A Systematic Review of Interventions for Carers in the UK: Outcomes and Explanatory Evidence

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Contents

EXECUTIVE SUMMARY ......................................................................................... 1

1. INTRODUCTION ......................................................................................... 13
   a. Background and aims ............................................................................ 13
   b. Report structure .................................................................................. 14

2. METHODOLOGY ......................................................................................... 15
   a. Review questions ................................................................................ 15
   b. Inclusion and exclusion criteria ......................................................... 15
   c. Search strategy .................................................................................. 17
   d. Quality appraisal ............................................................................... 18
   e. Data synthesis ................................................................................... 20

3. FINDINGS .................................................................................................... 22
   a. Nature of the evidence identified ...................................................... 22
   b. Interventions to support carers to access services ......................... 28
      i. Statutory carer assessment .............................................................. 28
      ii. Information services .................................................................... 40
      iii. Direct payment schemes ................................................................ 43
      iv. Support workers .......................................................................... 45
   c. Interventions focused upon carers’ health ....................................... 57
   d. Interventions focused upon emotional and social support ............. 59
      i. Carer support groups .................................................................... 59
      ii. Stress management, coping and counselling programmes ............ 67
      iii. Befriending schemes ................................................................... 76
      iv. Complementary therapies ............................................................ 77
   e. Education and training for carers ....................................................... 80
      i. Education programmes for carers ................................................ 80
      ii. Training for carers ....................................................................... 87
   f. Employment-related interventions ..................................................... 96
   g. Carer breaks .................................................................................... 98

4. CONCLUSIONS AND RECOMMENDATIONS ............................................ 114
   a. Future research ............................................................................... 114
   b. Learning about specific carer interventions ..................................... 116
   c. Overarching considerations for carer interventions ....................... 119

BIBLIOGRAPHY ................................................................................................. 123
   a. Studies included within the review ................................................... 123
   b. Other references .............................................................................. 131

APPENDIX 1: TABLES OF STUDY DATA ....................................................... 132
## Tables included in the report

1. Data sources for search strategy ................................................................. 17
2. Studies by intervention category and sector of provision ................... 22
3. Studies by condition of the people cared for by the sample carers ...... 23
4a. Studies by quality ratings and study design for outcome evidence .... 25
4b. Studies by quality ratings for explanatory evidence ......................... 25
5. Studies by outcomes assessed ................................................................. 27
6. Studies of statutory carer assessments .................................................. 132
7. Studies of information services ............................................................ 135
8. Studies of direct payment schemes ....................................................... 136
9. Studies of support workers ................................................................. 137
10. Studies of interventions focused upon carers’ health ......................... 141
11. Studies of carer support groups ............................................................ 142
12. Studies of stress management, coping and counselling programmes ... 144
13. Studies of befriending schemes ......................................................... 149
14. Studies of complementary therapies .................................................. 150
15. Studies of education programmes for carers ...................................... 151
16. Studies of training for carers ............................................................... 154
17. Studies of employment-related interventions ..................................... 158
18. Studies of carer breaks ................................................................. 159
EXECUTIVE SUMMARY

1. Review scope

Government policies of community care rely upon the contribution of carers who look after ill, disabled or frail family members on an unpaid basis. There is a need to support carers in their role in order to address the potentially negative outcomes which caring can have.

This review considers interventions designed to support carers. It seeks to answer the following questions:

- What is known about the outcomes of interventions for carers?
- What explanatory evidence exists about how interventions support carers and the contextual factors which influence outcomes?

This review is limited to interventions directly targeted at carers, rather than those aimed principally at the person who is receiving care which may also benefit carers. The interventions covered include: those concerned with supporting carers to access services; those targeted at carers’ physical health; interventions focused upon emotional and social support; education and training for carers; employment-related interventions; and carer breaks. Studies concerning interventions for any type of carer were included with the exceptions of young carers and those undertaking childcare (where this was not for a child with specific additional care needs, for example, through disability).

The review is restricted to the specific context of the UK since the introduction of community care reforms in 1990. Only studies based upon empirical research were included.

2. Methodology

Systematic reviewing has been developed as a specific method of identifying and synthesising research evidence (Petticrew & Roberts, 2006). Following this, this review seeks to: be comprehensive in its coverage of the literature; pay careful attention to the quality of included evidence; take a clear, systematic approach to the synthesis of the data; and generally follow transparent and rigorous processes.

The synthesis has been undertaken within the realist framework for understanding intervention outcomes (Pawson & Tilley, 1997). This seeks not just to identify outcomes (the change resulting from an intervention) but also to understand the explanatory mechanisms which create this change and the context within which this occurs.

A comprehensive search strategy was used encompassing sources of: systematic reviews and randomised controlled trials; evidence from the health care sector; academic social science research; and grey literature.

Two different approaches to quality appraisal were used to assess separately outcome measurement evidence (Thomas, n.d.) and explanatory evidence (Harden et al., 2001, pp. 62-63). Quality appraisal of outcome measurement evidence
assessed issues such as the overall research design, data collection methods and how representative the sample was. Quality appraisal of explanatory evidence considered whether the study clearly described its aims and objectives, the context of the research, the sample used and the methodology and the reliability and validity of data analysis.

Data from included studies was extracted to cover the following: study aims; intervention type; sample; research methods; and findings.

Mixed methods of synthesis were used. Evidence on the outcomes of interventions is presented in a narrative form in the body of the report (Popay et al., 2006). Explanatory evidence has been synthesised thematically (Pope, Mays, & Popay, 2007, pp. 96-97).

The findings are presented by intervention type. For each, the findings are divided into evidence on outcomes, explanatory mechanisms and significant contextual factors. Background details for each of the included studies are given in tables in the appendix.

3. Findings

a. Nature of the evidence included

The review included 107 studies offering some measurement of intervention outcomes for carers. Of these, 69 studies also included some explanatory evidence about how outcomes were produced and/or the contextual factors which influenced the achievement of outcomes.

There was a reasonable amount of evidence identified about interventions offering: access to support; emotional and social support; education and training; and carer breaks. There was very little evidence about: support to access services in personalised forms such as direct payments which give control to the person receiving support; interventions targeted at carers’ physical health; interventions aimed at helping carers to maintain or access employment; befriending schemes; and complementary therapies.

Many of the studies focused upon interventions for carers of people with particular conditions. The evidence split in this way as follows: range of conditions (28 studies); dementia (28); mental health difficulties (14); stroke (11); older people (10); acute, chronic and terminal illness (6); learning disability (5); and other specific conditions (5). Studies of interventions focused upon emotional and social support were quite heavily concentrated upon services specifically for carers of people with mental health difficulties or dementia. Studies of education and training for carers often evaluated services for carers of people with dementia. Studies of carer breaks particularly focused upon services for carers of people with dementia or of older people. Very few studies focused upon particular types of carer in terms of other carer characteristics, for example, ethnicity, age or relationship to the person receiving care.

The majority of outcome measurement studies were rated as weak on the quality appraisal tool used. However, over 40 per cent used longitudinal designs which allowed change in outcomes over time to be assessed. About half of these also included a control group allowing more rigorous comparisons to be made. These
studies with a stronger research design for outcome measurement were concentrated upon particular types of intervention, namely support workers, stress management programmes and education and training for carers.

The quality of the explanatory evidence was mixed: 43 per cent of the studies were rated as strong, 16 per cent as moderate and 41 per cent as weak.

Studies assessed a range of types of outcome. In particular, across intervention types, there was considerable focus upon emotional well-being (84 studies). Other outcomes often measured included: knowledge (42); satisfaction (40); social inclusion (27); ability to care including skills development and coping (23); service use (20); and achievement of a break (18).

b. Interventions to support carers to access services

b. i. Statutory carer assessment

The quality of the evidence available measuring assessment outcomes was weak because it was generally based upon small samples with no control group comparator. However, these studies suggested that assessment may lead to a wide range of outcomes. The most notable potential benefits were outcomes relating to emotional well-being and the uptake of support services. There was also some limited evidence of: increased knowledge; better physical health; and support to work. However, the achievement of positive outcomes via assessment was shown to vary considerably. In most studies, the proportion of carers who received additional services following assessment was relatively low, below half. In addition, where services were provided, carers were not necessarily satisfied with them.

The identified studies offered some high quality explanatory evidence which indicated some reasons for variation in assessment outcomes. It also suggested how assessment can lead to positive outcomes for carers. In particular, the subsequent provision of appropriate, helpful services was important, but the process of assessment can also be beneficial through giving carers a chance to express themselves, to feel recognised, valued and supported. A positive assessment was also shown to be influenced by: practitioner skills and approach; assessment processes and scope; the availability and nature of resources; and the characteristics of the carer. Carers may benefit more from assessments conducted by practitioners who: have good interpersonal skills; provide active assistance; are skilled and knowledgeable in carer support; follow up assessment efficiently; and maintain contact. Factors relating to the assessment process and scope of potential benefit included: providing relevant information to prepare the carer prior to assessment; consideration of whether others should be present at the meeting; allocation of sufficient time; a comprehensive, outcomes-based focus which considers the carer’s expertise; and the use of appropriate tools. The availability and appropriateness of resources with which to meet needs identified in assessment could also be significant. Carer characteristics could also influence outcomes, although practitioners should be able to find ways of delivering successful outcomes for any kind of carer through adaptation of their approach.

b. ii. Information services

Carers tended to be satisfied with information services. There was weak evidence that information-based services improved carers’ knowledge of and uptake of
services. There was also weak evidence from one study that the outcomes of information services may not go so far as to include making carers feel more empowered in their contact with service providers.

Potential mechanisms underlying the achievement of outcomes by information services suggested by the evidence included helping carers to feel less alone and that back up support was available if necessary, as well as providing access to the resources offered by services. There was some evidence that the following contexts may influence the outcomes of information services: the extent, relevance and layout of information; staff manner; staff follow through and resolution of queries; ease of access to the service; and the helpfulness of the services to which carers are referred. These findings were tentative as each was only supported by one study and tended to involve relatively small numbers of carers.

b. iii. Direct payment schemes

There was weak evidence from one study that direct payment schemes can achieve the following outcomes for parent carers of disabled children: alleviation of financial pressures; stress relief; and facilitation of the provision of appropriate, effective support services.

The study identified suggested that the success of the scheme could be explained primarily by the empowerment of parents to access the support most appropriate to their needs. In addition, direct payments enabled parents to avoid over-reliance on professionals and to provide payment for support relied upon from friends and family thus alleviating guilt felt about the provision of this help. A number of potentially significant contextual factors were identified. The flexibility and choice, particularly in relation to the employment of staff, offered were seen as critical (although appropriate staff also needed to be available locally to employ). In addition, the practical and emotional support of an independent direct payment support service enabled parents to use the scheme successfully. Within the local authority, the presence of a social worker experienced in this type of work was seen as important to its success.

b. iv. Support workers

There was some evidence of carer support worker interventions leading to improvements in a number of outcomes for carers. Evidence from the GP-based, mental health specialist, dementia carer, lung cancer carer and South Asian advocacy workers suggested that the intervention contributed to emotional well-being. However, this evidence was relatively weak in quality in terms of outcome measurement. The studies with stronger research designs for outcome measurement relating to stroke specialist workers did not show convincing evidence of improvements in emotional well-being. However, qualitative studies of these workers and particularly of the lung cancer carer service did suggest that carers were feeling benefits in terms of emotional well-being. Thus there are some grounds to believe that this intervention does contribute in this way even though there is not yet definitive evidence.

There was also some evidence that stroke specialist support workers and the lung cancer carer support service may have helped to improve carers’ knowledge base. The studies of the dementia carer workers and lung cancer carer worker also showed that the number of carer needs (covering information, access to practical support and
emotional support) could be reduced through these interventions. One study of a GP-based support worker and the advocacy workers for Pakistani and Bangladeshi parent carers showed that the intervention could lead to increased and improved service support for carers. There was also some qualitative evidence of this in relation to stroke specialist workers. The quality of the outcome measurement in these cases was relatively weak though.

Satisfaction was found to be improved in some of the studies of stroke specialist workers. This is useful because it suggests that carers feel some benefit from the intervention even where the other outcome measurements did not capture this.

The studies of stroke specialist workers also provided some weak evidence that there might be some negative outcomes in terms of rehabilitation and social adjustment from this intervention for stroke patients. Further research is needed into this.

The explanatory evidence suggested that the outcomes of support worker services were explained by emotional support and the facilitation of access to other resources including information and services. Emotional support appeared to be achieved in a number of ways including: feeling recognised by the worker; receiving moral support and enabling a better outlook on and more confidence about their situation; provision of an opportunity to discuss their feelings and needs; the feeling of being given permission to consider their own needs and to take time for themselves; and reassurance that there is someone they can contact for support if necessary.

The explanatory evidence also suggested a number of contextual factors which might influence the achievement of outcomes. Success might depend upon the nature of the problem or needs of the carer. Flexibility and individualisation or tailoring of the service also seemed to be helpful. Preferences for telephone or face-to-face contact or a combination varied. The continuity of and length of contact with one person was seen to be beneficial. Relevant worker qualities of benefit were noted including: motivation; conscientiousness; professionalism; tact; a caring attitude; empathy; friendliness; accessibility; and knowledge. A number of factors that might also hinder the achievement of outcomes were also identified. These included: mismatch between the service and cultural and family dynamics; mismatch between participants and service providers’ perceptions of the service; and contrasting patient wishes.

**c. Interventions focused upon carers’ health**

Only two studies of weak quality were identified of interventions focused upon carers’ health. Evidence from these suggests that this type of intervention would be worth exploring further as they may deliver outcomes in terms of: identification of and attention to health needs; emotional well-being; and access to other services.

**d. Interventions focused upon emotional and social support**

**d. i. Carer support groups**

The majority of carers were satisfied with carer support groups. A wide range of types of information and advice appear to be gained both from the input of professional group leaders and other carers to the group. This may be particularly useful for some Asian carers who find it difficult to access this type of information in a
language they can understand elsewhere. The evidence also suggested that improvements to emotional well-being were achieved principally through the mutual support that carers provided to each other within the groups, but also through the development of confidence and a positive self-identity as a carer. There was also evidence of the achievement of social support in terms of meeting others, building friendships and participating in social activities. Some limited evidence suggested that support groups can also have outcomes in terms of facilitating access to and improving relationships with service providers. The weak quality of the evidence (which was based solely upon cross-sectional and qualitative data) in terms of outcome measurement means that it is not possible to conclude about the extent to which these outcomes are achieved for carers through carer support groups.

The studies suggested that the mechanisms underlying support groups included the quite tangible provision of resources, namely: information and advice; friendships and social opportunities; and the facilitation of access to and contact with service professionals. In addition, improved well-being may be explained by the occurrence of emotional processes including the expression, recognition, validation and normalisation of feelings and situations related to caring. Carers may also feel less isolated, value providing help to others and develop a better self-awareness of their role and needs.

The studies also suggested a number of explanatory contexts that may influence group outcomes. There was relatively high quality evidence that the type of group can be quite significant (although this does rely upon only a small number of studies). Groups which were directly linked to another service (for example, a day centre) tended to focus more on outcomes related to links with the service, whereas free-standing groups provided a greater focus upon emotional support. There was also evidence that groups aimed at carers of a particular type (for example, those caring for people with a mental health difficulty) provided greater emotional and social support to members. Interestingly, there was evidence that members of professionally facilitated support groups may place particular value on the professional input received, but equally that members of peer-led groups may feel there is benefit to the self-help structure and prefer not to have professional input. It would be useful to have further research to explore the complexities of this. There was also weak evidence that the length of time for which the support group had been operating might also be influential. There was some limited and inconclusive evidence about how outcomes might be influenced by logistical factors concerning the operation of the groups (for example, regularity of meetings, topic coverage, provision of interpretation and timing) and carer characteristics. However, further research would be needed to consider the influence of these more definitively.

d. ii. Stress management, coping and counselling programmes

There was a considerable body of outcome measurement evidence for these types of intervention. These studies generally used designs involving comparison of control groups or longitudinal outcome measurement which offer reasonable quality evidence of this type (even though flaws in the execution of designs meant that overall quality ratings were not necessarily high).

The evidence showed that the majority of participants were satisfied with the interventions. One study considered the number of carer needs which had been addressed. This showed significant benefit for the intervention group immediately after the intervention but this was not maintained at later follow-up. Improvements in knowledge were identified in studies of interventions of this kind for carers of people
with schizophrenia, dementia, Parkinson’s Disease and of palliative care users. Between them, these studies reported better knowledge of: the relevant condition; ways of caring; stress and techniques for managing this and coping; and support services. There was mixed evidence about whether these interventions led to behavioural change with some weak evidence of change. However, two randomised controlled trials found no difference in coping amongst intervention and control groups. One of these also reported no difference in appraisals of caring.

There was also mixed evidence about whether these interventions influence emotional well-being. There was positive evidence of change from studies of interventions aimed at carers of people with dementia and Parkinson’s Disease, some weak positive evidence for carers of people with head injury and qualitative evidence of this for participants in a stroke-focused group. A study of carers of people attending palliative care did not find any statistical evidence of improvement to emotional well-being but did report some qualitative evidence of this. Two trials of programmes for carers of people with schizophrenia reported no benefit to the intervention group compared to the control group. However, one uncontrolled longitudinal study of a similar intervention, but targeted specifically at people at an early stage of caring, did report some evidence of benefits. Some studies also reported some limited evidence that these interventions can provide social support to participants. Many studies also showed benefits to the person receiving care, in particular, for programmes aimed at carers of people with schizophrenia, dementia, Parkinson’s Disease and head injury.

The relatively little explanatory evidence identified about these interventions was generally weak in quality. There was some limited evidence that the explanatory mechanisms at work included: the provision of information; development of coping skills, stress management and relaxation techniques; emotional processes such as having the chance to express oneself and to feel valued; and the exchange of social support. The evidence suggested that the use of a group format, the nature of the information covered and the programme structure might influence the outcomes of these interventions.

d. iii. Befriending schemes

The one study identified which evaluated a befriending scheme for carers of people with dementia provided high quality outcome measurement evidence. This showed no evidence of a benefit in terms of depression, anxiety, loneliness, positive affectivity or global health. This was based upon analysis which specified the intervention as access to befriending support. Analysis comparing depression amongst those who did actually use the befriending scheme with the control group did find a marginally significant difference in favour of the intervention group at fifteen months. This suggests that further exploration of the intervention could be warranted whilst bearing in mind the relatively low take-up achieved in this case.

d. iv. Complementary therapies

There was some evidence that both chair massage and aromatherapy can lead to improvements in physical and emotional well-being for carers. However, this evidence relied upon only two studies and the quality of the outcome measurement was weak.
The chair massage appeared to contribute to well-being through relaxation, both physical muscle relaxation and emotional relaxation. There was some evidence that the intensity, duration and location of massage as well as carer gender and relationship to the patient were associated with variation in the outcomes of chair massage. In relation to aromatherapy, it was suggested that the physical aspects of the therapy as well as the personal characteristics of the therapist were important to carers.

**e. Education and training for carers**

* e. i. Education programmes for carers

Studies of education programmes for carers provided relatively good measurement of outcomes as they were based primarily upon randomised controlled trial or uncontrolled longitudinal research designs. Satisfaction was reported with two interventions using a written booklet format. However, there were no or small differences in satisfaction amongst intervention and control groups for trials of stroke education programmes. Only one of these showed improvements to knowledge as well. This may be because usual care and information provision for carers of this type is sufficient. There was quite strong evidence of improvements to knowledge via other education programmes, specifically those for carers of people with dementia and of people with schizophrenia. There was mixed evidence about whether these interventions also led to some behavioural change in carers, for example, in coping strategies and services used. Further evidence would be needed to offer conclusions on this. Some studies showed some improvement to emotional well-being but generally changes were not reported. Thus the evidence on this as an outcome of carer education programmes was not convincing. There was some limited evidence that these interventions could also have benefits for the person receiving care.

