pretty hopeless.
45 So if you’ve got anybody who’s got any degree, I think, of...especially what I would call
46 “life experience”, which you can’t expect these young people to have, I think they
47 undervalue you. I would expect, my anticipation is, that they would undervalue my skills
48 and experience and I’m sure I’d be offered some work, but I’m equally sure that it wouldn’t
49 be work that I’d be...’ (Adult carer, not working)
- 50 • “But he actually did say to me, he said “you should have come to me and I could have
51 told you. I mean financially you weren’t any better off, why did you?” and I didn’t go back
52 because of money. I knew we weren’t financially better off by £20. It was my self-esteem I
53 wanted to do it for”. (Adult carer, not working)

- 1 • “Well when you have Carer’s Allowance, if you know you can have Carer’s Allowance,
2 because what I do is when we have new parents contact us, I send out a pack and I put
3 all that sort of information in there, because we didn’t know about it, we didn’t know about
4 Disability Living Allowance or anything, nobody told us. But if you get Carer’s Allowance,
5 wouldn’t that sort of thing, you know, could they not put a leaflet in about that?”. (Adult
6 carer, not working)
- 7 • “I think they need to have a bit of a more human approach to this, you know, because I’m
8 sure if this is happening with me and I’m not an unintelligent person “I dread to think how
9 some other people are coping with things. I think they probably don’t even bother to go
10 there with it. I don’t think people even realise the things you can claim. I didn’t actually
11 realise, you know, until the Deal Carers said to me oh wait a minute you should be getting
12 the carers’ “. (Adult carer, self-employed); “But generally every time you go in there you
13 get told something different. Even if you speak to the same person three months after
14 you’ve spoken to them before and they tell you something different again”. (Adult carer,
15 not working); “And Carer’s Allowance isn’t anywhere near enough. £50, they’re having a
16 laugh aren’t they? Especially for people that look after elderly people and they’re with
17 them all the day long”. (Adult carer, not working)
- 18 • “To keep the hours down, yes. But sometimes that puts you in a difficult position because
19 you might want to work a little bit more, but if you work a little bit more then the benefit is
20 taken away”. (Adult carer, employed); “But my main problem is that, you know, you can
21 only earn £95 a week because of the Carer’s Allowance so you can’t like work more
22 than...If you’re earning say £6 an hour, for example, you can’t really work more than 15
23 hours. And if you look at the jobs in the paper most of them are, like, 20-odd hours for
24 part-time work. So there are...What jobs there are there there’s very few that I can
25 actually apply to and even the ones that maybe do fall into the category I can apply for
26 sometimes, the advert will say “must be able to do extra hours during school holidays” or
27 something like that but I can’t commit to extra hours, not because I don’t want to but
28 because of this £95 ceiling. You’re not allowed to earn more than £95. £95 used to sound
29 a reasonable amount because I know obviously you can’t earn a fantastic salary and then
30 still claim for your Carer’s Allowance. I realise that. But, you know, £95 nowadays is
31 nothing, you know, so...”. (Adult carer, not working)
- 32 • “I am self-employed. I price work to customers and go and do work so if things like
33 hospital appointments turn up then I don’t go to work and if she doesn’t feel right I don’t go
34 to work. So it’s very, very flexible...But then there is...With being self-employed you’ve got
35 to find the work, you’ve got to price it, you’ve got to do invoices, you’ve got to do
36 everything. So in some respects it would probably be easier if you were working for
37 someone. But then when you can’t go to work it’s not so easy to be working for someone
38 and so on balance I would say being self-employed is the only thing I could do...really the
39 only way to go”. (Adult carer, employed)
- 40 • “A very flexible department who are willing for me to sort of work from home if necessary,
41 carry hours over so I can work from home if necessary. I’m fortunate enough to have a job
42 that allows this. A lot of my work is sort of computer-based, dealing a lot with sort of excel
43 document spreadsheets and so it is work that I can do at home. So they’re very
44 understanding and know that there are times when I have to leave early because I’ve got
45 appointments and they’re very helpful and very flexible and without that it would be
46 virtually impossible for me to work”. (Former carer, employed); “I suppose it can be
47 flexible. Because I’ve got regular clients I go to it’s sometimes...it’s difficult...Well I have to
48 take holiday...If I need to take time off if my husband needs to go to hospital I have to take
49 holiday or...you know, and sometimes they’re a bit off if I ask for time off.’ (Former carer,
50 employed)
- 51 • “In the past they’ve been...well I’ve had various different employers in schools so some
52 have sort of said “well, you know, you can have this week off but you will be unpaid”.
53 Some have said that and...But then the pressure’s there to go back really soon because

- 1 we can't pay the mortgage, we can't...you know, if you can't eat you can't care for
2 someone either so it's...you know.' (Adult carer, employed)
- 3 • 'Yes. But I don't have a contract as such because I'm a bank worker, so I don't have a
4 contract, I only work when they need me, or when I'm able to work"...[So, there are
5 advantages in not having an employment contract?]. "Yes. And I quite like not having a
6 contract, so that when the summer comes I can just say "I'm not available".'
- 7 • "When I was doing FPC qualification it was technically we have to go away to Birmingham
8 for three weeks, continuous weeks, and I had actually said to them that's there no way
9 that I could do that and what they eventually did was they actually got a trainer to come to
10 Edinburgh and train me one-to-one. They actually sent somebody here for three weeks
11 instead to train me one-to-one". (Adult carer, employed)
- 12 • "Well you have to ask and it's all at the director's discretion. That's the problem with the
13 University. It's not "here's a policy" and everyone has to follow it. They have policies and
14 then they say "ah but we'll just let all these little autonomous autocrats determine
15 everything for themselves" and there are all sorts of things going on here and it's different
16 all over the place". (Adult carer, employed)
- 17 • "They're great. They can be very, very supportive. They're always there to listen". (Adult
18 carer, employed); "I suppose there's the emotional support in terms of if I've had a bad
19 day or bad morning, there's always people I can have a moan to, let off a bit of steam
20 with. So I suppose they may not realise it but they do actually give me a degree of
21 emotional support as well". (Former carer, employed)
- 22 • "No, there's lots of people part-time. There was even one guy who's still there, he works
23 half time now, 50 per cent, and it's really because he wants to spend, he's got two young
24 children – he's a couple of years older than me and he's got these very young children –
25 and he just wants to spend more time with them...". (Adult carer, employed)
- 26 • "Yes we're lucky in that I don't have close family nearby but when they are available
27 they're pretty good with my children. If there is a hospital appointment people will collect
28 my kids from school...and give them their tea". (Adult carer, caring, not working);
29 "...everyone in the street is aware of Mark's illness [diabetes and epilepsy] Topsy [the
30 dog] saved [name] life twice – for some reason she can sense it...she brought him round
31 a couple of times". (Adult carer, employed)

32 Yeandle 2007

- 33 • Themes
- 34 • Information availability and appropriateness to carers' needs (Difficulties in accessing
35 social services support)
- 36 • "I found that if you didn't ask, you didn't get to know, and you didn't always know what to
37 ask. Very much a case of information is power – once you know what to ask, or what
38 you're entitled to (...) But you shouldn't really need to ask, that information should be
39 forthcoming. (...) You've got to get out there and learn it for yourself, because no one's
40 going to tell you". (Adult carer in part-time employment)
- 41 • "I think someone needs to sit down and go through that a bit more". (Adult carer full-time
42 employment)
- 43 • Limited flexibility to the carers' needs (Difficulties in accessing social services support)
- 44 • "If they had got me day care before now, I wouldn't even consider putting my father in a
45 home. Because the only thing wrong with my father is boredom. He's not got any
46 interaction with adults his own age. (...) I volunteered for it without realising the real
47 implications. I didn't think I'd be brought down so mentally as I have been – to the point
48 where you're bored and depressed. If I had day care, would it have been better for me?
49 Aye. Would it have been better and beneficial for my father? Aye". (Adult carer, not in paid
50 employment)
- 51 • Limited flexibility to the carers' needs (Difficulties in accessing social services support)