The explanatory evidence supplied by studies of education programmes was quite limited in its extent. The explanatory mechanism underlying the intervention implied by the evidence was the provision of information resources. Contextual factors that could influence outcomes suggested by the evidence were: the topics covered by the intervention; the format through which the intervention was delivered; the timing of delivery of the information; and the presence or not of the person receiving care. In particular, it seemed that face-to-face delivery may improve the achievement of knowledge outcomes, although accompanying written material appears to be an important support to this. The evidence also suggested that these interventions may be most beneficial at a relatively early stage of caring rather than when the carer has been in their role for some time.

* e. ii. Training for carers

The interventions covered in this section and the study methodologies used were quite diverse and this should be borne in mind when considering the findings.

The outcome measurement evidence of these studies was rated as weak in quality, although some studies did use randomised controlled trial or longitudinal designs. There were generally high levels of satisfaction with the interventions amongst carers. The studies provided some evidence that carer training could validate existing expertise and provide new knowledge and understanding and lead to the development and application of new skills. However, some evidence suggested that the use of new skills may not be maintained over time. In addition, there was some
evidence that carer training could improve perceptions of caring and ability to care, improve emotional well-being and provide social support. In most cases, there were neutral outcomes for the person receiving care.

The evidence suggested that the principal mechanisms explaining the achievement of outcomes were the provision of new (and validation of existing) knowledge about particular medical conditions and ways of managing symptoms and behaviours. There was limited evidence that the provision of social support may also be important. The studies also provided some explanatory evidence about contextual features of the interventions that might influence the achievement of outcomes. Training style was highlighted in particular. Aspects that appeared to be beneficial included: interaction, personalisation, problem-solving with others and the use of examples and light-hearted analogies. It could also be important to have sufficient time to do the training and to apply it. The evidence also suggested that the timing of the delivery of training in terms of stage of caring could be important and that some kind of follow-up might be needed to help carers maintain their newly developed skills. The response of the person receiving care to the new skills could also be important.

f. Employment-related interventions

There was outcome measurement evidence (of weak quality) that this type of intervention may help carers to gain employment suggesting that it may be worth exploring this further.

There was limited evidence (of weak quality) that the following may influence the achievement of outcomes via carer employment projects: sensitivity to the emotional needs and situation of participating carers; the local availability of work on a part-time basis, for certain hours or on a flexible basis; and the appropriate provision of support services for the person receiving care.

g. Carer breaks

Most of the carer breaks studies identified were based upon cross-sectional surveys or qualitative evidence and so offered weak findings in terms of outcome measurement. Some longitudinal studies were included which tended to concentrate upon measuring emotional well-being, with one focusing explicitly and exclusively upon sleep.

Overall, studies generally reported carer satisfaction with breaks. There was also strong evidence that breaks allowed carers to have a rest and experience physical and emotional relief. They also enabled carers to do everyday jobs, pursue social activities and interests and to a lesser extent, employment.

There was little robust quantitative evidence of improvements to emotional well-being achieved through carer breaks. However, several of the studies focused upon carers of people with dementia where the progressive nature of the condition might mean that carers’ emotional well-being might be expected to worsen over time. The studies did not adequately control for confounding factors such as these. There was some qualitative evidence that carers felt breaks benefited their emotional well-being particularly in terms of facilitating a sense of normality, freedom, peace of mind and relief. However, there was also evidence that breaks could cause carers to experience negative emotions including anxiety about the person receiving care,
sadness at being separated or leaving the person receiving care and most notably, guilt about using such services. These feelings could be related to the acceptability of the alternative care provision to the relative or friend receiving care.

There was some limited evidence of improvements to physical health achieved through carer breaks and of improved social inclusion.

There was also qualitative evidence that breaks enabled some carers to continue in their caring role who would otherwise have sought other options. Other studies looked specifically at whether there was a relationship between service use and subsequent institutionalisation of the person receiving care. The evidence on this was mixed and inconclusive. However, it seems that in some cases a breaks service is able to sustain a caring situation, whilst in others it is a step on a fairly inevitable journey towards permanent residential care.

Studies also reported upon the outcomes for the person receiving care. There were mixed findings with some very much enjoying the break and others finding it a very negative experience. Satisfaction was particularly high in two studies, one of family placements and one of holidays both for adults with learning disabilities. Some studies relating to care for a person with dementia reported some worsening in the person’s condition, particularly for longer stays in residential care. However, other studies found that some breaks services offered useful opportunities for additional medical care. For some, the service offered an opportunity to meet other people and to access stimulating activities. In particular, the services for people with learning disabilities evaluated offered these types of benefits and in addition, personal and social skills development.

The studies identified provided a considerable amount of explanatory evidence. This was of variable quality but included a few high quality studies. The evidence suggested that the following mechanisms contributed to outcomes: experiencing emotional and physical relief from caring; management of other activities of daily life; and time to maintain and develop other social interests and networks.

A number of explanatory contextual factors which could influence the perceived use of services were identified. There was some evidence of preferences between the different types of breaks services. However, this was not conclusive and suggested that a range of types of breaks service are likely to be needed to meet different needs and preferences. A key factor in the success of the services was confidence about the nature and quality of the alternative care that the carer’s relative or friend received during the break. The following particular factors relating to this were identified as potentially significant: the amount and nature of the activities provided; personalisation of the care; the opportunity for additional medical care; and general environmental factors. The qualities of the staff providing care were also considered to be significant. These included: their training and expertise; personal qualities such as warmth and empathy; continuity; and simply having a sufficient number as well. Studies also indicated that involvement of the carer through recognition of their knowledge and relationship to the person receiving care could also be beneficial.

Two important organisational factors potentially influencing the benefits of the service were the extent and timing of provision. In addition, the wider organisational support for the service could improve service satisfaction. There was also some evidence that the tailoring of services and service flexibility could be beneficial.
4. **Recommendations**

The report includes the following key recommendations.

Recommendations related to the nature of the research evidence included:

- Further research should be carried out to address the gaps identified.
- Priority areas for research should be the interventions about which there is currently very little evidence, yet which are highlighted as important in current policy debates. These include: personalised approaches to support, for example, individual budgets; interventions designed to support carer employment; and interventions focused upon carers’ physical health.
- Further research about carer services provided by the voluntary sector would also be useful.
- The validity and sensitivity of the way in which carer outcomes are measured should be carefully considered in future research. Qualitative research may be particularly useful to identify the range of outcomes which may be produced through an intervention. Quantitative research may then be needed to assess the size and extent of outcomes.
- Future research into carer services should both measure outcomes and consider the explanatory mechanisms underlying these and the contextual factors which may influence these. Analysis should link these together to provide a holistic understanding of whether and how carer interventions work.
- Generally further comparative research on carer interventions considering the relative value of different forms of intervention would be useful.

Recommendations concerned with specific types of intervention:

- The current focus of local authorities on meeting performance targets for the number of carer assessments achieved needs to be matched by concern with the quality of these assessments.
- Attention to staff training and approaches in helping carers to access services is particularly important.
- Further research is needed to consider the relative value of different models of helping carers to access support including carer assessment (conducted by social services or the voluntary sector) and carer support workers.
- The evidence suggests it is worth supporting and researching carer support groups further.
- Given the potential influence of support group characteristics upon their outcomes, those organising and running groups should consider the aims, activities, membership and leadership of individual groups carefully.
- Within local areas, it might be helpful to review the number and range of different groups available and to consider whether there are gaps in provision or whether some provision might benefit from changes.
- Stress management, coping and counselling programmes are worth exploring further. It may be particularly useful to carry out some qualitative research into how these interventions work and the contextual factors which may influence this.
- Education and training should continue to be provided to fulfil specific carer needs for knowledge and skills development. Those developing and running these types of intervention should consider structural aspects of the intervention likely to influence its success, particularly the timing and the format of delivery.
- Carer breaks should continue to be a priority in carer service development.
Those planning breaks services across a local area should consider whether they are offering an adequate supply and range of types of carer breaks. Those planning and running specific breaks services should consider, in particular, the flexibility of their provision and the nature and quality of the alternative care provided.

It would also be useful for service providers to consider how they can help carers experiencing difficult emotions such as guilt when using breaks services.

Recommendations which cut across the various interventions for carers:

- Future research and service planning must continue to consider any outcomes of carer interventions for the person receiving care and also how this may influence the use of and benefits gained by carers from services.
- A number of common factors relating to intervention delivery which came through particularly consistently as potentially significant need to be considered in the planning and delivery of carer services. These included: the approach and qualities of the staff delivering interventions; the flexibility, tailoring and personalisation of services; recognition by service providers of a carer’s role, knowledge and expertise; and structural aspects of interventions including the timing of delivery (generally earlier in the caring experience was better), content, the characteristics of the target group and the format of delivery.
- In some cases, it will be beneficial to develop services for specific groups of carers (according to either their own characteristics or those of the person they care for).
- Service providers should consider the needs of less assertive carers and consider proactive approaches to supporting these carers.
- Policy makers, commissioners and service providers should continue to consider carer specific needs as well as those of the person receiving care and their shared needs and preferences.
- Service providers should not be complacent about high levels of carer satisfaction but should continue to consider how services can better meet the needs of carers.
1. INTRODUCTION

1a. Background and aims

Government policies of community care rely upon the contribution of carers who look after ill, disabled or frail family members on an unpaid basis. Most carers wish to continue caring for their family members. However, whilst caring can have benefits, the significant negative impacts caring can have upon unpaid, family carers are well established. Thus, there is a need to support carers in their role to try to address these negative outcomes. We therefore need to know more about what does help carers.

There are existing systematic reviews of the evidence concerning the outcomes of interventions for carers (for example, Cooper, Balamurali, Selwood, & Livingston, 2007; Pusey & Richards, 2001). These focus upon particular types of intervention or particular groups of carers. This review seeks to bring together evidence for a range of types of carers and interventions. However, this is a large undertaking and accordingly this has been restricted to a specific context: the UK since the introduction of community care reforms in 1990. This review is limited to interventions directly targeted at carers, rather than those aimed principally at the person who is receiving care which may also benefit carers. The interventions covered include: those concerned with supporting carers to access services; those targeted at carers’ health; those focused upon emotional and social support; education and training for carers; employment-related interventions; and carer breaks.

This review differs from many traditional systematic reviews in that it seeks to include explanatory evidence about how and why interventions work and under what circumstances, as well as considering their outcomes. There are often difficulties in rigorously measuring the outcomes of interventions. Furthermore, outcomes are contingent upon many factors and differ amongst carers. It is therefore important to advance knowledge about the context and processes which influence the success or otherwise of interventions. Consequently, the review seeks to answer the following questions:

- What is known about the outcomes of interventions for carers?
- What explanatory evidence exists about how interventions support carers and the contextual factors which influence outcomes?
1b. Report structure

The next section of this report sets out the methods that have been used to conduct this review. The findings are then presented in Section 3. This begins with an overview of the nature of the evidence that has been identified and reviewed.

The findings are then presented in sections categorised by intervention types. This has been done as clearly as possible, but it is not entirely straightforward because there is much variety and overlap in the purposes and nature of interventions. Each section begins with a brief summary of the types of intervention covered. This is followed by an overview of the quality of the evidence that has been identified and accordingly some judgement about how much confidence can be had in the findings.

For each intervention category, the following is then presented:

- Outcome findings: evidence on the intervention outcomes that have been measured.
- Explanatory evidence of mechanisms: these are the processes which underlie and explain the achievement of outcomes.
- Explanatory evidence of relevant contextual factors: these potentially influence whether or not outcomes are achieved and/or the degree to which outcomes are achieved.
- Summary of findings.

Summary details of the included studies are given in tables in Appendix 1. These cover: the study design; sample characteristics; a brief description of the intervention assessed; the outcome measurements used and when these were taken; and the assessed quality of the evidence.

Conclusions and recommendations are discussed in the final section 4 of the report.
2. METHODOLOGY

2a. Review questions

The methodology has been designed to address the following review questions.

- What is known about the outcomes of interventions for carers?
- What explanatory evidence exists about how interventions support carers and the contextual factors which influence outcomes?

This is addressed within the context of the UK since the introduction of significant community care reforms via the NHS and Community Care Act 1990. The specific types of intervention covered are described in the next section.

2b. Inclusion and exclusion criteria

Studies were included in the review based upon the following criteria relating to: the study design; the type of intervention evaluated; the carer population considered; and the geographical and temporal context of the study.

Study design

Studies were included if they had a significant focus upon either:

- the outcomes of an intervention for carers; or
- explanatory evidence which considers how interventions support carers or the contextual factors which influence the achievement of intervention outcomes for carers.

The term ‘significant focus’ was used in order that studies of carers’ experiences which included a small section about service use were excluded as these were not expected to offer findings of significant depth relevant to the review question.

Studies using any outcome measure that could be considered to relate to the carer’s well-being or ability to care were included.

The review only includes studies based upon empirical research. All types of empirical study designs were included if the work met the other criteria set out here.

Intervention type

The review considers formal interventions: those provided by government bodies, voluntary sector organisations or private organisations and also peer-led support, for example, carer-led support groups. It does not include informal support from friends and other family. Furthermore, only interventions that aim to have direct outcomes for individual carers are considered. Indirect interventions such as training for social workers to raise their awareness of carers’ issues are excluded.
The review excludes studies of interventions targeted primarily at the person receiving care. These interventions may be very beneficial to carers. However, resources did not permit these to be covered here. Interventions which were jointly targeted at the person receiving care and the carer (for example, stroke family support workers) were included if they met all the other criteria for inclusion.

In addition, due to resource limitations, the review only includes studies focused upon specific interventions developed for carers. It does not include studies which reported on carers’ interaction with general public services and practice, for example, those reporting on their general interaction with GP services or social workers.

The following specific types of interventions targeted directly at carers were included in the review.

- **Interventions to support carers to access services.** These could include: carer assessments; information services; direct payment schemes; and support workers. Services were included which directly targeted the carer (although on some occasions, they were also directly aimed at the person receiving care), but which could help the carer to access further support for themselves or the person who received care.

- **Interventions focused upon carers’ health.** These could include any specific intervention concerned with promoting individual carers’ physical health.

- **Interventions focused upon emotional and social support.** These could include: support groups, befriending schemes, stress management, coping and counselling programmes and complementary therapies.

- **Education and training for carers in relation to their caring role.** These could cover education relating to the condition of the person receiving care and training in any skill related to caring, for example, moving and lifting or communication with people with communication difficulties. In addition, education and training for carers which focuses upon other types of skills, for example, negotiation with services could also be included.

- **Employment-related interventions.** These could include specific programmes to support access to or to maintain paid employment for carers.

- **Breaks for carers.** These could cover different types of provision designed to provide the carer with a break, for example, sitting services, social outings, day care and residential stays for the person receiving care.

**Carer population**

Studies were included if they were concerned with services for carers defined as: people who care for family members, friends or neighbours on an unpaid basis. The carer could be caring for someone with any type of condition, for example, mental health difficulty, terminal illness and so on and could have varying kinds of relationship to them, for example, parent, child or spouse. Studies which focused upon parents or other carers of non-disabled children and which are therefore concerned with general parenting or childcare were not included. Studies focusing upon young carers (those under the age of 18) were also excluded.
Study context

Studies were only included if they were conducted within the context of the UK since 1990.

2c. Search strategy

Data sources

Relevant evidence could take a number of forms as indicated in the left hand column of Table 1, for example, grey report literature or academic journal articles. Sources for each type of data were therefore searched as listed in the right hand column.

Searches were conducted between January and June 2008.

Table 1: Data sources for search strategy

<table>
<thead>
<tr>
<th>Type of data</th>
<th>Source(s) searched to identify evidence of this type / in this field</th>
</tr>
</thead>
</table>
| Systematic reviews and randomised controlled trials | • Cochrane Database of Systematic Reviews  
• CRD register – DARE, HTA and NHS EED  
• C2-SPECTR (Campbell Collaboration)  
• CCTR (Cochrane Clinical Trials Register) |
| Evidence from the medical / health care field | • Medline  
• British Nursing Index  
• HMIC |
| Academic social science research | • Applied Social Sciences Index and Abstracts  
• International Bibliography of the Social Sciences  
• Social Science Citation Index  
• Social Services Abstracts  
• Sociological Abstracts |
| Grey literature | • Social Policy & Practice (combines Social Care Online, AgeInfo, ChildData, Planex and Urbadoc)  
• Carer voluntary organisations (via the websites of the PRTC, Carers UK and Crossroads and all local carer centres via e-discussion list and local authority carer leads via e-discussion list)  
• Government department websites |
| Material that is poorly indexed on databases | • Citation tracking and above grey literature searches |

Search terms

Given that the inclusion criteria were quite broad as detailed above, it was necessary to use quite a sensitive search strategy. The search used in the HMIC database is given below.

((carer or carers or informal care or informal caring or family care or family caring or care-giver or care-givers or caregiver or caregivers or care giver or care givers))
AND ((service$ or support$ or intervention$ or program$ or scheme$ or help$ or strateg$ or assist$ or treatment$ or project or evaluat$)

OR (respite or break$ or relief or daycare or day care or day-care or sitting or holiday or information or helpline or help-line or discussion or chatroom$ or forum$ or referral$ or outreach or out-reach or advice or adviser or advisor or broker$ or advoca$ or counsel$ or therap$ or stress management or massage or self-help or selfhelp or befriend$ or social activit$ or social event$ or outing$ or trip$ or domiciliary or home care or home-care or home help or home-help or care attendant or learn$ or educat$ or class$ or course$ or skill$ or train$ or assess$ or ai$ or technol$ or telecare or tele-care or nur$ or health work$ or social work$ or worker$ or direct payment$ or individual budget$ or access to employment or job-search or job search or plan$ or emergenc$)))

NOT young carer$

Limited to 1990-2008

This search string was adapted as required to fit the specific requirements of individual databases.

One possible limitation of the search strategy is the potential omission of studies which focus upon interventions specifically for parents of disabled or ill children where this group is referred to in this way rather than as ‘carers’. However, the search strategy was already broad and the resource implications of covering this would have been problematic given that all kinds of interventions relating broadly to childcare would have been identified. The aim was instead to identify this literature through citation tracking.

2d. Quality appraisal

The different types of data included in this systematic review (outcome measurement and explanatory) required two different approaches to quality appraisal. Those used are outlined below. Where a single study included both outcome measurement and explanatory evidence, both types of quality appraisal were undertaken.

Reasons are given below for the approaches used here. However, it is recognised that the most appropriate approach to quality appraisal of social research is still a matter of debate. Thus, the appraisals given here should be considered as a guide for the reader on quality assessment rather than offering definitive conclusions. The details of the scores for individual aspects of quality are given in the study tables in the appendix so that readers can consider these in more detail for themselves if they wish.

i) Quality appraisal of outcome measurement

The number of high quality randomised controlled trials of interventions identified for this review was expected to be limited. It was therefore decided to include a wide range of study designs whilst recognising the potential bias of estimates of effect from some of these. This follows the approach taken by others such as Harding and Higginson and Stoltz et al in related reviews (2003; 2004). A quality appraisal tool
which could deal with a wide range of study designs for intervention impact was therefore sought.

A recent systematic review of methods for considering bias in non-randomised intervention studies identified six quality appraisal tools which could potentially be used in systematic reviews (Deeks et al., 2003). These were selected from a much larger collection of tools because they met certain important criteria concerning internal validity. One of these six tools, developed by Thomas, has been selected for use here because it: covers a range of study designs; considers key quality criteria; is relatively user-friendly and provides clear guidance about how to assess each criterion; and offers a summary conclusion about the strength of the evidence (Thomas, n.d.).

This tool considers quality in eight respects:

A. Selection bias: whether the participants selected to participate were likely to be representative of the target population.

B. Study design: randomised controlled trials and controlled clinical trials are considered strong; cohort analytic, case control, cohort and interrupted time series studies are considered moderate; and all other designs are considered weak.

C. Confounders: whether there were important differences between the groups compared and if so, whether these were controlled for.