- 1 • "I have to take time off. I had one a couple of weeks ago which I took a leave day for. If
2 they're first thing in the morning I probably wouldn't [take annual leave]. I would make the
3 time up [instead]". (Adult carer, in full-time employment)
- 4 • "That's not a good use of resources. There is no reason why they can't have staff there
5 from eight while six. Yes, it costs money because they're paid on an hourly rate, but who
6 are we running the service for? The service that's there...they really have to decide what
7 the service is. Is it a luncheon club that also has sort of a bit more to do? Is it a service for
8 people who are living in their own homes and want to come out to meet people? Or is it a
9 service for carers? At the moment, the day care centre is a service for people who are
10 living in their own home, who maybe couldn't get ready before half-past-nine and maybe
11 want to be back before it's dark...It's trying to do two things. (...) ...the service as it exists
12 at the moment prevents people from working unless they have extremely flexible
13 employers". (Adult carer, in part-time employment)
- 14 • Working hours and Flexibility
- 15 • "I work part-time. I'd rather work full time, but I decided I'd work part time because of
16 Michael's needs". (Adult carer, in part-time employment)
- 17 • "Actually they get more work out of me than they pay me for. That's what you've got to
18 do. That's what I feel you've got to do to get the flexible hours you want. Working
19 weekends, working evenings". (Adult carer, in part-time employment)
- 20 • "He's an old type boss, you know, he phones me up at half-past-six, so I turn my mobile
21 off now; the pressure's on all the time...He's totally unsympathetic to anything like
22 this...That type of firm, business comes first". (Adult carer, in full-time employment)
- 23 • "Fortunately you're on flexitime so that was a benefit, but since my daughter went into
24 hospital I've just done for her what she wanted me to do, and my employer has been
25 absolutely brilliant". (Adult carer, in full time-employment)
- 26 • Other carers, currently working in the private sector, aspired to find employment in the
27 public sector:
- 28 • "You get flexitime if there's medical problems in your family – children, partners, whatever.
29 They're quite considerate. Because I would like to be employed in a normal environment".
30 (Adult carer, in part time-employment)
- 31 • The highest praise was often given to employers by carers working in the voluntary sector:
- 32 • "I think they're just brilliant in how flexible they are – and there's never an issue if you can't
33 come in. It works both ways, because the people there give 110%". (Adult carer, in part
34 time-employment)
- 35 • "I did find it hard to start with, because I always had money. Money had not been a
36 problem, we've always had money. It was nae bother just to go to the bank and £200,
37 £300, £400, and this and that. But I found it hard to start with". (Adult carer, not in paid
38 employment)
- 39 • Commitment to care recipient (Barriers to obtain work or to return work)
- 40 • "It's got harder, as she's got bigger. I think as a baby you care for them anyway, even as
41 toddlers, 5 or 6 years old you're still caring for them in a way. But now she's 17, she's a
42 young woman – and you're still doing personal care which is sometimes degrading for her
43 – and it feels as if it never ends". (Adult carer, not working)
- 44 • "I had to gradually give up (working), the more and more I couldn't leave him. There was a
45 time when you could stay at home on your own, and I was still working for quite
46 sometime". (Adult carer, not working)
- 47 • Wishes of care recipients (Barriers to obtain work or to return work)
- 48 • There were difficulties too when the cared for person did not wish to use services:
- 49 • "(I recognised that) she needed looking after virtually 24 hours a day, and there was
50 nobody else to do it. The maximum amount of time I can leave her is 3 hours – after that