D. Blinding: whether outcome assessors and study participants were aware of participant allocation to the intervention or control group when they were measuring outcomes.

E. Data collection methods: whether these have been shown to be valid and reliable.

F. Withdrawals and drop-outs: whether participant withdrawals from the study were reported and their level.

G. Intervention integrity: how many participants actually received the intervention; consideration of the consistency of the intervention; and the possibility that participants received other unintended interventions.

H. Analyses: whether the units and methods of analysis were appropriate and whether analysis was conducted on an intention to treat basis.

The tool provides guidance for scoring each study as strong, moderate or weak in each of these categories. An overall score is then arrived at through summing the individual scores for categories A to F. (The ratings for G and H are given separately and are not included in the overall score.) The overall scores of bodies of evidence by intervention type are commented upon in section 3 of the report. The overall and component quality scores for individual studies are included in the Appendix 1 study tables.

Cross-sectional surveys and qualitative studies containing outcome evidence were automatically given an overall rating of weak for outcome measurement.

ii) Quality appraisal of explanatory evidence

Explanatory evidence about how interventions produced outcomes and the relevant contextual factors which influenced outcomes required a very different kind of quality appraisal tool. Most of these studies were qualitative, although some quantitative research also included relevant data. There is no definitive agreed framework for assessing the quality of qualitative research but a number of different models have been proposed.
The approach used here has been developed by the EPPI Centre (Harden et al., 2001, pp. 62-63). This was based upon a review of a range of approaches to quality appraisal of qualitative evidence which identified common themes and developed a tool which covered these. This tool also has the advantage that it can be used not just for qualitative studies, but for others which report on processes or service users' views.

The tool assesses quality on the basis of the inclusion of the following seven items.

1. An explicit account of the theoretical framework used and/or inclusion of a literature review.
2. Clearly stated aims and objectives.
3. A clear description of the context in which the research was undertaken.
4. A clear description of the sample.
5. A clear description of the methodology including data collection and analysis methods.
6. Evidence of attempts made to establish the reliability and validity of data analysis.
7. Sufficient original data to mediate between data and interpretation.

The tool provides brief guidance about how the inclusion of each item can be judged. A yes/no answer was allocated for each question. This breakdown of ratings for individual studies is given in the study tables in Appendix 1. An overall score was also given to each study including explanatory evidence: a strong rating was given for studies which included six or more of the above items; a moderate rating was given for studies which included five; and a weak rating was given to those which included less than five.

**2e. Data synthesis**

Data from included studies was extracted and stored in a database with details recorded under the following categories (via detailed sub-headings).

- Study aims.
- Intervention type.
- Sample.
- Research methods.
- Findings.

Mixed methods of synthesis have been used. Evidence on the outcomes of interventions is presented through narrative synthesis in the body of the report (Popay et al., 2006). Statistical meta-analysis has not been used because the diversity of the interventions considered would have rendered this problematic. Explanatory evidence has been synthesised thematically (Pope et al., 2007, pp. 96-97). This has drawn principally upon the explanatory data provided directly by individual studies (mainly qualitative research) as well as sometimes the comparison of individual studies of slightly different interventions or samples.

The synthesis has been undertaken within the realist framework for understanding intervention outcomes (Pawson & Tilley, 1997). This seeks not just to identify outcomes (the change resulting from an intervention) but also to understand the mechanisms which create this change and the context within which this occurs. Mechanisms are the underlying processes which explain change. These could
include individuals’ decision making processes, reasoning and feelings (choices) and their resources to achieve something (capacities). Context consists of all the possible factors which may influence whether or not a mechanism occurs and an outcome is achieved. These could include the characteristics of the carer, the context of the caring situation and varying aspects of the intervention. Hence, using this framework each section of the findings is divided into evidence on outcomes, explanatory mechanisms and significant contextual factors.

The realist aim is ultimately to link outcomes, mechanisms and contexts into configurations illustrating how the triggering of certain mechanisms in certain contexts leads to particular outcomes. This would then provide a holistic theoretical model of how an intervention works. However, this has only been done to a very limited extent in this synthesis as the evidence available is generally not presented or detailed in such a way as to enable this. Yet, the synthesis does suggest relevant mechanisms and contexts which future research could investigate to see how these work in configurations to achieve outcomes.
3. FINDINGS

3a. Nature of the evidence identified

3a. i. Studies by intervention category

This review included 107 studies in total. (There are slightly more references than this because some studies were written up in more than one separate report.) All of these studies included some form of outcome measurement. Explanatory evidence was also provided by 69 studies.

Table 2 presents the number of studies included by intervention category and sector of provision.

There was a reasonable amount of evidence identified about interventions for carers offering: access to support; emotional and social support; education and training; and breaks. However, within these categories there was very little evidence about: personalised approaches to access to support such as direct payments; befriending services and complementary therapies. In addition, very little evidence was identified about interventions focused upon improving carers’ physical health or upon carer participation in paid employment.

Over half of the studies included were of interventions developed and delivered within the health sector. The main form of direct social services provision evaluated was statutory carer assessment. Evaluated services provided by the voluntary sector predominantly included carer support workers and breaks services.

Table 2: Studies by intervention category and sector of provision

<table>
<thead>
<tr>
<th>Intervention focus</th>
<th>Total</th>
<th>Health</th>
<th>Social services</th>
<th>Voluntary sector</th>
<th>A mix/other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>107</td>
<td>61</td>
<td>16</td>
<td>20</td>
<td>10</td>
</tr>
<tr>
<td>Access to services</td>
<td>33</td>
<td>11</td>
<td>14</td>
<td>8</td>
<td>-</td>
</tr>
<tr>
<td>- Assessment</td>
<td>11</td>
<td>-</td>
<td>11</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>- Information services</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>- Direct payments</td>
<td>1</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>- Support workers</td>
<td>16</td>
<td>10</td>
<td>-</td>
<td>6</td>
<td>-</td>
</tr>
<tr>
<td>Health</td>
<td>2</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Emotional &amp; social support</td>
<td>25</td>
<td>20</td>
<td>1</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>- Support groups</td>
<td>8</td>
<td>5</td>
<td>1</td>
<td>1</td>
<td>1 self-help</td>
</tr>
<tr>
<td>- Stress management</td>
<td>14</td>
<td>13</td>
<td>-</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>- Befriending</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>- Complementary therapies</td>
<td>2</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Education &amp; training</td>
<td>21</td>
<td>20</td>
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<td>1</td>
<td>-</td>
</tr>
<tr>
<td>- Education</td>
<td>9</td>
<td>9</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>- Training</td>
<td>12</td>
<td>11</td>
<td>-</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Employment</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Breaks</td>
<td>25</td>
<td>8</td>
<td>1</td>
<td>7</td>
<td>9 mixed</td>
</tr>
</tbody>
</table>
Many of the studies focused upon interventions for carers of people with particular conditions. A breakdown of the conditions covered is presented in Table 3 and split by intervention category. Overall, studies focused particularly upon interventions for carers of people with: a range of conditions (28 studies); dementia (28); mental health difficulties (14); stroke (11); and of older people (10).

Within intervention categories:
- Studies of access to support tended to focus upon carers of people with a range of conditions, although there were a lot of studies of support workers specifically targeted at carers of people who had had a stroke.
- Studies of interventions focused upon emotional and social support were quite concentrated upon services specifically for carers of people with mental health difficulties or dementia.
- Studies of education and training for carers often evaluated services for carers of people with dementia.
- Studies of carer breaks particularly focused upon services for carers of people with dementia or of older people.

<table>
<thead>
<tr>
<th>Intervention focus</th>
<th>Mix</th>
<th>MH</th>
<th>LD</th>
<th>D</th>
<th>OP</th>
<th>S</th>
<th>I</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>28</td>
<td>14</td>
<td>5</td>
<td>28</td>
<td>10</td>
<td>11</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Access to services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Assessment</td>
<td>16</td>
<td>4</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>7</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>- Information services</td>
<td>8</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>(1 OP+MH)</td>
</tr>
<tr>
<td>- Direct payments</td>
<td>4</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>- Support workers</td>
<td>1</td>
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<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<td></td>
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<td>Health</td>
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<td></td>
</tr>
<tr>
<td>Emotional &amp; social support</td>
<td>5</td>
<td>7</td>
<td>0</td>
<td>7</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>- Support groups</td>
<td>4</td>
<td>4</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>(1 OP+MH)</td>
</tr>
<tr>
<td>- Stress management</td>
<td>-</td>
<td>3</td>
<td>-</td>
<td>6</td>
<td>-</td>
<td>1</td>
<td>3</td>
<td>1 HI</td>
</tr>
<tr>
<td>- Befriending</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>- Complementary therapies</td>
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<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Education &amp; training</td>
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<td>3</td>
<td>0</td>
<td>7</td>
<td>0</td>
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<td>-</td>
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<td>-</td>
<td>3</td>
<td>-</td>
<td>2</td>
<td>1 HI, 1 A</td>
</tr>
<tr>
<td>- Training</td>
<td>1</td>
<td>1</td>
<td>4</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>2 ED, 2 A</td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Breaks</td>
<td>2</td>
<td>-</td>
<td>4</td>
<td>11</td>
<td>6</td>
<td>-</td>
<td>1</td>
<td>1 AU</td>
</tr>
</tbody>
</table>

Key: Mix (of conditions); MH – mental health difficulty; LD – learning disability; D – dementia; OP – older people; S – stroke; I – acute, chronic or terminal illness; Other – other specific condition including HI - head injury, A - aphasia, ED - eating disorder, AU - autism.

Notes: Where these sample characteristics were not given, it was assumed that carers of people with a mix of conditions could have been included. Where the sample was focused upon carers of people with dementia specifically, these have been included within this specific category but not in the older people category. Studies which specified that carers of older people with mental health problems constituted the sample have been included within the older people and mental health difficulties categories.
A small number of studies focused upon particular types of carer in terms of other carer characteristics including:

- Parent carers (7 studies);
- Spouse carers (4 studies);
- Carers from black and minority ethnic groups (2).

These were scattered across intervention categories.

**3a. iii. Studies by evidence quality and research design**

Tables 4a and b present the quality ratings of the outcome measurement and explanatory evidence of studies within each intervention category. A breakdown of study design is also given for outcome measurement evidence.

The majority of outcome measurement studies were rated as weak on the quality appraisal tool used. This is unsurprising given the stringent requirements for higher ratings which can be difficult to meet on practical and ethical grounds in social research. However, it does mean that caution should be exercised in considering the strength of the outcome findings of this review.

It is also useful to consider the research design used by studies to measure outcomes. Over 40 per cent of the studies used longitudinal designs which allowed change in outcomes over time to be assessed. About half of these also included a control group permitting more rigorous comparisons to be made. These studies with a stronger research design for outcome measurement were concentrated upon particular types of intervention, namely support workers, stress management programmes and education and training for carers. The use of qualitative assessment of outcomes should not be dismissed lightly though. These can say little about the extent to which outcomes might be achieved across a population. However, the spontaneous, qualitative feedback from carers has a particular validity in terms of capturing the nature of the outcomes experienced. Standardised quantitative outcome measures may not always be assessing the relevant outcome domains.

The quality of the explanatory evidence was mixed: 43 per cent of the studies were rated as strong, 16 per cent as moderate and 41 per cent as weak. The evidence in the access to support intervention category was stronger than for other intervention types.
Table 4a: Studies by quality ratings and study design for outcome evidence

<table>
<thead>
<tr>
<th>Intervention focus</th>
<th>Quality rating</th>
<th>Research design</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strong</td>
<td>Mod.</td>
</tr>
<tr>
<td>Total</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
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Key: Research design – CL: RCT/other controlled longitudinal; UL: uncontrolled longitudinal; CS: cross-sectional survey; Q: qualitative.

Table 4b: Studies by quality ratings for explanatory evidence

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<th>Intervention focus</th>
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3a. iv. Studies by outcomes measured

Studies assessed a range of types of outcome as shown in Table 5. Across the range of intervention types, there was a particular focus upon carers’ emotional well-being (84 studies). Significant proportions of the studies also reported upon: knowledge (42); satisfaction (40); social inclusion (27); ability to care including skills development and coping (23); service use (20); achievement of a break (18); ability to continue caring (10); and physical health (10). Just over a third of the studies also included some reporting on outcomes of the intervention for the person receiving care (39 studies).

Variation in the outcome measures used by intervention category was largely as might be expected.

- A relatively high number of access to support studies included measures of service use, but also of emotional well-being and knowledge.
- Studies of emotional and social support often reported on emotional well-being, knowledge and social inclusion.
- Studies of education and training often focused upon knowledge, skills development and emotional well-being.
- A large number of breaks studies focused upon emotional well-being, achievement of a break and social inclusion. In contrast to studies of other intervention types, these studies also often included consideration of whether these services enabled carers to continue caring or not.

Measurement of emotional well-being could incorporate a wide range of concepts and measures. The concepts measured included burden, stress, strain, anxiety, depression, self-esteem and confidence. A number of specific standardised measures were used including commonly: various forms of the General Health Questionnaire (GHQ); the Hospital Anxiety and Depression Scale (HADS); Beck Depression Inventory (BDI); Caregiver Strain Index (CSI); Caregiver/Zarit Burden Inventory (CBI); and the Relative Stress Scale (RSS). General qualitative reports of improved emotional well-being were also presented by some studies. The outcome measures used by individual studies are given in the appendix tables of study details.
Table 5: Studies by outcomes assessed

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<th>Intervention focus</th>
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<th>N</th>
<th>E</th>
<th>H</th>
<th>K</th>
<th>Sk</th>
<th>A</th>
<th>C</th>
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Key: S – satisfaction; Su – service use; N – number of needs; E – emotional well-being; H – physical health; K – knowledge (of services, condition, stress management etc); Sk – ability to care including skills development and coping; A – ability to continue caring; C – appraisal of caring; SI – social inclusion or support; M – employment; B – achievement of a break; O – other including empowerment, process outcomes, financial situation and quality of life; P – outcomes concerning the person receiving care.
3b. Interventions to support access to services

The interventions covered in this section are primarily intended to provide access to direct support and services for carers. They are divided into the following categories.

- Statutory carer assessment.
- Information services.
- Direct payment schemes.
- Support workers.

As noted previously, it is difficult to categorise carer services neatly and some of these interventions also offer some direct support themselves. However, the common, predominant underlying aim of these interventions is to help carers to access other support.

3b. i. Statutory carer assessment

There are statutory guidelines about the purpose and form of carer assessments undertaken by local authorities. However, there is some variation in the interpretation of and compliance with guidelines by local authority and by individual practitioner. Generally it is difficult to identify clear variations between the local authority and/or practitioners included in studies of assessment. This is because this variation tends to be a matter of degree and slight difference (with the one notable exception of the outcomes-focused assessment evaluated by Nicholas, 2003). However, variation and its significance does become apparent in the explanatory evidence provided within studies as discussed later in this section. The legislation and guidance concerning carer assessments has changed over time since its introduction in 1995. Consequently some change might be expected according to the date of individual studies. However, it has not been possible to assess this satisfactorily because study designs differ and generally involve small samples.

The studies of carer assessment identified consist of cross-sectional surveys and qualitative studies [1-12]. The evidence in terms of identifying outcomes is accordingly weak given the small samples used and/or reliance upon retrospective assessment of change. However, they generally offer high quality explanatory evidence. This is rich in terms of suggesting contextual factors which may influence the outcomes of assessment and in providing insight into the mechanisms of change operating through assessment.

Outcome findings for carer assessment

Studies have used a variety of measures to provide insight into the outcomes of assessment. Evidence is presented below by outcome. General evidence of carer satisfaction with assessment is given first. Then some of the intermediary outcomes arising from the process of assessment which might be expected to link to ultimate outcomes are considered, for example, carer recollection of and clarity about assessment and the adequacy of the information collected. Outcomes relating to emotional well-being resulting from participation in the assessment process are also discussed. Knowledge of services, service receipt and satisfaction with services are then detailed. Finally, the evidence about wider outcomes, such as improved health, which might be considered to be the longer term, ultimate goals of assessment is presented.
A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence

Carer satisfaction with assessment

Three of the included studies reported on carer satisfaction with assessment.

- A study [9, 10] of carers of people with learning disabilities reported that ten carers (56%) were satisfied, but eight (44%) were dissatisfied.
- Another study [4] of a larger sample of various types of carer found that 341 carers (70%) were satisfied, nearly one in seven (15%) was dissatisfied and the same proportion (15%) gave no answer.
- An early study [5] found that 76 per cent of carers were happy with the process of assessment and 59 per cent were happy with the outcomes. Dissatisfaction was found to be linked to the services provided as a result of assessment (where these were either not sufficient, not appropriate or too costly).

Assessment process outcomes

There are a number of intermediary outcomes arising from the process of assessment which might reasonably be expected to occur if the ultimate outcomes of assessment are to be achieved.

Firstly, recollection of and clarity about the assessment on the part of the carer could reasonably be expected. A number of studies of assessment found, however, that the majority of carers did not remember their assessment or were very unclear about what had happened and why [1-3, 9, 11, 12]. The evidence showed that poor recollection and clarity was common amongst different types of carer including carers of people with learning disabilities, Asian carers and carers of older people with dementia. One of the larger studies of various types of carer [1] also disaggregated the sample to show that the level of awareness and recollection of assessment did not vary by length of time caring, types of disability or relationship between the carer and the person receiving care. However, they did find that a higher proportion of those heavily involved in care (as judged by the extent of care required day and night) and of older carers (those aged 65 and above) were unaware of their assessment compared to other carers.

Other process outcomes that might be expected from assessment concern the adequacy of the understanding of and information collected about the carer’s situation and needs and the extent of the involvement of the carer. Several studies provided some interesting evidence about this. Those of ‘standard’ carer assessment [2, 3, 11] showed that these outcomes are often not achieved. The study [7] of an outcomes-based approach to assessment reported more promising results.

- A study [11] of assessment of carers of older people with dementia found that 38 per cent (n=24) of carers felt able to convey their needs and concerns during the assessment and 42 per cent (n=27) felt that their care manager had a satisfactory understanding of their circumstances and support requirements. Over half, 54 per cent (n=35) felt actively encouraged by their care manager to participate in the assessment discussions. The authors reported that others had less positive experiences. Two thirds, 67 per cent (n=43) complained that care managers disregarded their caring skills and did not pay enough attention to their strengths and ways of coping.
- An analysis of 271 assessment records in one local authority [2] found that 63 per cent of the assessment forms provided sufficient evidence to construct an
action plan, 37 per cent did not. The authors judged that in 54 per cent of cases, the action plan would meet the needs identified in the text of the form, 46 per cent would not. In a slightly later study of another local authority [3] the content of 87 per cent of assessments was judged to provide sufficient quality to construct an action plan. This suggests that the specific context of this local authority or the later point in time contributed to a better recording of information. The authors judged that nearly two thirds (64%) contained an action plan which would meet more than half of the needs identified. However, where the carer was Asian/Asian British then only 55 per cent contained an action plan that would meet most of their needs.

- The study [7] of outcomes-focused assessment identified qualitative evidence of a number of improvements in process outcomes achieved through using this approach. Practitioners found that the use of outcomes-focused tools helped them to broaden their understanding of the impact of caring and the wishes of individual carers. They also thought that this approach helped to engage carers more directly in defining and providing feedback on the outcomes of most significance to them. The use of an initial form helped practitioners to understand if a more detailed assessment would be helpful. Practitioners also found that a structured approach helped them to focus their thoughts and to maintain a clear view of the carer’s perspective (separate to that of the person receiving care). There was also evidence of improved care planning. There were examples of the purpose, nature and timing of breaks being carefully considered to achieve particular benefits for the carer. Practitioners also felt that they and carers were more creative in thinking about service responses.

**Emotional well-being outcomes of assessment**

The literature shows that a number of outcomes relating to carers’ emotional well-being can result from the process of carer assessment. High quality quantitative evidence of change in measures of emotional well-being has not been collected. However, there is qualitative evidence of these outcomes in nearly every qualitative study of assessment, many of which are high quality.

- Firstly, and most strongly, it is reported that carer assessment can provide carers with recognition and validation of the care they provide, their experience and identity [1-3, 9, 11, 12].
- Secondly, carers can also find it useful emotionally to have this time to talk about and reflect upon their situation, coping strategies and needs [7, 12].
- Thirdly, practitioner contact through assessment can help carers to feel less alone as they feel there is someone they can turn to if they need help [1, 2].
- There is some evidence that these outcomes can be achieved and important even when outcomes relating to service provision are not satisfactory. One study [9] provided examples of carers of people with learning disabilities who still felt positively about assessment on this basis even when service receipt had not been satisfactory. In addition, another study suggested that a number of carers felt more supported where practitioners maintained contact with them even if practical support was not provided [1].

However, there is also some suggestion that some carers perceive assessment as a test of their ability to care [12]. Thus these emotional benefits might not be expected to be present for these carers. There is insufficient evidence to judge this further.
Knowledge gained through assessment

One aim of assessment can be to inform carers about their rights and the support available. Relatively little evidence has been identified relating to this other than the following.

- One study [1] noted that the carer assessment forms used in two of the authorities included in the research specifically prompted staff to ask about any information needs carers had. However, the data did not suggest that carers from these two authorities felt any better informed than others.
- In a qualitative study [3], practitioners reported that the information about available support passed onto the carer in assessment could be very helpful to the carer.
- A comparative cross-sectional study [8] found that carers in areas where needs assessments were provided (compared to areas where they were not said to be provided) were significantly more likely to say that: they were asked whether they needed any help; told what help was available and whether it would be paid for; told about benefits; told how to complain; introduced to someone whom they could contact if they were worried; and that they were currently receiving all the help they needed to have a break.

Service provision following assessment

Some studies considered the services offered and acceptance levels as well as the level of service use.

- One cross-sectional survey study [4] reported that about half (52%) of assessments led to the offer of extra help; 14 per cent resulted in information; 9 per cent resulted in others form of support. About half (49%) of carers said that the help/support offered was the right help for their needs. Six in ten (60%) of carers said that the help/support offered was the right help for their needs. Six in ten (60%) of carers accepted the help or support offered. Where carers did not accept the help, they identified the following reasons: the costs (28%); the service was not what was wanted/needed (54%); other reasons (18%).
- Another study [5] found that a similar proportion of those offered support accepted it (66%). There were similar reasons for rejecting services: services were inappropriate; too costly; or the carer wanted to manage without the help or extra help offered.

The level of additional services provided following assessment is reported in a number of studies and varies [1-3, 6, 7, 9, 12]. However, some studies reported that there was some difficulty identifying which services had specifically been provided as a result of the carer assessment rather than any other assessment or process [1, 3, 9]. Thus this evidence should be taken as indicative rather than as definitive.

In most studies, the proportion of carers who received additional services following assessment was relatively low, below half. This was the case even in studies which looked at change over a reasonable period of time – six months [1] or a year [9]. It is notable that the study of outcomes focused assessment [7] reported a higher level of changes in services, for about three quarters (76%) of carers.

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1 This study compared areas where carer assessment was said to, and not to, be available. However, this categorisation should be treated with caution as local authorities in all areas of England had a legal duty to provide carer assessments at this time.
Macgregor and Hill [6] provided some additional interesting information. They showed that of the 57 per cent of their sample who saw no change in the level of service provision, two thirds (66%) of these said that they did not get all the support they needed. In this case, this showed that the absence of additional services was not a reflection of an absence of need. They also noted that the figures on subsequent service provision varied according to the condition of the person receiving care. Carers of people with mental health difficulties were least likely to see an increase in services following assessment (25%). Yet amongst the total sample of mental health carers, 75 per cent said that they do not get enough support. The increase in services was highest for carers of an adult with a physical disability (40%). The increase in services was lower than this for carers of disabled children (31%) and carers of adults with a learning disability (33%).

Obviously the provision of services is not necessarily a positive outcome for carers if they are not happy with the services provided. Several studies provided evidence about satisfaction with the services provided [1-3]. Again these showed quite varied experiences for carers, some negative and some positive. Some of the contextual factors which begin to explain this variation are considered in the next explanatory section of the report.

Wider outcomes of assessment, for example, health and employment

Service provision may be an outcome of assessment in itself but this is often intended to contribute to other outcomes, for example, improvements in carer health and carers’ ability to pursue their own leisure, education and work interests. The included studies provided some limited information on these ultimate outcomes. The limited extent of this may well reflect the fact that assessments are often not focused on outcomes [2, 3] despite statutory guidance that this should be their focus. The evidence that does exist is as follows.

- One study [6] reported qualitative evidence that some carers felt assessors helped them to stay in work, whereas others felt assessors’ attitudes were not supportive of their wish to work and care. The researchers also found some carers who felt that support following assessment had improved their health problems.

- Another study [1] found some changes to carer health over the six month period following assessment. These were generally improvements but were not large. This study also considered employment. The twelve working carers in the sample said that assessors did not address work matters in any great detail in their assessments. One carer had gone back to part-time work in the six months since assessment but said that they had not received any support or information from the assessor despite mentioning this wish in the assessment. However, many of the practitioners felt that they were sympathetic and supportive in relation to employment. Some gave examples of care packages they had put together to help carers stay in work including practical assistance. Generally carers did not feel the help received significantly reduced any difficulties they had combining work and care.

- The one study of outcomes focused assessment [7] found that approximately 70 per cent of the outcomes prioritised by carers at assessment were achieved (the nature of these was not specified). However, some expected outcomes had not been realised and some unanticipated outcomes had been successfully achieved. Feedback from carers often reported improved emotional health, but less frequently a good fit between the services provided and the carer’s life.
**Explanatory findings about carer assessment**

A thematic analysis of the findings of assessment studies has identified the following contexts and mechanisms as potentially significant in the achievement of outcomes. The quality of the explanatory evidence in the studies drawn upon is generally strong. Thus, particularly where the same themes are identified in a number of studies, reasonable confidence can be felt about the validity of these findings.

**Enabling mechanisms**

The evidence on assessment outcomes suggests that the two following groups of mechanisms occur where assessment is successful.

**Emotional support mechanisms**

- Assessment supports the carer by making them feel recognised and valued.
- Assessment helps the carer to feel less alone and more supported by knowing that there is someone they can contact for support even if this is not needed immediately.
- Assessment provides an opportunity for the carer to consider and express their feelings. This can be a release and can give them a new perspective on the present and future.

**Resource mechanisms**

Assessment can improve outcomes for the carer by providing them with resources in the form of helpful, appropriate services which may give them more time for themselves, support in providing care and access to finance.

**Enabling contexts**

There was evidence that a number of contextual factors could influence the likelihood of these mechanisms occurring and producing the desired outcomes of assessment. These can be broadly divided into those relating to: practitioner skills and approach; assessment processes, scope and structure; the availability and nature of resources; and carer characteristics. The weight of good quality, explanatory evidence from a number of studies provides confidence that each of these four categories is of significance. The detail of the individual factors within each tends more often to be supported by one or two studies and thus may need further replication. Each category is discussed separately below. However, there are links between these. For example, the availability of resources may influence the approach used by practitioners.

**Practitioner skills and approach**

There was evidence that assessment was more likely to be successful in a context where the assessors had the following skills and approaches.

- **Good interpersonal skills and empathy.** One study [1] specifically mentioned the benefits of the practitioner: not using jargon; being a good listener; and being someone it was comfortable to talk to. Practitioners noted the significance of this in another study [2].
• **Relationship building and familiarity.** Similarly, one study [3] noted that the creation of a relationship of trust with carers was necessary. This was discussed specifically in relation to whether the assessor was previously known to the carer or not by two studies [3, 9]. One [9] noted that where the assessor was previously unknown to the carer they needed to establish a rapport through good, responsive listening. In addition, a new worker needed to read the file beforehand, and find out the details of the family situation, rather than asking the carer to repeat the entire history. The other study [3] also found that if a new social worker knew little of the background of the case, carers could find the process annoying and repetitive. In addition, the lack of an existing relationship was felt to limit the topics covered. However, the other study (specifically of carers of people with a learning disability, who had often been in contact with various services for some time [9]) found that some families liked to have a fresh start with someone who was there specifically to concentrate on their own needs. However, parents’ attitudes to this depended a lot on what type of service they received from the new practitioner.

• **Personal experience as a carer** was mentioned as an advantage by practitioners in one study [2].

• **Similar characteristics to the carer.** In one study [1], there was limited evidence that carers found it easier to talk to an assessor of the same gender as them.

• **Training and/or experience in carer assessment** was noted as important by practitioners in two studies [2, 3].

• **Knowledge.** This was mentioned as potentially significant in relation to: carer services and support [3, 9]; the law [2]; and the ‘system’ or social care support and services generally [1, 2]. One study also noted the value of being able to communicate well with other services [9].

• **Carer specialism.** One study [3] found that it was beneficial to have an assessor whose role was specifically carer support. In such cases: the practitioner aimed to establish longer term relationships with carers; to facilitate access to services; and in one case, there was less paperwork involved in assessments because of their role.

• **Provision of active assistance.** One study [1] reported the benefit of assessors: being forthcoming with information; ready to help and advise on the process (such as form filling); and recognising the need for encouragement and guidance. Another study [9] found that carers were most satisfied where the assessor was described as a kind of advocate.

• **Response and follow-up.** Studies noted that it was important to respond and undertake follow-up work quickly and reliably [1] and that assessors were efficient [9]. Another study noted that it could be detrimental if the original assessor was not responsible for follow-up [2].

• **Maintenance of contact.** The significance of this was noted by two studies [1, 9]. One of these [9] noted that being kept in touch with progress could compensate for delays or problems in service provision in the eyes of carers. This study also found that families with whom contact had been maintained were more likely to feel able to re-contact the practitioner if needed, whereas others felt they no longer knew how to access support. Where contact was not maintained, carers
could feel very let down. One study also suggested that it was preferable to have one person co-ordinating support with whom the carer could maintain contact [2].

The study of outcomes-focused assessment [7] found that to deliver this specific approach, practitioners need to be skilled, to have time to develop their understanding and skills in the use of these tools and to be reassured that the process is not too time-consuming, intrusive or emotional for carers. They also needed to feel that they can manage expectations within the context of the resources available to them.

Assessment processes and scope

The following evidence has been identified which suggests some factors relating to assessment processes and scope which may influence outcomes.

- **Provision of information before the assessment.** There was evidence from a number of studies [1, 3, 11] that some carers found it helpful to be well informed and prepared for the assessment interview. However, some caution is needed here as one study [3] reported practitioner views that providing a copy of the assessment tool could cause anxiety or apprehension and that a softer approach to explaining the assessment process including dealing with requests for further information on an individual basis was needed. One study [1] noted that some carers wanted some time to digest relevant information prior to the assessment. Sometimes this was the case for new carers where they were still coming to terms with their situation or might be managing anxieties about dealing with social services. This study also found that some carers had found it helpful to be supported by carer support groups or condition specific organisations in their preparation for assessment. Another study [11] also noted that carers could find it difficult to participate fully in assessments where they were unclear about their relationship to the care manager as a carer. Thus, it might help to provide information about this.

- **Presence of others at the assessment.** One study [11] noted that carers found it more difficult to participate fully in an assessment in the presence of the person with dementia who they were caring for. This was because they wanted to protect the other person’s self-esteem and minimise awareness of degeneration in their abilities. In addition, discussion about the carer’s wish for breaks could be difficult whilst the person receiving care was present. In another study [3], practitioners reported the difficulty of asking some questions about caring risks in the presence of the person receiving care. A study [1] of a range of types of carers reported that carers differed in their preferences for a private assessment. Differences of opinion often related to how carers saw themselves: as part of a caring relationship or family (in which case they tended to prefer to have their assessment in the presence of the person receiving care); or as an individual (then they preferred to have it separately). The sample involved was small, but there was some evidence that suggested that carers likely to want a private discussion: support younger people with learning disabilities or people with mental health problems associated with advancing age (this last group reinforces the evidence mentioned previously - [11]); and/or have poor or less close relationships with their partners. A study of carers of people with a learning disability [9] noted that it could also matter to carers whether or not their partner was involved in their assessment. Many felt they needed time to discuss things from their point of view without their partner present, although they were happy for the assessor to talk to their partner separately.
• **Allocation of time.** One study [3] found that it could be helpful to do more than one assessment visit to gather additional information and formally agree the plan. However, some practitioners felt this depended on the information gathered in the first visit and the relationship built with the carer. Another study [11] also suggested that time pressures on assessment completion could limit the meaningful participation of the carer.

• **Assessment focus and scope.** The studies identified suggested various factors relating to assessment focus and scope that were perceived to be conducive to successful outcomes.
  - Some carers felt that too much focus on the person receiving care was unhelpful [1].
  - One study [9] found that the more comprehensive the scope of the assessment the more it was appreciated. For some carers, the main issue was housing, yet the assessment did not address this.
  - The same study also found that satisfaction with assessment increased when the expertise and knowledge of carers in relation to the individual's needs was taken into account by the assessor. Another study [11] also found that a lack of validation of carers’ skills, strengths and means of coping left carers reluctant to participate fully in assessment.
  - One study [1] reported that generally carers would have appreciated greater recognition of their need for emotional support as practitioners primarily focused on practical support. Similarly another study of carers of older people with dementia [11] found that carers and practitioners thought that assessment sometimes focused on practical care issues to the neglect of the emotional and relational elements of caring.
  - A needs-led approach was seen to be appreciated by carers in one study in contrast to approaches which began with a tick list of services [9, 12]. The evidence [7] on an outcomes-focused approach to assessment also suggests that this type of approach can be particularly successful.

• **Assessment tools.** Three studies [2, 3, 7] also provided some detail on the value of particular assessment tools. In consideration of one local authority’s assessment form, one study [3] reported largely positive feedback based on: the appropriate length of the form; the breadth of issues covered including sections on employment and benefits; the inclusion of requests for feedback on services; and the inclusion of open questions to allow the carer to expand on issues and needs. There were some concerns about: questions about carers’ learning needs which might be patronising; and whether carers knew what to do in an emergency when it could be more useful to provide information about this. It was also noted that the assessor generally guided carers around the form avoiding repetition and phrasing questions carefully but this was difficult when an interpreter was used in an assessment with carers who did not speak English well. Another study [11] noted that excessively long and complex assessment forms could lead to less positive assessment experiences. The specific outcomes-focused tools developed for one study [7] were seen to be a helpful part of delivering this approach to assessment.

• **Self-assessment.** Two studies commented on the use of self-assessment [1, 12]. One [12] found that carers felt constrained by tick-box self-completion assessment forms. The other study [1] looked at self-assessment in more detail. They did not find any link between the use or not of self-assessment and satisfaction with the services provided consequently. However, carers did
appreciate going through the form with the assessor because of the recognition and validation this provided. They also noted that many carers, particularly older carers, found it difficult to complete assessment forms on their own. Specifically, it was difficult to answer questions about what they wanted when they felt they did not know what might be possible. There were some perceived benefits to completing a self-assessment as preparation for a face-to-face interview though.

- **Interaction with others.** Two studies [3, 9] noted cases where the involvement of health professionals in the assessment as well as social services was highly valued.

- **Information and choice.** One study [9] found that the provision of information about different service options and a choice were more likely to lead to satisfaction with services following assessment.

- **Case closure.** Some practitioners emphasised the importance of keeping the case open for as long as the implementation of the carer's plan required further action [3]. This supports the findings in the previous section about the significance of the maintenance of contact with carers by practitioners.

**The availability and nature of resources**

- **The availability of resources.** Practitioners in two studies [2, 3] reported that the availability of resources and suitable services to meet identified carer needs was important to the outcomes of assessment. In the later study, some practitioners felt that assessment was increasingly needs led as the range of resources and services available now meant most needs could be addressed, although others still felt they had to be realistic about what they could provide. The significance of resources was also noted in a cross-sectional survey of carers in Wales [4]. If no help was offered following assessment, the following reasons were given: lack of resources (42%); the services that carers wanted were not available (32%); the carer was not eligible (11%); and other (15%). Another study [6] noted that staff felt reluctant to raise expectations when they felt they were unlikely to be able to offer practical support. It seems that this is likely to be partly about the level and nature of the resources actually available but also about practitioners' own perceptions and interpretations of this and its significance.

- **Nature of subsequent service provision.** Even where some resources and services are available for carers, the outcome of satisfaction with services has been shown to depend on the nature of these. The literature reports evidence of a number of relevant factors influencing satisfaction with services provided through assessment. In general, flexibility, personalisation and choice contributed to satisfaction [1, 3], but cost could deter carers from accepting services [5]. In relation to breaks for the carer (where the person receiving care was cared for outside of the home), potential issues were the appropriateness and quality of the provision for the particular individual receiving care [1, 3], transport provision [1] and costs [3]. In terms of alternative care and practical support provided in the home, potential issues influencing satisfaction were the flexibility, availability, reliability and timing of provision [1-3] and continuity of staff [1].
Carer characteristics

There was some evidence that the following characteristics relating to the carer (and the person they care for) may influence the outcomes of assessment. There was relatively little evidence concerning the first two points, but the final point is more clearly evidenced.

- **Condition of the person receiving care.** One study [6] found evidence that the proportion of carers who received services following assessment varied according to the type of condition which the person they cared for had (see page 32). However, no further evidence which might support or explain this further has been identified. Another study of carers of people with a learning disability [9] found that those caring for people with the greatest or most complex needs often felt let down by the process and outcomes of assessment.

- **Age.** One study [1] noted that social workers seemed to be more forthcoming with younger carers about their rights and ensuring they were informed about the process of assessment. The emphasis with older carers was more on supportive care package planning but without ensuring the carers were aware of their distinct rights. The only outcome identified in the study to which this may be linked was recollection and clarity about the assessment, however, this does not necessarily relate to better or worse ultimate outcomes from assessment.

- **Attitude.** Two studies, one of a range of carers [1] and one of carers of people with learning disabilities [9], contained evidence that the attitude of the carer could be significant. It was people who clearly and forcefully articulated their needs for help or services that were more likely to receive support. Being persistent, confident and not deferential, not being ‘side-tracked’, and not taking ‘no’ for an answer were also seen as important to accessing support. It could also be important to be well informed about service provision and to understand the social services system. Persistence was needed following the assessment interview to ensure follow-up action was taken. It was also noted that making staff feel appreciated could help to ensure progress. Some elderly carers had asked their children to be present in meetings with social workers to help put their case. Some carers had also resorted to approaching more senior people, including a local councillor, and/or making formal complaints. Some of the carers of people with learning disabilities had drawn on their networks with other families of people with learning disabilities to keep informed and know when to push for support. Some carers also felt that they needed to communicate the worst case scenario to ensure they received support. Whilst a persistent, forceful approach is likely to increase the chances of success, not all carers want or can take this approach. One study [1] also notes that some carers want advice and guidance from practitioners, rather than to be given all the information to make their own decisions, and hence are looking for more support rather than having to push for particular services.
**Summary of findings about statutory carer assessment**

**Outcome findings**

The quality of the evidence available measuring assessment outcomes was weak because it was generally based upon small samples with no control group comparator. However, these studies suggested that assessment may lead to a wide range of outcomes. The most notable potential benefits were outcomes relating to emotional well-being and the uptake of support services. There was also some limited evidence of: increased knowledge; better physical health; and support to work. However, the achievement of positive outcomes via assessment was shown to vary considerably. In most studies, the proportion of carers who received additional services following assessment was relatively low, below half. In addition, where services were provided, carers were not necessarily satisfied with them.