- 1 the alarm bells start ringing, and you get twitchy and you can't concentrate on what you're
2 doing, because you need to be here to look after her". (Adult carer, not in employment)
- 3 • Carers' personal factors (for example identity, commitment to career)
- 4 • Commitment to career
- 5 • "I can't see any way me moving forward. I'd love to go into nursing or mental health
6 because I've got that interest now, but I can't see how I'm ever going to be able to do the
7 training or anything I want to do anyway because I'm stuck". (Adult carer, in part-time
8 employment)
- 9 • "The fairest thing to say is; I would once have described myself as highly ambitious, and I
10 did achieve some of my ambition in my previous job. I now have no career ambition
11 whatsoever. I work hard for, you know, pay and hopefully something that's fairly
12 congenial, but I never want to have such an all consuming job again. I have plenty to do
13 here (at home)". (Adult carer, not working)
- 14 • Respite care
- 15 • "Roland is at Headway today, so I'd normally be out at work, because I know Roland is in
16 a situation that is quite safe....They are valuable to quite a large degree, because they do
17 give me those extra hours in the week". (Adult carer, in part-time employment)
- 18 • "It's only in the last year that I've had Direct Payments that's enabled me to have any time
19 to myself at all, because I dread holidays. I'm a prisoner in my own home... It's worked
20 absolutely brilliantly. So well, in fact, that I was able to think about getting a job...I hadn't
21 worked since I had my first child. I could not work at all without Direct Payments. I just
22 wouldn't be able to do it at all. I wouldn't even entertain it". (Adult carer, in part-time
23 employment)
- 24 • "It lets me get on with my work without having to worry. And I know if there's anything at
25 all, they'll phone me. It takes a bit of weight off your shoulders for a few hours a day, so
26 you can go about your normal business". (Adult carer, in full-time employment)
- 27 • Financial support for carers (for example Carer's Allowance)
- 28 • "If I had been able to work all the days that I could without taking time off for
29 appointments and things then I might have been [better off]. But the fact is there was
30 several days, sometimes a week here and there, that I had to take off and I wasn't getting
31 paid for it". (Adult carer, not in paid employment)
- 32 • Supportive employers, managers and colleagues
- 33 • Her new employer, a sole trader, is far more understanding and flexible:
- 34 • "I'm a very lucky person at the moment. This is how understanding my boss is. He turned
35 round to me and said, bearing in mind I've only been there since October, he said 'What
36 would you like to do for yourself?' I said, 'What do you mean?' and he said, 'Well you
37 never do anything for yourself ever. You're always running around after other people'.
38 (Adult carer, in full-time employment)
- 39 • Support from family and friends
- 40 • One carer explained his understanding of his own situation, in which his mother-in-law
41 provided a good deal of his wife's care, without which he felt he would have to leave work:
- 42 • "Without her mother around I honestly don't know what would be the case. Probably I
43 would need to give up work because I couldn't see any other way of managing the
44 situation. (...) It's not something I relish, a life with caring for my wife – and my goal is to
45 continue working to my retirement. Whether that's feasible and realistic at this stage I just
46 don't know". (Adult carer, in part-time employment)
- 47
- 48

1 Appendix N: Expert witness testimonial

2 **Table 40: Expert witness testimonial for review question: What are the most effective,**
 3 **cost-effective and acceptable interventions, tools or approaches to support**
 4 **adult carers to enter, remain in, and/or return to (i) work, (ii) education, and**
 5 **(iii) training? Madeleine Starr MBE and Ian Peters**

Section A: completed by the developer	
Name:	Madeleine Starr MBE; Ian Peters
Role:	Director of Business Development and Innovation; Chair of Employers for Carers
Institution/Organisation (where applicable):	Carers UK
Contact information:	20 Great Dover Street, London, MBE SE1 4LX
Carers UK,	
Guideline title:	Carers: provision of support for adult carers
Guideline Committee:	Guideline Committee meeting 6
Subject of expert testimony:	Support for adult carers to enter, remain in or return to work, education and training.
Evidence gaps or uncertainties:	<i>What are the most effective and cost-effective interventions, tools or approaches to support adult carers to enter, remain in, and/or return to (i) work (ii) education and (iii) training?</i>
<p>The objective of the review question was to determine the best ways of supporting adult carers to enter, remain in, and/or return to work, education, and/or training by locating evidence about the effectiveness and cost-effectiveness of interventions as well as evidence on the views and experiences of carers, people using services or relevant practitioners in relation to those interventions.</p> <p>The results of the review highlighted a dearth of evidence about the effectiveness and cost-effectiveness of interventions, with only one correlational study and no economic evaluations. The aim of the quantitative, correlational study (Pickard 2015) was to assess the effectiveness of paid services in supporting unpaid carers' employment in England, by examining the association between the use of paid social care services by the cared-for person and the employment rates of unpaid carers (n = 6304). The study found that many paid services for the cared-for person are positively associated with carers' employment. Specifically, the use of home care and a personal assistant were associated on their own with the employment of both men and women carers, while using a combination of paid care and support (e.g. home care, day care and personal assistant) were associated specifically with women's employment. However due to the limitations in terms of study design, the research did not provide any data to address the outcomes in the review protocol. By contrast, 8 qualitative studies were included in the review. They were all conducted in the UK and published between 2003 and 2014. The studies provided data on the following themes: carers' pre disposing factors to seeking support; barriers to remaining in education (e.g. balancing education and training with care); barriers to remaining in work (e.g. a lack of workplace flexibility, unsupportive colleagues); barriers to entering work (e.g. a lack of confidence and self-esteem and factors relating to the care recipient). Most of the data related to balancing caring with work rather than education or training.</p> <p>In light of the lack of data relating to education and training and the lack of effectiveness and cost-effectiveness across the whole review question, the Committee agreed to try and supplement the data by inviting an expert witness. Committee members are looking for the witness(es) to present evidence relating to the costs and outcomes of a service or intervention aimed at supporting adult carers to enter, remain in or return to work, education and/or training. Interventions or approaches are relevant if their primary aim is to support adult carers to enter, remain in, and/or return to work, including:</p> <ul style="list-style-type: none"> • Return to work plans (including paid or unpaid work) • Workplace support (e.g. flexible working hours) 	