**Explanatory evidence**

The identified studies offered some high quality explanatory evidence which indicated some reasons for variation in assessment outcomes. It also suggested how assessment can lead to positive outcomes for carers. In particular, the subsequent provision of appropriate, helpful services was important, but the process of assessment can also be beneficial through giving carers a chance to express themselves, to feel recognised, valued and supported. A positive assessment was also shown to be influenced by: practitioner skills and approach; assessment processes and scope; the availability and nature of resources; and the characteristics of the carer. Carers may benefit more from assessments conducted by practitioners who: have good interpersonal skills; provide active assistance; are skilled and knowledgeable in carer support; follow up assessments efficiently; and maintain contact. Factors relating to the assessment process and scope of potential benefit included: providing relevant information to prepare the carer prior to assessment; consideration of whether others should be present at the meeting; allocation of sufficient time; a comprehensive, outcomes-based focus which considers the carer’s expertise; and the use of appropriate tools. The availability and appropriateness of resources with which to meet needs identified in assessments could also be significant. Carer characteristics could also influence outcomes, although practitioners should be able to find ways of delivering successful outcomes for any kind of carer through adaptation of their approach.
3b. i. Information services

The information services considered in this section of the report include those concerned with providing information specifically to enable carers to access services. Other information services which are primarily concerned with educating carers about medical conditions and caring are considered in the education section (page 80 onwards), although there is some overlap as some of these also offer information about services. In addition, information about services is also often included within both statutory carer assessments and in support worker services considered separately in this report.

Perhaps partly because of these overlaps, only five studies which focus specifically on interventions offering information about services have been identified here [13-17]. Thus the extent of the evidence is limited. The interventions evaluated are quite diverse and so they are considered individually below. The evidence measuring outcomes is weak in quality as it is based upon small sample sizes and/or retrospective measurement. However, there is some interesting suggestive evidence about the mechanisms and contexts which explain and influence outcomes.

Outcome findings for information services

The first study [13] evaluated a helpline set up for carers on a national carer awareness day. This used a cross-sectional survey plus some follow-up telephone interviews. They found that as a result of receiving information via this helpline: one third of the sample applied for benefits for carers; one sixth asked for their Pension Credit to be reassessed; 21 per cent asked for a carer assessment; and 12 per cent said they had read the information but did not need anything particular. About half (51%) said that the information had made them aware of the assistance available if they required this in future.

Clarke [14] evaluated a one day social services training workshop to provide carers with information about opportunities for involvement with service providers and the services available. Comparing measures before and after the intervention, he found significant improvements in carers’ self-perceived knowledge of services and knowledge of involvement. However, these were not matched by increases in measures of psychological empowerment including perceived control at individual, organisational or community level or self-efficacy and self-esteem. Again the quality of this outcome evidence is weak as it is based on a relatively small sample.

Jarvis and Worth [15] found that the distribution of a screening questionnaire to patients on a GP register identified a considerable number of carers and provided them with the opportunity to request information. The information pack sent to responding carers was found useful by all but one carer in a small sample of twelve.

Via a cross-sectional survey, Reeve and Baker [16] reported high satisfaction ratings with an information mailing service and a phone and advocacy service provided by a voluntary sector carers centre. They also found that carers in contact with the carers centre were more knowledgeable about and had used more carer services than carers who were not in contact with the centre. However, the quality of this outcome evidence is weak. The sub-sample of carers not in touch with the centre was very small and confounding factors were not considered.
The final study [17], based upon qualitative interviews, considered a social services welfare benefits advice scheme. The findings were mixed. Some received additional support through financial benefits such as Carer’s Allowance and funding for social services input, but others did not. Where additional support was received, this could give carers more control and choice over their lives, particularly in practical ways where they were able to buy in additional care services. It could also enhance quality of life, for example, by enabling carers to continue to attend social activities. However, a few carers did feel some concern about getting too used to having extra money and were afraid that this might be taken away from them at some point in the future.

**Explanatory evidence about information services**

The studies suggest a number of underlying mechanisms potentially explaining the outcomes of these interventions as well as relevant contexts likely to influence these. This evidence is tentative as it is based on a small number of studies with a relatively small number of carers.

**Explanatory mechanisms**

- Information may be felt to be useful ‘just in case’ [13, 15]. In other words, it can provide reassurance even if it is not used directly immediately.
- Similarly, information may influence carers’ emotional well-being by making them feel in touch and less alone [16].
- Information can enable carers to access services which may directly help them in a variety of potential ways [16, 17].
- Information services can help carers by negotiating and completing complex procedures on their behalf (for example, benefits applications) that they find difficult [17].

**Explanatory contexts**

The following factors may influence whether or not information services achieve particular outcomes.

- The extent - not too much [15] or too little [16] - of the information provided was perceived as significant.
- The relevance of the information influenced its perceived use to carers [15].
- That information is well laid out can be important to carers [16].
- Staff manner, being friendly and reassuring, was highlighted as significant by carers [16].
- Carers found it important to be able to access the service, for example, to be able to get through on the phone [16].
- Staff follow up of contacts and queries was important [16].
- Referral to *helpful services* was mentioned as important [16].
### Summary of findings about information services

#### Outcome findings

Carers tended to be satisfied with information services. There was weak evidence that information-based services improved carers’ knowledge of and uptake of services. There was also weak evidence from one study that the outcomes of information services may not go so far as to include making carers feel more empowered in their contact with service providers.

#### Explanatory evidence

Potential mechanisms underlying the achievement of outcomes by information services suggested by the evidence included helping carers to feel less alone and that back up support was available if necessary, as well as providing access to the resources offered by services. There was some evidence that the following contexts may influence the outcomes of information services: the extent, relevance and layout of information; staff manner; staff follow through and resolution of queries; ease of access to the service; and the helpfulness of the services to which carers are referred. These findings were tentative as each was only supported by one study and tended to involve relatively small numbers of carers.
3c. iii. Direct payment schemes

There is a strong focus in current government policy upon the use of direct payments and similar schemes which give community care service users the power to choose and control their own support. There have been many studies evaluating the success of such schemes from the perspective of social service users, for example, disabled people. One study [18] was identified here which considered these from the perspective of the carer. Another significant study is expected to be published shortly by the Social Policy Research Unit at the University of York which is to consider both the perspective of service users and carers.

The small scale study discussed here examined the use of direct payments by parent carers of disabled children in one local authority. The evidence on outcomes is weak because of the small sample size and retrospective measurement. There was some suggestive explanatory evidence about the mechanisms which may underlie outcomes and contextual factors which may influence their success.

Outcome findings for direct payment schemes

The outcomes identified were as follows.

- Alleviation of some of the financial pressures these families faced.
- Relief of carer stress.
- Successful arrangement and use of flexible support services that effectively met the needs of the parents and children.

Explanatory evidence about direct payment schemes

Explanatory mechanisms

- The primary mechanism appeared to be that the direct payments allowed parents to access support that they felt was most appropriate to their needs.
- This could also relieve them of some of the guilt of relying upon friends and family for support as they were able to offer some payment for this.
- It was also suggested that carer stress was relieved as parents no longer had to depend upon a number of professionals to make decisions about how their child was supported.

Explanatory contexts

- *Flexibility and choice.* The flexibility and choice offered by direct payments, particularly in relation to the employment of staff, was emphasised in the evidence as key to the success of the intervention. This included allowing parents to pay friends and family to provide support or to recruit staff based upon recommendations of friends and family or via specialist recruitment agencies. In addition, it was noted that parents valued the opportunity to recruit staff based upon their own criteria of what characteristics were important rather than having to leave this decision to social services staff.
• **Labour supply.** However, it was also noted that some parents found it difficult to recruit carers suggesting that the availability of appropriate care workers locally is also important to the success of such schemes.

• **The independent direct payment support service.** This enabled parents to achieve their desired outcomes. This occurred through practical support, for example, with financial matters, and emotional support. It was also important to parents that the service was approachable and friendly.

• **Expertise within social services.** Within the local authority, social care staff were enabled to provide direct payments to parents by the presence of a social worker who had previous experience of this and could provide advice and reassurance about the intervention.

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**Summary of findings about direct payment schemes**

**Outcome findings**

There was weak evidence from one study that direct payment schemes can achieve the following outcomes for parent carers of disabled children: alleviation of financial pressures; stress relief; and facilitation of the provision of appropriate, effective support services.

**Explanatory findings**

The study identified suggested that the success of the scheme could be explained primarily by the empowerment of parents to access the support most appropriate to their needs. In addition, direct payments enabled parents to avoid over-reliance on professionals and to provide payment for support relied upon from friends and family thus alleviating guilt felt about the provision of this help. A number of potentially significant contextual factors were identified. The flexibility and choice, particularly in relation to the employment of staff, offered were seen as critical (although appropriate staff also needed to be available locally to employ). In addition, the practical and emotional support of an independent direct payment support service enabled parents to use the scheme successfully. Within the local authority, the presence of a social worker experienced in this type of work was seen as important to its success.
3c. iv. Support workers

Carer support workers may work within a statutory (health or social services) or voluntary sector context and may specialise in working with particular groups of carers. The range of tasks they undertake varies. In the studies discussed here, information, advice and liaison with other agencies to facilitate access to services were significant parts of their work. However, in some cases, they also provided additional help and this should be borne in mind in considering the findings.

The support worker interventions covered by the studies discussed here differed in varying ways. They are therefore discussed in the following categories.

- GP-based carer support workers [19, 20].
- Advocacy workers for Pakistani and Bangladeshi parent carers [21].
- Mental health specialist carer support workers [22, 23].
- Support workers for carers of older people with dementia or psychiatric problems [24-26].
- Support nurse work with carers of people with lung cancer [27].
- Stroke specialist support workers [28-34].

GP-based support workers

Two studies focused upon support workers based in GP surgeries who worked with all types of carer. Their role was principally to offer information and to liaise with other services, although in the first study the support worker also offered counselling [20]. The first analysed change over time but its evidence on outcomes is weak as there was no comparator group. The second also presents weak outcome evidence as although outcomes for carers from the GP surgery with a carer support worker were compared to those using a GP surgery without any such support, confounding factors are not adequately accounted for [19].

Outcome findings for GP-based support workers

Emotional well-being

The first study [20] found that the carer support worker had a large positive impact upon the psychological well-being of carers. The large majority of carers reported that the service had made some difference to their lives.

Service provision

The other study [19] concentrated upon outcomes relating to the service support consequently offered to or used by carers with and without access to a support worker. There were better outcomes amongst carers with access to the support worker in terms of:

- Receipt of personal support;
- Receipt of help with benefits claims;
- Perception that they had the sort of help they required;
- Perception that there was choice in the support they received;
- Feeling that their needs were understood;
- Feeling that they were listened to;
- Feeling involved in the planning of care for the person receiving care;
Satisfaction with the response rate of the support worker (contrasted with that of social services in the control group);
Ease of contact.

There was also qualitative evidence that the carers received recognition from the support worker. The study reported that the first two findings were statistically significant, it does not make clear whether the others were. The differences in frequencies tended to be large but the sample size was small. The study also noted that the level of practical support provided to both groups was very similar and slightly higher amongst carers without access to a support worker.

**Explanatory evidence about GP-based support workers**

These studies included little explanatory evidence. The first included some limited evidence of factors suggested by carers which could help the service to work more effectively in future [20]: wider advertising of the service; regular monitoring support; and assistance with benefits for new carers.

**Advocacy workers for Pakistani and Bangladeshi parent carers**

One study [21] evaluated an advocacy support worker service targeted specifically at Pakistani and Bangladeshi parent carers of children with severe disabilities. The small sample size of this qualitative, longitudinal study means that the evidence on outcomes is weak. However, it also provided some interesting explanatory evidence.

**Outcome findings for advocacy workers for Pakistani and Bangladeshi parent carers**

**Meeting of expectations and needs**

Many families reported that the service had met their expectations and solved their outstanding problems and needs, but equally this had not been achieved for a significant number. Workers found it most difficult to address housing problems, although it was easier to secure household adaptations than a transfer to a new council property. Significant additional benefits income was secured for families.

**Emotional support**

Parents felt the service provided them with emotional support.

**Empowerment**

The service was limited to nine months. The aim was that during this period, staff would work with carers to empower them to be able to deal successfully with service providers themselves once the support worker service ceased. Afterwards, three of the nineteen families said they could deal with service providers themselves, whereas generally families did not feel able to do this.
Explanatory evidence about advocacy workers for Pakistani and Bangladeshi parent carers

The mechanisms implicit in the outcome findings were emotional support and the resolution of problems and needs.

A number of contextual factors relevant to the achievement of outcomes were also identified.

- **Nature of problems.** As noted above, different types of problems were more or less easily solved.

- **Cultural and family dynamics.** Where individual mothers were empowered by the service to make certain decisions and take action, these were sometimes consequently overturned by the husband or extended family. This was because the work of the service did not always fit with some of the existing cultural and family dynamics.

- **Gender.** Female advocates found it difficult to engage and work with fathers. There was one exception with a worker specifically supporting Bangladeshi parents. She thought that this was because she was older and because no-one in these families spoke English and thus they relied upon her to negotiate with English-speaking service providers.

- **Frames of reference.** One barrier to success relating to empowerment seemed to be a mismatch of perceptions whereby parents did not understand or relate to the service providers’ concept of self-advocacy and intention to work towards empowering parents to advocate for themselves.

- **Language.** In relation to achieving empowerment and self-advocacy, language was seen as the major barrier to this in cases where the parents did not speak English.

**Mental health carer support workers**

Two studies focused upon support workers specialising in work with carers of people with mental health difficulties. The first was a small qualitative study of support workers based in the community mental health team. This offers some weak evidence on outcomes and some explanatory evidence [22]. The second compares the situations of new and existing cases of carers supported by voluntary sector support workers. The outcome evidence is weak as confounding factors are not accounted for [23].

**Outcome findings for mental health carer support workers**

The first study [22] reported qualitative identification of the following outcomes.

- Emotional well-being including: an improved outlook on their situation; being more relaxed; and feeling more confident.
- Feeling better able to care.
- Better health.
- Greater uptake of social opportunities and activities.
The second study [23] also found a positive impact, specifically on measures of burden and quality of life, plus high levels of satisfaction. However, the differences were not statistically significant with one exception: the impact of the patient’s illness on the carer’s work life.

**Explanatory evidence about mental health carer support workers**

The first study provides qualitative evidence of a number of mechanisms that could explain the success of work [22].

- Access to advice.
- The opportunity to discuss ways of coping.
- The provision of moral support and recognition by the support worker.
- Support and ‘permission’ for carers to make more time for themselves as well as this time itself.
- Reassurance through knowing that there was someone to call for help if necessary.

There was also some evidence of contextual factors that may influence the achievement of outcomes as follows.

- The intervention was judged to be most successful where additional support was also being provided for the person receiving care [22].
- The flexibility of the service was particularly welcomed by carers [22].
- Other practitioners felt that certain personal qualities of the support worker enabled success, namely: high levels of motivation; a caring attitude; empathy; accessibility; knowledge; and a conscientious approach [23].

**Support workers for carers of older people with dementia or psychiatric problems**

Three studies of support worker interventions for carers of older people with dementia or psychiatric problems were identified [24-26]. One [25] used a randomised controlled trial (but rated of weak quality) to evaluate a key worker service offering social support, information and advice about the condition and managing financial and social problems and referral to specialist services for psychiatric and psychological treatment if necessary. About six in ten of the carers in this study were caring for someone with dementia and the others for elderly people with depression or anxiety. The other two both evaluated the Admiral Nurse service for carers of people with dementia [24, 26]. One [24] was a brief report based upon uncontrolled longitudinal outcome measurement of an early pilot of the service. The other [26] is a more recent controlled longitudinal outcome measurement study (rated of moderate quality) of the service. The Admiral Nurses (typically trained mental health nurses) work primarily with the carer for as long as appropriate and offer information, co-ordination of practical support and emotional support. These studies provided outcome measurement evidence only.
**Outcome findings for support workers for carers of older people with dementia or psychiatric problems**

**Emotional well-being outcomes**

There was some limited evidence that these interventions could improve emotional well-being as detailed below.

- One study [25] found no significant difference between scores of emotional well-being (as measured by the GHQ) between the intervention and control group (those who did and did not receive the service at three months). However, at six months, there was a positive association between higher emotional well-being scores and a greater amount of intervention time received by study participants. This suggests that the service may have some impact.

- The controlled study of the Admiral Nurse service for carers of people with dementia [26] found one significant difference in emotional well-being scores favouring the intervention group over the control (usual care) group after an eight month period. This was in relation to the sub-scale of the GHQ measuring anxiety and insomnia (no differences were found overall or for somatic symptoms, social dysfunction or depression). The study also noted that whether the carers (in either the intervention group or control group) had received continuing key worker support over time or assessment only was significant to emotional well-being as analysed in a regression model of factors explaining variation in GHQ scores.

**Number and extent of carer problems or needs**

- One study [25] also measured outcomes using the Social Problems Questionnaire to assess the severity of difficulties in housing, finance, marriage and social life. However, no significant changes attributable to the intervention were found on this measure.

- The first pilot study of the Admiral Nurse service for carers of people with dementia [24] assessed nineteen carer needs at the beginning of the intervention and three months later. There was a mean reduction in the mean total number of needs from nineteen to eleven in this period. The study also reported that generally some practical and informational needs could be met for carers, but that emotional needs were more difficult to address even though considerable time was spent on these by the workers.

**Outcomes for the person receiving care**

One study considered outcomes for the person receiving care [26]. This found no significant difference between the intervention and control groups in terms of the proportion who remained at home, had entered a residential or nursing home or hospital at eight months.

**Support nurse work with carers of people with lung cancer**

A study of a support nurse intervention for carers of people with lung cancer using uncontrolled longitudinal outcome measurement plus qualitative interviews was identified [27]. The intervention began with a systematic assessment of need which
consequently led to a tailored twelve week support plan potentially including information and advice and emotional support for the carer. The study offered high quality explanatory evidence but weak outcome measurement although it did consider change in outcomes over time.

**Outcome findings for support nurse work with carers of people with lung cancer**

A greater number of carer needs (viewed as of average or extreme importance) were met at twelve weeks than prior to the intervention. These mainly covered informational needs. Quantitative data showed a trend for improvement over the period in physical, psychological and spiritual well-being and social concerns but this was not statistically significant. However, analysis of change in the mean score of emotional well-being (as measured by the GHQ) showed a statistically significant improvement from just before the intervention to twelve weeks later.

In addition, this and the following other outcomes were identified in the qualitative data.

- Receipt of helpful, appropriate information.
- Receipt of practical support such as referral and liaison to access other services.
- Facilitation of some improvement in difficult communication between family members.
- Reassurance and support felt through knowing that someone was there to support them if needed.
- Feelings of their experience being acknowledged and understood and the value of having the opportunity to express themselves.
- A feeling of being supported.
- A perception that the above enabled the carer to support the patient better.

**Explanatory evidence about support nurse work with carers of people with lung cancer**

As implied in the outcome findings discussed above, a number of mechanisms were at work:

- The provision of emotional support through listening to and validating carer experiences and feelings.
- The provision of information resources.
- Referral and liaison with other services.

The study also provided some information about what could help to achieve the desired outcomes as follows.

- Individuals had different preferences for face-to-face, telephone or a combination of methods of interaction with the support nurse. Some found it helpful to receive information verbally rather than in a written format.
- It was particularly appreciated that support (including information) was tailored to the carer’s individual situation and was arranged flexibly to fit in with their other commitments as far as possible.
Stroke specialist support workers

The largest body of evidence on the outcomes of carer support worker interventions relates to those specifically developed both for stroke patients and their carers. The main purpose and form of the intervention considered in these studies was very similar with some slight variations in this and the way the study was conducted. These studies discuss outcomes and processes in relation to both patients and carers. The information included here relates to carers only unless it is specifically stated otherwise.

Five randomised controlled trials have been identified of these interventions [28, 30, 32-34]. Randomised controlled trials are commonly held to be the most rigorous way of measuring outcomes. However, the practical difficulty in achieving all the various requirements of randomised controlled trials (for example, blinding of both assessors and study participants to their allocation in the trial) in the social sciences mean that the ratings of these studies on the quality appraisal tool used in this review were: strong [33]; moderate [28]; and weak [30, 32, 34]. This evidence should still be understood to be of relatively high quality in terms of the internal validity it offers in measuring outcomes. However, it can only offer findings on the very specific outcome measures used. In addition, as some of the authors [33] have noted themselves, their aggregate measures of outcomes may mask considerable differences in effect for families who required and received much greater or lesser help from their support worker.

Two of these trials [30, 32] were also accompanied by qualitative pieces of research ([29] and [31] respectively). Whilst there are only two such studies, these do offer reasonably high quality qualitative evidence with which to start to understand the mechanisms underlying carer outcomes and the contextual factors which influence the achievement of these. (One [31] received an overall rating of strong for explanatory evidence and the other [29] was rated moderate for explanatory evidence.)

Outcome findings for stroke specialist support workers

Emotional well-being outcomes of stroke specialist support workers

There was mixed quantitative evidence in relation to the achievement of outcomes measuring emotional well-being but this tended to show little intervention effect.

- Two studies found no apparent change caused by the intervention. One measured this in terms of total and subsection scores of the General Health Questionnaire measured at twelve months since the beginning of the trial [30]. Another measured this using the General Health Questionnaire and the Caregiver Strain Index at four and nine months [32].
- Another also found no change after a year (using the Caregiver Strain Index and Hospital Anxiety and Depression Scale), but had identified one (marginally significant) better outcome (proportion who felt that some good had come out of the stroke) in the group who received the intervention compared to the control group at three months [34].

2 The quality of these studies has been appraised in relation to their evidence on carer outcomes. The ratings may have been better for patient outcomes as these were generally the primary focus of the evaluations.
Only one study [28] found significant improvements for carers in the intervention group for mood symptoms using the General Health Questionnaire and the depression part of the Hospital Anxiety and Depression Scale and of borderline significance for the anxiety part of the Hospital Anxiety and Depression Scale and hassles (the Caregiving Hassles Scale) (these were at six months follow up).

However, the qualitative evidence relating to these interventions suggested that support workers were having some influence on the emotional well-being of carers. It may be that this is to a lesser extent than the quantitative studies seek to identify or that it is in a way that is not adequately captured in the outcome measures used by the trials. The qualitative evidence suggested the following outcomes relating to emotional well-being.

- Patients and care-givers reported the beneficial effect of knowing someone was interested in them and feeling less isolated or abandoned than the control group [29, 31].
- Provision of a sense of direction and encouragement in moving forwards [31] [29]. This came principally from evidence that the control group felt a lack of this compared to those who received the service.
- A feeling of relief through having someone to help deal with the complexity of the system and to deal with other professionals (as compared to having to deal with several different professionals and being passed around the system) [31].

**Knowledge outcomes of stroke specialist support workers**

There was mixed quantitative evidence about the knowledge outcomes of the intervention.

- One study [32] found that carers in the intervention group reported significantly better knowledge of strokes, how to reduce the risk of strokes and of who to contact for community services and emotional support, than the control group. This finding was found at both four months and nine months following recruitment to the research, except in relation to community services where there was no difference at nine months. However, it found no difference in knowledge about benefits or practical help at four or nine months between the two groups.
- Another study [33] found that carers in the intervention group felt more satisfied than those in the control group with their understanding of stroke, its causes and how to prevent another stroke. However, the study also looked at measurements of carers’ actual knowledge and did not find any significant difference. This suggests there was a difference between carers’ perceptions of their knowledge and formal measures of this.

The qualitative studies provided some evidence that the intervention contributed to knowledge outcomes as follows.

- A lack of personally relevant information was commonly reported by interviewees in the control group in one study [29].
- Carers in the intervention group also expressed gratitude for help with understanding the complexities of the system [29].
However, this study [29] also showed that some of those in the control group found other ways of increasing their knowledge, for example, by visiting their local library. Yet, not all carers in the control group did this. In addition, the other study [31] notes how there was uncertainty about how to access relevant information in the control group and that this seemed to restrict knowledge and that help was found by accident and luck.

Service use outcomes of stroke specialist support workers

There was little quantitative evidence about the impact of the intervention on service use. One study compared the family’s use of a range of services but found only one statistically significant difference – that the control group used physiotherapy services more than the intervention group [33]. Another study [34] found no significant differences in the proportion who attended a support group or had had a break from caring at twelve months.

One qualitative study [29] reported that the provision of practical help for patients was attributed to the work of the support worker. Carers also reported that they had found out about and accessed benefits based on the information and encouragement given by the support worker. This study also found that the control group interviewees more often described unmet needs in relation to information, advice and support. Similarly, the other qualitative study [31] reported the greater difficulties expressed by control group interviewees about accessing practical support.

Quality of life outcomes of stroke specialist support workers

One study [33] assessed quality of life using the short form 36 and Dartmouth co-op charts. This found significantly higher scores for carers in the intervention group than the control group at six months on the quality of life item on the Dartmouth co-op charts and on five parts of the SF-36 (energy and vitality, mental health, pain, physical function and general health perception). There was no significant difference on the other parts (SF-36: change, role limitation (emotional), role limitation (physical), social function; Dartmouth co-op charts: physical fitness, feelings, daily activities, social activities, pain, change in health, overall health, social support).

Satisfaction with stroke specialist support workers

Generally the quantitative evidence shows higher levels of satisfaction amongst carers who received the intervention compared to the control groups.

- One study [32] found that the intervention group was significantly more satisfied with the information received to reduce the risk of stroke (at four months, but not at nine months) and with information on practical help and emotional support (at both four and nine months). They found no significant difference in satisfaction on information about stroke, recovery, benefits, community services or overall.
- Another study [28] found higher satisfaction in the intervention group in relation to the following statements: "the staff attended well to my needs whilst he/she was in hospital"; "I am satisfied with the outpatient services provided by the hospital"; "I have received enough information about recovery and rehabilitation after stroke"; "somebody has really listened and understood my needs and problems since they left hospital"; "I have not felt neglected
since he/she left hospital”; and "I know who to contact if I have problems relating to caring for him/her".

Higher levels of satisfaction amongst those who received the intervention were also reinforced by the qualitative studies [29, 31].

The evidence on satisfaction is potentially important because it suggests that even where no differences are found on other outcome measures, carers seem to feel some benefit. It may be that this has not been captured adequately by the specific outcome measures used in the trials.

**Patient outcomes of stroke specialist support workers**

Given that this intervention is targeted at both the carer and the stroke patient, it is important to note the main findings in relation to patient outcomes as well. These were mixed and included some negative findings although the statistical significance of these was generally weak.

- One study [33] reported no adverse or beneficial outcomes for patients.
- Similarly, Forster and Young [30] found no significant differences between the intervention and control groups other than an improvement in social outcomes for a sub-group of mildly disabled patients with stroke.
- Another study [32] reported differences on some outcome measures but not others. There were no significant differences in patients’ mood and independence in personal or instrumental activities of daily living. However, patients in the intervention group were more satisfied with the information they had had and more knowledgeable about whom to contact for stroke information, reducing the risk of stroke, practical help, community services and emotional support.
- One study [34] reported weak evidence of worse scores on the Reintegration to Normal Living Index for patients in the intervention group than in the control group after a year and also that patients in the intervention group were more likely to think that ‘stroke still had a negative effect on their life’.
- One study [28] found that patients in the control group tended to have better outcomes than the intervention group, although this difference was only significant for social adjustment and was of borderline significance for helplessness and depression. However, this study did find that patients in the intervention group were more satisfied with specific elements of their post-hospital care than those in the control group.

**Explanatory evidence about stroke specialist support workers**

**Explanatory mechanisms**

The following mechanisms are suggested by the qualitative evidence as explaining the achievement of outcomes.

- **Emotional support.** Carers felt supported and less isolated through the assistance provided by support workers.
• **Provision of guidance and access to resources and information.** The support worker could guide, direct and encourage families in their new context. This included providing information and liaison with other service providers.

**Explanatory contexts**

The following factors were identified as potentially significant in contributing to the successful achievement of outcomes.

• **Tailoring of support.** The tailoring and individualisation of support was appreciated by carers [29, 31].

• **Accessibility.** Carers valued being able to contact the support worker easily by telephone and that they would ring back and save them telephone costs [29].

• **Longer-term and continuity of commitment and involvement of workers with the families** [29, 31].

• **Professionalism, tact and friendliness.** These characteristics of support workers were positively commented upon [29].

• **Timing.** Several carers mentioned that the time at which support was most needed was upon the patient's discharge from hospital.

Some contextual factors were also identified which potentially hindered the achievement of improvements in carer outcomes.

• **Perceptions of the service.** Some carers viewed the support worker as just someone else from social services and this appeared to affect uptake of the service offered and restricted the type of support requested [31].

• **Patient wishes.** There was evidence that if the patient did not want certain support then this could limit the support received by the carer [29].

• **Reluctance to initiate contact.** In one study [31], whilst the importance of knowing there was someone to turn to if things became overwhelming was mentioned by all, approximately half of both patients and carers reported a reluctance to make a call to the support worker even when it was needed.

### Summary of findings about support workers

**Outcome findings**

There was some evidence of carer support worker interventions leading to improvements to a number of outcomes for carers. Evidence from the GP-based, mental health specialist, dementia carer, lung cancer carer and South Asian advocacy workers suggested that the intervention contributed to emotional well-being. However, this evidence was relatively weak in quality in terms of outcome measurement. The studies with stronger research designs for outcome measurement relating to stroke specialist workers did not show convincing evidence of improvements in emotional well-being. However, qualitative studies of these workers and particularly of the lung cancer carer service did suggest that carers were feeling...
benefits in terms of emotional well-being. Thus there are some grounds to believe that this intervention does contribute in this way even though there is not yet definitive evidence.

There was also some evidence that stroke specialist support workers (and the lung cancer carer support service) may have helped to improve carers' knowledge base. The studies of the dementia carer workers and lung cancer carer worker also showed that the number of carer needs (covering information, access to practical support and emotional support) could be reduced through these interventions. One study of a GP-based support worker and the advocacy workers for Pakistani and Bangladeshi parent carers showed that the intervention could lead to increased and improved service support for carers. There was also some qualitative evidence of this in relation to stroke specialist workers. The quality of the outcome measurement in these cases was relatively weak though.

Satisfaction was found to be improved in some of the studies of stroke specialist workers. This is useful because it suggests that carers feel some benefit from the intervention even where the other outcome measurements did not capture this.

The studies of stroke specialist workers also provided some weak evidence that there might be some negative outcomes in terms of rehabilitation and social adjustment from this intervention for stroke patients. Further research is needed into this.

Explanatory evidence

The explanatory evidence suggested that the outcomes of support worker services were explained by emotional support and the facilitation of access to other resources including information and services. Emotional support appeared to be achieved in a number of ways including: feeling recognised by the worker; receiving moral support and enabling a better outlook on and more confidence about their situation; provision of an opportunity to discuss their feelings and needs; the feeling of being given permission to consider their own needs and to take time for themselves; and reassurance that there is someone they can contact for support if necessary.

The explanatory evidence also suggested a number of contextual factors which might influence the achievement of outcomes. Success might depend upon the nature of the problem or needs of the carer. Flexibility and individualisation or tailoring of the service also seemed to be helpful. Preferences for telephone or face-to-face contact or a combination varied. The continuity of and length of contact with one person was seen to be beneficial. Relevant worker qualities of benefit were noted including: motivation; conscientiousness; professionalism; tact; a caring attitude; empathy; friendliness; accessibility; and knowledge. A number of factors that might also hinder the achievement of outcomes were also identified. These included: mismatch between the service and cultural and family dynamics; mismatch between participants and service providers’ perceptions of the service; and contrasting patient wishes.
3c. Interventions focused upon carers’ health

This section covers interventions specifically set up to address the health needs of carers (but not carers’ general experiences of health services which are outside the criteria for inclusion in this review). Studies of support worker interventions located within GP practices but designed to enable carers to access general support and services, rather than specifically health related support, were included in the previous section.

Two relevant studies [35, 36] were identified of broadly similar interventions located in general practices. These consisted of individual appointments with a nurse offering basic health checks, listening or emotional support (or referral to this) and relevant information (including about other support services). The reports of these studies are very brief and are rated weak in quality for both outcome measurement and explanatory evidence because there is little methodological reporting and reliance upon very small samples. Thus the findings given below should be treated as indicative only. The limited explanatory evidence provided is incorporated into the outcome findings.

**Findings for interventions focused upon carers’ health**

*Identification of and attention to health needs*

Both studies reported the identification of a number of health problems or needs amongst participating carers including: raised blood pressure [35, 36]; the need to review complex medication regimes [35]; urge incontinence [36]; and being overweight [36]. One study [36] noted that the problems identified were followed up and addressed by the nurse in various ways. The other study [35] found that the participants reported that they had paid more attention to their own health needs and taken action to reduce their stress levels following attendance at the clinic.

*Emotional well-being outcomes*

There was qualitative evidence from both studies that carers found the time to talk and express their feelings helpful and that this seemed to be the most significant outcome for participants receiving this intervention. In particular, it was specified that this included: having their own needs focused upon [35]; feeling valued [36] and reassurance that there was someone to turn to for advice if necessary [36]. One study [35] noted that referral to a stress management therapist sometimes involved quite a lengthy appointment which could sometimes cause anxiety because of the consequent time away from the person receiving care.

*Access to services outcomes*

The studies reported some limited evidence of subsequent carer referral to or contact with other formal support services. However, it was also noted that many opted not to use services available across the city which they had been informed about because of the travel time involved.
Summary of findings about interventions focused upon carers’ health

Only two studies of weak quality were identified of interventions focused upon carers’ health. Evidence from these suggests that this type of intervention would be worth exploring further as they may deliver outcomes in terms of: identification of and attention to health needs; emotional well-being; and access to other services.
3d. Interventions focused upon emotional and social support

This section includes studies of interventions which were focused primarily upon providing carers with emotional and social support. They also generally included some information or education but went beyond those included in the education and training section in their focus upon addressing emotional needs in particular. These have been divided into the following categories.

- **Carer support groups.**
  These are focused primarily upon the provision of social, emotional and informational support in a group format. Support may be provided through mutual exchange between carers and/or from a professional leading the group.

- **Structured stress management, coping and counselling programmes.**
  These generally quite tightly structured interventions have a particular focus on the development of stress management and coping strategies aimed at improving the emotional well-being of carers. They are generally condition-specific and include some education about the relevant condition.

- **Befriending interventions.**

- **Complementary therapies** including massage and aromatherapy.

### 3d. i. Carer support groups

Carer support groups are generally designed to provide carers with an opportunity to meet, get to know, share experiences with and learn from other carers in similar situations. They may also offer some more formal, practitioner input including information and education, although some are purely carer led. They tend to be ongoing with different carers joining and leaving the group over time. Some are generic and others are focused upon specific groups of carer, often determined by the condition of the person they care for.

Eight studies of carer support groups are included here [37-45]. The interventions covered include generic carer groups (self-help groups and those with various links to formal services), as well as some which catered specifically to: Asian carers; carers of people with dementia; and carers of people with mental health problems.

These studies all relied upon cross-sectional survey data and/or qualitative data. Thus, the findings in terms of outcome measurement are weak. However, the depth of the qualitative work offers detail about the types of outcomes which might be achieved even if the extent to which these are achieved cannot be judged from this evidence.

The studies also provided considerable explanatory evidence. However, the quality of this was variable. Five studies [37-40, 43] were rated as weak in quality generally because the reports of these were very brief. Thus there was insufficient detail about the sample and/or methodology and little inclusion of original data. One study [45] was rated as moderate. The other three offered strong explanatory evidence [40-42, 44].
Outcome findings for carer support groups

The studies of carer support groups included evidence of a variety of outcomes including satisfaction, social support, access to and improved relationships with services, practical support and some relating to the person receiving care. The main focus of the data, however, is upon outcomes covering the receipt of information and advice and improvements to emotional well-being.

Satisfaction with carer support groups

Four studies [37-40] reported on carer satisfaction with support groups. They all found that a high proportion of (but not all) carers were satisfied with the support group they (had) attended.

Knowledge outcomes from carer support groups

The majority of studies reported some knowledge-based outcomes from carer support groups [37-42, 44, 45]. As the details of the evidence provided by specific studies shows below, carers gained a wide range of types of information and advice through a number of sources. There was some limited evidence that this can be particularly significant for Asian carers who find it difficult to access relevant information in their own language elsewhere. This evidence is useful in detailing the range of knowledge-based outcomes which can be achieved through carer support groups. However, it can tell us little about the extent to which these are achieved because of the reliance upon qualitative and/or cross-sectional data.

- A wide range of knowledge was gained. This specifically included: information on benefits [41, 42], services [41, 42] including recommendation of specific local services [44], medical knowledge and/or understanding of a specific condition [37, 41, 42, 45]; practical tips on providing personal care [41, 42]; and coping strategies [44, 45]. The general provision of advice was also frequently reported [38, 40-43]. In addition, one study [44] noted that some carers in a self-help group described learning outcomes relating to personal and interpersonal skills development. These specifically included: learning to listen without judgement and to appreciate others’ experiences; having a stronger sense of their own strengths and weaknesses; and broadening their perspective on their own and others’ situations.

- Information was gained through: the input of professional group leaders [41, 42]; invited speakers [41, 42]; and through the sharing of information and advice between group members [44]. One study [44] noted that carers shared knowledge and skills from other aspects of their lives, for example, past careers as well as from caring. One study [41, 42] noted that carers particularly welcomed the professional workers’ knowledge about community care policy and practice.

- A study of a support group for Asian carers of people with mental health difficulties [37] reported that 97 per cent of members found the group was the only place where they were able to gain information regarding mental illness in the language they could understand and within a supported environment. Similarly another study [41, 42] noted that carers in an ethnic minority support
A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence

group mentioned translation facilities as something they gained from the group.

- One study of support groups for carers of elderly people with psychiatric problems [39] reported that not all carers perceived support groups to offer informational outcomes. Just over half (54%) of the carers felt that receipt of advice on the management of problems was a beneficial aspect of the groups; 67 per cent considered that they benefited from information on illness; and 38 per cent that they benefited from information on services.

*Emotional well-being outcomes from carer support groups*

A number of studies reported outcomes relating to emotional well-being achieved through carer support groups [40-45]. The studies provided evidence of a number of particular outcomes as follows. However, again, the evidence does not allow robust conclusions to be reached about the extent to which these outcomes are achieved.

- *The giving and receipt of support between carers.* In particular, the mutual support received by group members from each other was noted [41-43]. This was specified as the main benefit of the support group in some studies [41-44]. The evidence suggested that this specifically included the following elements of support. It could be helpful for carers to talk about their own experiences and feelings and to be amongst people in similar situations who will listen [37, 38, 43, 45]. In particular, this could help carers to normalise and validate their experiences, what they were doing well and where they needed help [44]. Carers could feel they gained respect from other people who understand their situation [43]. It could be helpful for carers to know that they were not alone [37, 43, 45] and could contact others outside the group if necessary [44]. There was evidence not only that carers find it beneficial to receive this support, but also that it can be helpful to give it. Two studies [40-42] found that former carers could find it beneficial to their own emotional health to continue to attend support groups and to help others currently caring. One [40] mentioned specifically that this could provide the former carer with a sense of belonging and a role following the loss of their caring role.

- *Increased confidence.* Some studies noted that carers gained confidence and/or assertiveness through the groups [37, 38, 41, 42, 44].

- *Changes to identity.* One study [41, 42] noted that the groups had given carers a more positive attitude towards and identification with their role as a carer (in contrast to understanding their role just in terms of kinship). Another study [43] found that members of a support group which had been going for eight years described how the group had enabled them to look beyond the primary caring relationship and acknowledge their own needs as carers. This was also evidenced in one other study [38].

*Social outcomes from carer support groups*

The benefit of mutual support has already been mentioned in the context of emotional well-being. Studies also showed that carers could value the social opportunities provided by groups [40-42]. This could specifically provide value in the form of: meeting others [43]; building friendships [40, 44]; and providing opportunities
to go out and do different activities [43].