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Supporting adult carers to enter, remain in or return to work, education and training

- Individualised support (e.g. Carers' Lead, work coach/adviser at Job Centre Plus)
- Financial assistance (e.g. Carer's Allowance, Flexible Support Fund)
- Interventions, tools or approaches to improve carers' education, or provide training opportunities/work placements for carers (including volunteering)
- Interventions, tools or approaches for improving carers' ability to enter, remain or return to education or training (e.g. information about working rights/benefits)
- Work-specific carer passports

In summary, evidence on the following aspects of support for adult carers would enable the committee to develop recommendations and add weight to the results of the systematic review:

- The effectiveness and cost-effectiveness of different approaches or services for supporting adult carers to enter, remain in or return to
 - Employment
 - Training
 - Education

Data demonstrating effectiveness would ideally show changes in

- Carer quality of life
- Employment rates
- Productivity
- Financial burden or other financial issues
- Carer mental health

The views and experiences of carers, people using services and relevant practitioners about the accessibility and acceptability of services or interventions to support carers to enter, remain in or return to training and education.

Section B: Completed by the experts

The image shows the front cover of a report. On the left, the Carers UK logo is at the top, followed by the title 'Carers and Work: support in and into work for carers' in a large, bold, black font. Below the title, the authors' names and titles are listed: Ian Peters, Chair, Employers for Carers, Chair, Barts Health NHS Trust; and Madeleine Starr MBE, Director of Business Development and Innovation, Carers UK. At the bottom left is the 'ec employers for carers' logo. On the right side of the cover, there is a large, stylized red graphic element consisting of two curved, overlapping shapes that form a partial 'S' or 'B' shape.

carersUK
making life better for carers

There are **6.5 million carers** in the UK today. That's **1 in 8 adults**.

This **unpaid** care saves the state **£132 billion** a year.

carersUK
making life better for carers

3 million carers combine paid work with care. That's **1 in 9 people** in any workplace.

ec employers for carers



Impacts of caring on work

- Over 2 million people have given up work at some point to care
- Older workers are most likely to be carers too, and it is estimated that by 2030 1 in 3 people will be over 50
- 3 million carers have reduced their working hours
- 70% of carers report being over £10,000 worse off as a result of reduced earnings, higher costs and lower pensions



Impacts of caring on work

- Caring affects the type of work carers can do
- Fear of stigma and perceived impact on opportunities and advancement at work can lead to carers being hidden
- Problems accessing suitable care services – flexible, accessible, affordable - are a significant reason carers give up work or reduce working hours





Impacts of caring on work

- The experience of caring can have a significant impact on the ability to return to work post-caring or when caring changes
- There are challenges for young adult carers who might have high levels of skills but limited conventional work experience and qualifications
- The impact of caring on work is a growing economic challenge for employers and the UK economy as well as families.



Impacts of caring on work

- The experience of caring can have a significant impact on the ability to return to work post-caring or when caring changes
- There are challenges for young adult carers who might have high levels of skills but limited conventional work experience and qualifications
- The impact of caring on work is a growing economic challenge for employers and the UK economy as well as families.