Carer support group outcomes concerning access to and relationships with services

Some of the support groups were linked to other formal services concerned with carers and/or the people receiving care. Accordingly there was some evidence of outcomes relating to access to and relationships with these services. The extent of this evidence is quite limited however.

- Some carers appreciated the direct contact with staff provided by support groups [38, 41, 42]. Another study [39] found that 82 per cent of carers identified meeting the staff as one of the most important aspects of the groups. In addition, staff feedback from this study reported that despite having already well established channels of communication between the carers and the day hospital, 78 per cent of the staff felt that the carer support groups created more effective communication.
- In addition, there was some limited evidence that carers could value support where a professional group leader acted as a facilitator or mediator with other services [41, 42].
- Two studies also commented on the potential campaigning and lobbying outcomes of carer support groups. One [41, 42] found that few carers in the support groups studied had wanted to become involved in a wider forum to express their views to service providers and policy makers. However, another study [43] found that carers in a long established support group (eight years) saw lobbying for change in service provision as an important role of the group.

Practical support outcomes from carer support groups

One qualitative study [40] mentioned that support groups also provided instrumental support, that is practical help with daily activities, for example, domestic chores and financial matters. However, this was not referred to in other studies apart from in terms of giving advice about these types of matters.

Outcomes for the person receiving care from carer support groups

Only one of the identified studies included information about outcomes for the person receiving care. This is unsurprising given that the interventions considered were targeted directly at the carer and not at the person receiving care. This one study [37] reported group facilitator feedback that the information and advice given through the support group contributed to a reduction in GP and out-patient psychiatric appointments and hence a reduction in relapse rates. However, there is no robust quantitative outcome evidence supporting this.

Explanatory findings for carer support groups

Explanatory mechanisms of carer support groups

The evidence of outcomes suggests a number of mechanisms explaining improvements in carer outcomes. Many of these were found across a number of
studies suggesting that reasonable confidence can be felt about the existence of these.

- Firstly there is the quite tangible provision of resources including: information and advice; friendships and social opportunities; and the facilitation of access to and contact with service professionals.

- Secondly there are the emotional processes and resources which are less tangible. These included the provision of the opportunity to talk about and express feelings about one’s situation and needs and to have these recognised, validated and normalised. Other processes in operation included: feeling less isolated; feeling the value of giving help to others; and better self-recognition and understanding of one’s caring role and needs.

**Explanatory contexts relating to carer support groups**

The studies suggested a number of relevant contextual factors which may influence the achievement of outcomes through support groups. These include characteristics relating to: the type of support group in place; the logistical arrangement of the group; and the carer. Some limited evidence about potential barriers to the achievement of successful outcomes was also noted. The explanatory evidence from three studies [40-42, 44] was of high quality in contrast to that of the other studies. Consequently their findings (which comment principally on the influence of the specific type of support group) should be regarded as more robust than others included here.

**Type of carer support group**

The studies included here covered a range of different types of group. It is difficult to compare these directly to assess the influence of the particular group type because of the different methods and outcome foci of the studies. However, some individual studies covered a number of types of group and these do provide some evidence about how this might affect outcomes. These report on the significance of a number of aspects of group type as detailed below.

- **Support group link to services.** One study [41, 42] covered six different carer support groups. Two groups were off-shoots of particular services: one of a centre for adults with learning disabilities and one of a centre for adults with a physical disability. Another two groups were free-standing, generic groups open to all carers. The final two groups were free-standing but for specific groups of carers: one for carers of stroke patients and one for ethnic minority carers caring for children and young adults with special needs, mainly with a learning disability. The study found that there was a strong emphasis upon informational outcomes amongst all the groups. The free standing groups placed a strong emphasis upon emotional support and encouraging carer self-identity in contrast to a moderate and low emphasis upon these respectively in the two service linked groups. Unsurprisingly emphasis upon contact with service providers was greatest in the two groups directly linked to services.

- **Specificity of group membership.** This study [41, 42] also found that the emotional support provided in the groups focused on a particular type of carer seemed to be more intense than in other groups. There also seemed to be the strongest emphasis upon the social side of the groups here. Several
carers stated that they wished to talk to other carers looking after people with a similar disability because they felt they would understand their experiences best. The same study also found that the similarity of the characteristics of other group members might influence carers’ decisions about whether to join the group. The group members and worker in the ethnic minority group shared a common language but efforts to recruit carers from other ethnic minorities to join this group had been unsuccessful. A member of a generic group commented that a few relatives of adults with mental health problems had attended a meeting but had decided it ‘was not for them’. Another study [40] also noted that about a quarter of the male attendees thought groups might be less useful to men because there tended to be considerably more female participants than male. However, one group had overcome this by having a male section.

- Professionally facilitated or peer-led. One study considered the role of professional input to the six groups it focused upon in some detail [41, 42]. This found that all the carers felt the group would be less effective without professional support. Some specifically said that they felt the social worker enabled carers to understand developments in community care policy and practice. Some also expressed the view that the professional welcomed new carers and encouraged everyone to participate. They also found the workers’ focus and objectivity beneficial to the group. Another study [38] reported that carers found it helpful to have input from staff who were entirely separate to those involved in the care of the person they cared for because this helped carers to feel supported themselves.

In contrast, another study [44] focused specifically upon self-help groups for carers where there was no professional input. They reported that for some carers, the self-help group was important because they had lost their trust in the ability of services and professionals to address their needs and those of the person they cared for. The group helped some of them to challenge service providers about their provision and to feel more confident about these negotiations. In addition, views were expressed that the self-help group enabled a more honest exchange of situations and emotions than might be available in a professional setting. It was felt significant that relations were based upon reciprocity and equality. It was suggested that carers might feel relatively powerless with a professional leader.

- Length of time established. One study [43] considered two carer support groups based within a health unit. One had been meeting for six months and the other for eight years. The authors noted that certain outcomes were only identified in the group which had been established for eight years and not in the other. These outcomes were: increased self confidence; consideration of one’s own needs outside caring; and a focus upon lobbying for change in service provision.

The logistical arrangement of support groups

The studies contained some limited and inconclusive evidence about the potential significance of the logistical arrangement of support groups.

- Regularity. There was some feedback in a study of a monthly support group [38] that carers would like to meet more frequently. However, another study
[37] reported that 93 per cent were happy with a monthly meeting and 7 per cent would have liked to have had a second meeting.

- **Topic coverage.** One study [37] reported carer suggestions to increase the variety of speakers talking about specific illnesses.

- **Provision of interpretation.** In a study of a support group for Asian carers [37], approximately a quarter felt that the simultaneous interpreting needed to improve when invited speakers were speaking in English.

- **Timing.** One study of a support group for carers of children staying in a mental health hospital unit found that it was difficult to identify a good time to hold the group [45]. It had to be late enough for parents to attend after work but was therefore outside professionals' normal working hours. The group partly took place during visiting hours but this meant that some did not attend because of loss of contact time with their child.

Relationships between carer characteristics and support group outcomes

There was some limited explanatory evidence about how carer characteristics might influence the outcomes achieved through carer support groups. Further research on this would be useful.

- One study [38] reported that it seemed that people who had been caring for more than ten years and who had therefore probably adjusted more to the role found the support group most helpful (in contrast to those who were quite new to the role).

- One study [40] found that previous experience of caring (and hence knowledge about caring) might limit the perceived informational benefits of a support group.

- As noted previously [44], carers who have negative feelings about service providers may benefit particularly from a self-help group.

Contextual barriers to support group outcomes

Some studies also suggested some specific contextual factors which could potentially hinder the achievement of outcomes.

- One [38] found some limited evidence that a support group might not lead to benefits if negative feelings about the difficulties of the person receiving care were overwhelming the carer.

- Two studies [38, 45] reported some reluctance to attend because carers did not necessarily want to share painful experiences with others.

- One study [39] reported that just over half of the staff involved occasionally felt that their skills or knowledge were not sufficient to meet the needs of the carers.
Summary of findings about carer support groups

Outcome findings

The majority of carers were satisfied with carer support groups. A wide range of types of information and advice appear to be gained both from the input of professional group leaders and other carers to the group. This may be particularly useful for some Asian carers who find it difficult to access this type of information in a language they can understand elsewhere. The evidence also suggested that improvements to emotional well-being were achieved principally through the mutual support that carers provided to each other within the groups, but also through the development of confidence and a positive self-identity as a carer. There was also evidence of the achievement of social support in terms of meeting others, building friendships and participating in social activities. Some limited evidence suggested that support groups can also have outcomes in terms of facilitating access to and improving relationships with service providers. The weak quality of the evidence (which was based solely upon cross-sectional and qualitative data) in terms of outcome measurement means that it is not possible to conclude about the extent to which these outcomes are achieved for carers through carer support groups.

Explanatory evidence

The studies suggested that the mechanisms underlying support groups included the quite tangible provision of resources, namely: information and advice; friendships and social opportunities; and the facilitation of access to and contact with service professionals. In addition, improved well-being may be explained by the occurrence of emotional processes including the expression, recognition, validation and normalisation of feelings and situations related to caring. Carers may also feel less isolated, value providing help to others and develop a better self-awareness of their role and needs.

The studies also suggested a number of explanatory contexts that may influence group outcomes. There was relatively high quality evidence that the type of group can be quite significant (although this does rely upon only a small number of studies). Groups which were directly linked to another service (for example, a day centre) tended to focus more on outcomes related to links with the service, whereas free-standing groups provided a greater focus upon emotional support. There was also evidence that groups aimed at carers of a particular type (for example, those caring for people with a mental health difficulty) provided greater emotional and social support to members. Interestingly, there was evidence that members of professionally facilitated support groups may place particular value on the professional input received, but equally that members of peer-led groups may feel there is benefit to the self-help structure and prefer not to have professional input. It would be useful to have further research to explore the complexities of this. There was also weak evidence that the length of time for which the support group had been operating might also be influential. There was some limited and inconclusive evidence about how outcomes might be influenced by logistical factors concerning the operation of the groups (for example, regularity of meetings, topic coverage, provision of interpretation and timing) and carer characteristics. However, further research would be needed to consider the influence of these more definitively.
3d. ii. Stress management, coping and counselling programmes

The interventions evaluated in this section are distinguished from the support groups considered in the previous section by their relatively tight, defined structure and their content. They have been developed principally within health services and are tailored to the needs of carers of people with particular types of condition. The interventions generally offer some information and education about the relevant medical condition. However, they go further than the education interventions considered elsewhere by having a particular focus on the development of stress management techniques and coping strategies for carers. They use various approaches such as counselling, problem-solving and cognitive behavioural therapy to achieve this. They potentially also focus upon the behavioural management of the relevant condition. In some cases, they may have originated out of efforts to improve patient symptoms through enhancing the care they receive and/or their wider social environment. They are often referred to as psychoeducation or psychosocial interventions. Some are delivered in a group format and others on an individual or family basis. They are generally delivered through a fixed number of sessions each covering specific content, although a more tailored approach may be taken with those delivered on an individual rather than group basis.

There is quite a substantial body of evidence on these types of intervention. The studies identified for this review can be categorised according to the medical condition with which the intervention was concerned.

- **Schizophrenia.** Three studies [46-49] focused upon psychosocial programmes for carers of people with schizophrenia. One was a randomised controlled trial of moderate quality of an individually-based programme [46, 47]; one a randomised controlled trial of strong quality of individual family sessions followed by a group programme [49]; and one used uncontrolled longitudinal outcome measurement plus a cross-sectional survey to evaluate a group programme [48].

- **Dementia.** Six studies [50-55] evaluated interventions for carers of people with dementia. These included: a randomised controlled trial [50]; two controlled longitudinal studies [53, 54]; two uncontrolled longitudinal studies [51, 52]; and a cross sectional survey [55]. All of these evaluated group based interventions except for two [50, 53]. One study [54] specifically compared the outcomes of a problem-solving group focused upon development of ways of coping with an information-based group (such as those covered in section 3e. i. on educational programmes).

- **Conditions requiring palliative care.** One study [56, 57] used controlled longitudinal outcome measurement plus qualitative research to evaluate a structured group programme for carers of people attending palliative care.

- **Stroke.** A cross-sectional survey and qualitative evaluation were used to explore a structured psychoeducation group for stroke carers [58].

- **Parkinson’s Disease.** There were two studies of interventions for carers of people with Parkinson’s Disease. One was a randomised controlled trial of individual cognitive behavioural therapy [59]. The other used uncontrolled longitudinal outcome measurement plus qualitative feedback to evaluate a group-based intervention [60].
• **Head injury.** A randomised controlled trial was conducted of an educational training programme of eight sessions run in separate groups for people with head injury and their carers [61].

As noted these interventions have been principally developed and delivered within the health service and accordingly they have also generally been evaluated by health care researchers. Following the dominant tradition in this area of research, they tend to focus upon outcome measurement. Many of the studies included here therefore are randomised controlled trials or otherwise offer longitudinal outcome measurement. Some still received weak overall quality ratings because of flaws in the execution of these designs. For example, in some cases, the samples were unlikely to be representative of the target population or there were significant differences between the intervention and control group prior to service receipt. However, the designs still offer some insight into change over time and/or for comparison groups.

There was relatively little explanatory evidence provided by these studies. This evidence was also not highly rated in terms of quality with the exception of the study considering an intervention for carers of people attending a palliative care service [56, 57].

**Outcome findings for stress management, coping and counselling programmes**

These studies included consideration of satisfaction and the number of carer needs met. Some also considered the outcomes that these interventions might be expected to produce in a relatively direct and immediate way, namely, greater knowledge and use of particular stress management or coping techniques. However, the main outcome focused upon by most of these studies is emotional well-being. There is also consideration of social support provided by these programmes. Finally, a summary of reported outcomes for the person requiring care is given.

**Satisfaction with stress management, coping and counselling programmes**

Some studies included findings about participant satisfaction [48, 51, 54, 55, 58, 60]. The majority of participants were satisfied with the interventions which were variously targeted at carers of people with schizophrenia, dementia, stroke and Parkinson’s Disease. The study comparing an information-based group and a coping and problem-solving group for carers of people with dementia [54] found high levels of satisfaction amongst members of both groups with no significant difference between these.

**The resolution of carer needs through stress management, coping and counselling programmes**

One study [46, 47] evaluated an individually based psychosocial intervention for carers of people with schizophrenia which was based upon a model of addressing identified carer needs. Fourteen potential carer needs or problem areas were considered covering: support, information and liaison; coping with symptoms; relationships; hardship; and negative emotions associated with the illness. Outcome
assessment at six months [46] showed that the number of problems decreased to a significantly greater extent in the intervention group than in the control group. Although the study acknowledged that not all needs were met in the intervention group due to time constraints. However, at twelve month follow up [47] the difference between the intervention and control groups in the number of carers' needs which had been met was not significant. The post-intervention difference was not maintained. There was a tendency for all need areas to reduce over time in both groups. This suggests that this was caused by factors other than the intervention.

Knowledge outcomes from stress management, coping and counselling programmes

As noted, one aspect of these interventions is to provide information and education about the relevant medical conditions and as such, improvements in knowledge might be expected as an outcome. Improvements in knowledge were found in studies of interventions for carers of people with schizophrenia [48], dementia [51, 52, 54, 55], Parkinson's Disease [60] and of users of palliative care [56, 57]. The findings of two studies [48, 54] are more reliable as they are based upon pre and post measurement of knowledge rather than the retrospective self-assessment of change in knowledge used in the other studies. The evidence identified specific improvement in knowledge about: the condition [48, 54, 56, 57]; ways of caring [51, 56, 57]; stress and techniques for dealing with this [52]; and support services [51, 56, 57]. There was no significant difference in the knowledge gains from an information-based group compared to a coping and problem-solving group for carers of people with dementia [54]. A small scale study of a dementia carer psychoeducation group [55] showed that the proportion of participants who felt they had gained new information from the programme varied by individual session.

Behavioural change from stress management, coping and counselling programmes

Some studies provided some evidence about outcomes in terms of the types of behavioural change these interventions seek to achieve in order to improve carer well-being. The findings are detailed below. These are mixed. Those with the most rigorous designs using randomisation and validated measures of coping do not provide any evidence that these interventions enhance this. Further evidence would be needed to assess this more definitively.

- The evaluation of the Parkinson’s Disease education programme [60] reported that 80 per cent of participants felt they handled problems caused by the condition better after the intervention.
- A small scale study of a dementia carer psychoeducation group [55] reported that some group members had made changes as a result of attending to look after themselves better including taking time for themselves away from caring. A small scale evaluation of a stress management programme for dementia carers [52] found that, one month after the intervention compared to beforehand, participants had better scores on: ability to assess own strengths and needs; and ability to make requests. However, there were worse scores on: ability to say what you mean; finding it easy to say no and negotiate; and ability to deal with criticism.
- One study [54] compared the use of three types of coping amongst dementia carers who attended an information-based group and those who attended a problem solving style coping group. They found a significant increase in the use of problem solving as a method of coping in both groups and no significant difference between groups. This is surprising but, as the authors
note, suggests that other factors, for example, perhaps the contact with professionals explains this rather than the specific focus of the group. Both groups also showed a decrease in ‘distancing’ (where a person distances themselves emotionally from a problem) overall, although the coping-based group showed greater use of this immediately following the course than the information-based group. For ‘acting out’ (the use of displacement activities, for example, taking out one’s feelings on someone or something else) between the first and second session there was a tendency for carers from the coping-based group to do more of this, whilst those who had attended the information-based group stayed at the same level.

- In a randomised controlled trial of a programme for carers of people with schizophrenia [49], no significant differences in coping scores were found favouring the intervention group compared to the control group. However, there was a cohort effect over time for the whole group showing an improvement in effective coping. This raises the question of whether the improvements found in other studies can, in fact, be attributed to the intervention or are a result of other changes occurring over time.

- Similarly a controlled longitudinal study of a group programme for carers of people using palliative care [56, 57] found no significant differences between groups in coping immediately post-intervention or at follow-up. However, the qualitative part of this study suggested that some carers participating in the intervention did feel that their coping skills had been enhanced through gaining a new perspective from the group.

Changes in appraisal of caring from stress management, coping and counselling programmes

Another intermediate step in the operation of these programmes towards improvement in emotional well-being could be a change in carers’ perceptions of caring. Two studies considered this. A small scale study of a stress management support group for carers of people with dementia [52] reported mixed findings about whether carers felt that the number of dementia related problems had increased, decreased or stayed the same since the intervention. The carer burden caused by these was reported to have decreased in the majority of cases. However, a randomised controlled trial of a programme for carers of people with schizophrenia [49] found no significant differences in the appraisal of caregiving (using the Experience of Caregiving Inventory) between the intervention and control groups. There was a cohort effect over time for both the intervention and control groups showing a reduction in the perceived severity of caring difficulties.

Emotional well-being outcomes of stress management, coping and counselling programmes

Most of the identified studies considered whether the interventions influenced emotional well-being. Some details are given below. Two studies of schizophrenia programmes [46, 47, 49] found no change but one (specifically for people at an early stage of caring [48]) did report improvements, although there was no control group to compare this finding with. The two randomised controlled trials of dementia programmes [50, 53] reported some evidence of significant improvements to emotional well-being. A study of an intervention for carers of people using palliative care [56, 57] did not find any statistical evidence of improvements to measures of emotional well-being. However, it did report some qualitative evidence which suggests that the programme did provide some benefits for emotional health. The
studies of interventions for carers of people with Parkinson’s Disease [59, 60] reported significant improvements to various measures of emotional well-being with the exception of depression. There was weak, limited evidence of a beneficial effect in the study of a programme for carers of people with head injury [61]. There was qualitative evidence of a benefit from a group programme for carers of people who had had a stroke [58].