A snapshot of work and care

- State of Caring 2015:
 - 51% of carers had given up work to care
 - 56% of carers who had given up work cited the stress of juggling work and care and 34% the lack of suitable care services
 - 13% had to take a less qualified job or turn down promotions to fit around caring
 - 21% had reduced their working hours to care
 - 34% had used annual leave or sick leave to care



Legislation and policy

- Right to emergency leave
- Right to request flexible working
- Protection from discrimination or harassment
- Debate on right to paid Care Leave
- Work and care issues identified explicitly in the Industrial Strategy
- Work and care expected to be part of the Social Care Green Paper consultation





Focus on carer returners

- First funded programme on carer returners – Surrey County Council, 1998-2000
- New Deal for Disabled People and Carers, Carers UK and DWP, 1999-2000
- Action for Carers and Employment (ACE National), Carers UK-led ESF partnership, 2002-2007
- Review of National Carers Strategy, 2008



Support measures achieved

- City&Guilds *Learning for Living* programme
- Dedicated carer return-to-work services in local authorities
- Care Partnership Managers in JC+
- Fund for replacement care for carers taking up education and training
- Inclusion of carers in JC+ scripts and online training for JC+ staff





Work and Pensions Select Committee: Support for Carers

- Carers UK evidence:
<https://www.carersuk.org/for-professionals/policy/policy-library/response-to-work-and-pensions-committee-s-support-for-carers-inquiry>
- Other current returners evidence demonstrates that the main findings of ACE in terms of challenges and employment return rates are similar
<https://www.parliament.uk/business/committees/committees-a-z/commons-select/work-and-pensions-committee/inquiries/parliament-2017/support-carers-inquiry-17-19/>



Key messages on returners

- The impact of being outside the labour market is the same across different groups of carers, no matter what their level of skills and experience
- Carers need support to recognise the skills they have gained through caring and their transferability
- Funding should be made available to carers for engagement in education and training
- Everyone working in front line employment support should have carer awareness training
- There should be incentives for implementing carer support in employment, education and training, e.g., funding support (tax breaks, direct funding)



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Employers for Carers

Our membership forum Employers for Carers:
110 members: all sizes; public, private and not for profit; most sectors; representing 1.25m employees

Informed by Business

- Supported by the specialist knowledge of Carers UK
- Self financing

- **supports** employers to develop carer friendly workplaces
- **promotes** the business benefits of supporting carers
- **influences** employment policy and practice

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Success factors for workplace support

- Mindset is as important as money
- Executive leadership and role modelling crucial
BUT ALSO
- Bottom up support and understanding from managers
- Implementation requires policy AND practice
- Internal promotion – on a regular basis - is critical
- Communicate numbers and stories, internally and externally
- Carer networks - face to face and virtual

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Success factors for workplace support

- Flexible working arrangements
 - Ad hoc arrangements are as important as formal arrangements
- Flexible leave arrangements
- Flexible benefits
 - EAP, disability or health insurance
- Practical support
 - Private space to make or take a call
 - Parking space close to the office
- Signposting to information and support



Identified business benefits

- Improved recruitment, retention and productivity
 - Reduced costs
 - British Gas estimates potential recruitment savings of £2.5m plus further experience upside through increased staff retention and £4.5m through reduced unplanned absenteeism
 - Reduced staff turnover
 - Listawood (SME) - while only 56% of employees felt their pay was competitive 97% felt they offered better work life balance





Identified business benefits

- Improved resilience and results
 - Reduced stress and absenteeism
 - BT achieved a productivity increase of 21% a year
 - Rewards in engagement
 - EfC members report increased employee engagement through staff satisfaction surveys
 - Reasonable cost vs outcome
 - Experience shows that flexible working and carers leave are not abused; carer networks offer highly cost effective peer support



Challenges and solutions

- Winning hearts and minds
 - Making the connection ('lightbulb moment' becoming easier with demographic change and awareness)
 - Business case for action: risk (compliance) and reward (positive benefits)
- White collar vs blue collar
 - Recognise and promote different approaches
- Corporates and SMEs are different
 - Tailor business case and solutions
- Gaining momentum
 - Long game vs quick wins
 - Simple and replicable actions
 - Umbrella membership / SME reach



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Employers as champions

- EfC exemplars:
 - Pioneering workplace support and championing it to others
 - Capturing and communicating the business case
 - Engaging externally to inform and influence policy
 - Contributing to research on key workplace issues
 - EfC and Carers UK reports
 - ESRC Sustainable Care programme

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Evolving Context

- Managing an ageing workforce
- Supporting distance caring
- Recognising issues for ‘sandwich’ caring
- Signposting to care and support
- Promoting the role of technology in helping employees to work and care
- Looking at retention → recruitment
 - return to work
 - Positive recruitment
 - Returnships

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Source: madeleine.starr@carersuk.org; katherine.wilson@carersuk.org; www.employersforcarers.org

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