- **Schizophrenia programmes.** A randomised controlled trial of a needs-based psychosocial intervention for carers of people with schizophrenia [46] found that distress scores in both the intervention and control groups showed a high degree of stability over the six month period and there were no differences between or within the two groups (using the General Health Questionnaire (GHQ) and Beck Depression Inventory and Social Behaviour Assessment Schedule D). This was also the case at twelve month follow up [47]. Another randomised controlled trial of a programme for carers of people with schizophrenia [49] also found no significant differences between the intervention and control group for psychological morbidity (using the Clinical Interview Schedule Revised). An uncontrolled longitudinal study [48] did find significant improvements in emotional well-being (GHQ scores). Due to the absence of a control group, it is not clear that this change can be attributed to the intervention. Alternatively the difference could be explained by the fact that this last study was aimed particularly at first episode carers or people who had become carers quite recently, whereas those in the first study [46] were caring for someone with at least a two year history of schizophrenia or a related illness and the other study appears to have been open to people who had been caring for any length of time.

- **Dementia programmes.** A randomised controlled trial of an individually based intervention for dementia carers [50] did find a significant difference at post treatment in favour of the intervention group compared to the control groups both immediately after the intervention and at three month follow-up for emotional well-being (as measured by the GHQ and Beck Depression Inventory). There was not a statistical difference in the mean GHQ score for the intervention group at baseline and after the intervention, but there was a significant reduction in the number of psychiatric cases at baseline compared to immediately after the intervention and at follow-up. Another randomised controlled trial of a programme for dementia carers which incorporated memory management training as well as psychosocial intervention [53] found some evidence of improvements in the emotional well-being of the intervention group (on measures of GHQ and the anxiety and depression sub-parts of the Hospital Anxiety and Depression Scale). (There was also a trend towards improvement on the Beck Depression Inventory, a more sensitive measure of depression.) Another study of two less extensive group programmes for dementia carers [54] (one was information-based and the other focused upon the use of problem-solving) found no significant change in depression or strain over time or between the two groups. Three small scale studies of group programmes for dementia carers [51, 52, 55] found mixed evidence about emotional well-being outcomes.

- **Programme for carers of palliative care users.** A controlled longitudinal study of a psychosocial group for carers of people attending palliative care [56, 57] found that there were no differences between the groups for any of the psychological measures of well-being used (the Zarit Burden Inventory, General Health Questionnaire-12 and State Anxiety Scale Shortened Version)
at post-intervention or follow-up. However, the qualitative data also collected as part of this study suggested some potential benefits to emotional well-being. Carers felt reassured that there were others in similar situations to them and felt that sharing similar experiences helped to validate and legitimise their own feelings. Meeting others also helped to reduce feelings of isolation. Attendance also made some carers feel more valued.

- **Parkinson’s Disease interventions.** A randomised controlled trial of individualised cognitive behavioural therapy for carers of people with Parkinson’s Disease [59] found a significantly larger improvement in mean scores of emotional well-being (as measured by the GHQ, Caregiver Burden Inventory and Caregiver Strain Index) for carers in the intervention group compared to the control group from baseline after three months and maintained at six months. When the component parts of the GHQ were analysed, this finding also held for somatic symptoms, anxiety and insomnia and social dysfunction but not for severe depression. Similarly, changes in depression as measured by the Geriatric Depression Scale were small and did not differ between the two groups. In terms of identified cases on the GHQ, there was a significantly greater reduction amongst the intervention group than the control group at three months, although this was not maintained at six months. The study of a Parkinson’s Disease psychoeducation group programme [60] did not find a significant change in the self-rating depression scale. However, it did report a significant improvement using a visual analogue mood barometer immediately following each individual session except for one focused upon information. It was noted that some participants became angry and upset (discussing possible barriers in information search) because they felt they were, or had been in the past, both under-informed and ignored by healthcare professionals.

- **Head injury programme.** The study of an educational training programme for carers of people with head injury [61] found some weak evidence of improvements in emotional well-being. There were no significant differences for either the intervention or control group in the mean scores of the anxiety or depression parts of the Hospital Anxiety and Depression Scale. There were improvements on all parts of the General Health Questionnaire for the intervention group but this was only significant for part D (severe depression). This was also significant in comparison to the control group. A slight improvement was also found in self-esteem in the intervention group over time but this was not significant.

- **Stroke intervention.** A small scale study of a small group course for carers of people who have had a stroke based upon coping theory and cognitive behavioural therapy [58] reported positive qualitative feedback from participants. They said that they felt more optimistic and empowered following the intervention.

**Social support outcomes from stress management, coping and counselling programmes**

Some of the interventions were group-based and thus might have been expected to offer benefits in terms of social inclusion and support. Several small scale studies [52, 55, 56, 60] included evidence that participants found it helpful to meet other carers. One randomised controlled trial included some evidence related to this. This evaluation of a programme for carers of people with schizophrenia [49] found no...
significant differences favouring the intervention group on measures of social support (using two summary scales from the Self Evaluation and Social Support Schedule concerned with confidants or very close others and general community support). It may be that these particular outcome measures do not capture the type of social support which the other qualitative evidence suggests that group participants may enjoy.

Wider health outcomes from stress management, coping and counselling programmes

The study of a Parkinson’s Disease educational programme [60] found no significant differences in pre and post intervention outcome measures for health (as measured by EQ-5D).

Outcomes for the person receiving care from stress management, coping and counselling programmes

Some of the interventions evaluated by studies included here also involved the person receiving care and where they did not, it might still be anticipated that changes in carers’ knowledge, approach to caring and emotional well-being might also have an impact upon the person receiving care. Accordingly a number of the studies also report outcomes for the person receiving care. These show various benefits for people with schizophrenia [46, 47], dementia [50, 51, 53], Parkinson’s Disease [60] and head injury [61].

Explanatory evidence about stress management, coping and counselling programmes

As noted previously, the identified studies provided limited explanatory evidence and this was generally weak in quality.

Explanatory mechanisms

The outcomes evidence suggests that the provision of information resources is one explanatory mechanism occurring in these interventions. The theory underlying these interventions also suggests that explanatory mechanisms would include the development of coping skills and strategies and the promotion and facilitation of relaxation and stress management. However, there was only some limited evidence of this [48, 51, 56, 58].

Some of the qualitative evidence also suggests that the following mechanisms may be occurring through these interventions to contribute to well-being.

- For group interventions, the sharing and comparing of experiences [51, 55, 56], the reassurance of knowing others are in similar situations and that others understand your own [56] and the general receipt of social support [56].
- The opportunity to talk and be listened to and to unburden oneself [55, 56].
- The feeling of being valued and that others care about your needs and are interested in your situation and well-being [56].
• The opportunity for a short break from caring whilst attending the intervention [56].

Explanatory contexts

There was some limited evidence that the following factors could influence outcomes: use of a group format; information content; and programme structure.

• Group format. There was evidence from some of the group-based interventions that this particular format offered specific benefits as noted above [48, 51, 56]. However, one study did report that some carers (not all) found group role play in particular a rather daunting aspect of the intervention [48].

• Information content. There was some evidence that the type of information included in the intervention could be significant [55]. One study [48] reported that some carers found some of the information too complex and thought more time was needed to cover the topics. In another study [56], some expressed a desire for more information about the patient’s condition. In addition, some carers thought that it was problematic that the groups included carers of people with quite a diverse range of illnesses as this meant that answers to questions could not always be generalised.

• Programme structure. One study [48] found that carers commonly felt that there should have been more time to cover the topics. A few carers in another study [56] also would have liked more sessions, although overall the majority felt the length and number of sessions were appropriate. This study also reported that the most appropriate number of group members was felt to be twelve. Larger groups might mean less focus on individual problem solving and sharing whilst with smaller numbers there might be insufficient exchange of ideas.

Summary of findings for stress management, coping and counselling programmes

Outcome findings

There was a considerable body of outcome measurement evidence for these types of intervention. These studies generally used designs involving comparison of control groups or longitudinal outcome measurement which offer reasonable quality evidence of this type (even though flaws in the execution of designs meant that overall quality ratings were not necessarily high).

The evidence showed that the majority of participants were satisfied with the interventions. One study considered the number of carer needs which had been addressed. This showed significant benefit for the intervention group immediately after the intervention but this was not maintained at later follow-up. Improvements in knowledge were identified in studies of interventions of this kind for carers of people with schizophrenia, dementia, Parkinson’s Disease and of palliative care users. Between them, these studies reported better knowledge of: the relevant condition; ways of caring; stress and techniques for managing this and coping; and support services. There was mixed evidence about whether these interventions led to behavioural change with some weak evidence of change. However, two randomised
controlled trials found no difference in coping amongst intervention and control groups. One of these also reported no difference in appraisals of caring.

There was also mixed evidence about whether these interventions influence emotional well-being. There was positive evidence of change from studies of interventions aimed at carers of people with dementia and Parkinson’s Disease, some weak positive evidence for carers of people with head injury and qualitative evidence of this for participants in a stroke-focused group. A study of carers of people attending palliative care did not find any statistical evidence of improvement to emotional well-being but did report some qualitative evidence of this. Two trials of programmes for carers of people with schizophrenia reported no benefit to the intervention group compared to the control group. However, one uncontrolled longitudinal study of a similar intervention, but targeted specifically at people at an early stage of caring, did report some evidence of benefits. Some studies also reported some limited evidence that these interventions can provide social support to participants. Many studies also showed benefits to the person receiving care, in particular, for programmes aimed at carers of people with schizophrenia, dementia, Parkinson’s Disease and head injury.

Explanatory evidence

The relatively little explanatory evidence identified about these interventions was generally weak in quality. There was some limited evidence that the explanatory mechanisms at work included: the provision of information; development of coping skills, stress management and relaxation techniques; emotional processes such as having the chance to express oneself and to feel valued; and the exchange of social support. The evidence suggested that the use of a group format, the nature of the information covered and the programme structure might influence the outcomes of these interventions.
3d. iii. Befriending schemes

Only one study of a befriending scheme for carers was identified [62]. This was a randomised controlled trial of a scheme specifically for carers of people with dementia. The randomised controlled trial study design offers high internal validity, and overall the study received a high quality appraisal rating for outcome measurement. The study does not provide any explanatory evidence.

**Outcome findings for befriending schemes**

**Depression**

The study did not find any evidence of better outcomes for depression (the study’s chosen primary outcome measure) for the intervention group compared to the control group at six, fifteen or twenty four month follow-up. This analysis specified the intervention as access to a befriender facilitator and the offer of contact with a trained volunteer befriender. However, only 37 of the 116 carers allocated to the intervention group actually took up befriending support. When the analysis was repeated comparing those who did and did not actually use the befriending support, there was a marginally significant difference for depression in favour of the intervention group at fifteen months. The original analysis was also conducted for spouse carers only but no significant difference was found for this group.

**Other outcome measures**

The study did not find any evidence of benefits for the intervention group compared to the control group for any of the secondary outcome measures: anxiety, loneliness, positive affectivity or global health. No difference was found either in the number of people being cared for who were subsequently admitted to care homes. The economic analysis reported a trend towards increased health related quality of life in the intervention group but this was not statistically significant. (Again all these analyses were based upon a comparison of those who had access to the intervention rather than actual use.)

**Summary of findings about carer befriending schemes**

The one study identified which evaluated a befriending scheme for carers of people with dementia provided high quality outcome measurement evidence. This showed no evidence of a benefit in terms of depression, anxiety, loneliness, positive affectivity or global health. This was based upon analysis which specified the intervention as access to befriending support. Analysis comparing depression amongst those who did actually use the befriending scheme with the control group did find a marginally significant difference in favour of the intervention group at fifteen months. This suggests that further exploration of the intervention could be warranted whilst bearing in mind the relatively low take-up achieved in this case.
3d. iv. Complementary therapies

Two studies evaluating the use of complementary therapies (specifically, chair massage and aromatherapy) with carers have been identified.

The first study [63] evaluated a fifteen minute chair massage offered to carers of patients with cancer within a hospital setting. The research involved mixed methods incorporating: a review of 182 user records of pre and post-massage well-being scores; a pre and post test design with 34 carers using the service in one week with a further semi-structured interview and structured questionnaire to gain next day feedback. The study design does provide for measurement of change in outcomes over time. However, the absence of a comparator intervention or control (for example, a fifteen minute break to the café) means that we cannot attribute causation directly to the massage. In addition, participants were self-selecting rather than necessarily representative of this group of carers. The outcome findings need to be considered with this in mind. The explanatory evidence included in the study was of high quality.

The second study [64] sought qualitative feedback from a small sample of four carers who had been receiving aromatherapy for at least a year. Given the small sample size, the outcome measurement evidence is weak in quality. The study also provides a small amount of explanatory evidence of moderate quality.

Outcome findings for complementary therapies

Emotional and physical well-being outcomes

- The first study [63] found evidence of significant improvement in carer well-being immediately following the massage. Using the ‘feeling good’ visual analogue scale, this was recorded for 97 per cent of carers in the larger records sample analysis and for 91 per cent in the one week survey. Improvements were also seen using the physical and psychological well-being Likert scale scores, with the greatest improvement being on the physical well-being scale. Next day scores remained higher than pre-massage but lower than the immediate post-massage scores. In the next day assessments, carers also reported reductions in levels of worry and improved sleep.

- Qualitative feedback from the aromatherapy study suggested that: relaxation and stress relief; reduced physical stress and pain; easing of sleep; and feeling better able to cope with caring were all achieved. One participant felt that the benefits could possibly last two weeks; two that they lasted a few days; and one that they lasted for the day.

Explanatory evidence about complementary therapies

Explanatory mechanisms

The qualitative data suggested the following mechanisms to explain the outcomes.

- Physical effects. Renewed muscle flexibility and eased pain in participants’ upper bodies was reported through massage.
A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence

- The massage was reported to be relaxing, calming and soothing.
- A small number of participants reported that the massage had promoted a feeling of sleepiness, followed by a decrease in tiredness.
- A few participants also stated that the massage had allowed them to detach from their present circumstances and to receive time and attention alleviating the emotional difficulties they were experiencing in their lives.

When asked what they liked best about aromatherapy sessions, the responses were: combination of touch, smell and aromatherapist as a person (three carers); and lotion used at night (one carer). These factors may contribute to explaining the outcomes achieved.

**Explanatory contexts**

A number of contextual factors were suggested by the data as potentially significant to the outcomes of the intervention as follows. The first three of these appear to be largely a matter of personal preference.

- **Massage pressure and intensity.** Some participants had sometimes desired more pressure or work in a particular muscle area. This suggests that individuals may need and or respond to slightly different approaches to the massage.

- **Duration.** Some would have liked a longer massage but others did not want to be away from the patient for too long.

- **Location.** Some participants would have preferred to have the massage in a quieter, more private setting. However, others liked being able to have the massage near to the patient.

- **Gender.** Female carers expressed a higher level of benefit than men, although they started and finished at a lower point of well-being compared to men (it is not made clear if this difference was statistically significant).

- **Relationship.** Carers who were parents of the patient benefited more than other carers and those who were the partner of the patient benefited the least compared to other carers (again it is not made clear whether this difference is statistically significant).

- **Person delivering the therapy.** The personal characteristics of the aromatherapist were commented upon as part of what participants liked best about this intervention. Unfortunately the evidence does not reveal what these personal characteristics were.

**Summary of findings about complementary therapies**

**Outcome findings**

There was some evidence that both chair massage and aromatherapy can lead to improvements in physical and emotional well-being for carers. However, this evidence relied upon only two studies and the quality of the outcome measurement was weak.
Explanatory evidence

The chair massage appeared to contribute to well-being through relaxation, both physical muscle relaxation and emotional relaxation. There was some evidence that the intensity, duration and location of massage as well as carer gender and relationship to the patient were associated with variation in the outcomes of chair massage. In relation to aromatherapy, it was suggested that the physical aspects of the therapy as well as the personal characteristics of the therapist were important to carers.
3e. Education and training for carers

3e. i. Education programmes for carers

The education programmes identified in this review consisted both of written information and interactive sessions in group or individual formats. In all cases, they were developed specifically for carers of people with a particular medical condition including stroke and aphasia, head injury, dementia and schizophrenia. The interventions generally provided education about the condition and about ways of dealing with possible problems arising from the condition. Some were aimed solely at carers and others were targeted at both the person with the condition and their carer. The findings reported here are for carers only except where it is stated otherwise.

The interventions covered and the study methods used were quite diverse. A summary of the studies is therefore provided below.

- A controlled longitudinal outcome measurement study of an education programme for carers of people with schizophrenia delivered in three ways: through group sessions, information booklets and videos [65].

- A cross-sectional survey gathering feedback about a written booklet about stroke and communication problems for carers of people with aphasia [66].

- Qualitative research focused upon what carers of people with schizophrenia found helpful and unhelpful about a four week family education programme [67].

- Three studies of education programmes for carers of people with dementia. These included: a randomised controlled trial plus qualitative interviews of a six week education programme [68]; a qualitative study of a nine week series of information groups [69]; and uncontrolled longitudinal outcome measurement of six group sessions [70].

- Uncontrolled longitudinal measurement of the outcomes of an information booklet for carers of people with head injury [71].

- Two randomised controlled trials of stroke education programmes for carers and stroke patients. The first intervention evaluated consisted of a rolling programme of an hour long small group educational sessions followed by six educational sessions of an hour following discharge [72]. The second was focused around the process of rehabilitation goal setting using a Stroke Recovery Programme manual and specifically convened meetings every two weeks with members of the patient’s multi-disciplinary team [73].

The majority of these studies used either a randomised controlled trial or uncontrolled longitudinal design to measure outcomes. Whilst the trials only received moderate or weak quality ratings overall because of flaws in their execution, this design does offer relatively good evidence of outcomes. The longitudinal studies also provide a reasonable starting point for considering outcomes given that there is some measurement of change over time. However, the evidence cannot be regarded as definitive.
These studies provided relatively little explanatory evidence. Two provided some explanatory evidence rated as high quality [67, 71] and one some of moderate quality [66].

**Outcome findings of education programmes for carers**

These studies reported on outcomes covering: acceptance of and satisfaction with the interventions; knowledge; behavioural change; emotional well-being; social inclusion; and health and quality of life more generally. Some also reported on patient outcomes. Each of these is now considered individually.

**Acceptance of and satisfaction with carer education programmes**

Two studies of written information (relating to head injury [71] and aphasia [66]) reported high levels of acceptance and satisfaction with the interventions. However, the studies of stroke education programmes found no [72] or small differences [73] between satisfaction levels amongst intervention and control groups. The one study assessed satisfaction with thirteen aspects of support and found a statistical difference favouring the intervention group at six months for satisfaction with the amount of information they had received about allowances; and satisfaction with the amount of contact they had with the hospital after discharge. The lack of difference suggests that perhaps stroke carers found the information provided in the ‘usual care’ model sufficient or found other ways of accessing this if they wanted it rather than through the specific intervention evaluated. In addition, in the first of these studies [72] there was quite a low rate of programme attendance (only 20 of 107 carers allocated to the intervention group attended 3 or more of the 6 outpatient educational sessions) which may contribute to explaining the absence of difference between the intervention and control group.

**Knowledge outcomes from carer education programmes**

These outcomes might be expected to be the primary outcome of educational programmes. A number of studies of education programmes specifically for carers of people with dementia and of people with schizophrenia showed significant and often quite large improvements to knowledge. However, this was not the case for one of the stroke programmes which may be for the reasons suggested above that usual information provision is adequate. Some details of study findings are given below.

- All three studies of dementia carer education [68-70] reported increased knowledge as an outcome via different methods (randomised controlled trial, uncontrolled longitudinal measurement and qualitative feedback). One study [70] showed that the change in knowledge was quite large in size and covered knowledge of dementia and knowledge of relevant support services.
- A controlled study of an education programme delivered in different ways for carers of people with schizophrenia found that knowledge scores significantly increased across all information areas for the total sample following the intervention [65]. Again the change was quite large in size. These improvements were maintained at six month follow up. Individuals receiving education in a group acquired more knowledge overall and particularly concerning hospital procedures than relatives receiving information in booklet and/or video format only. However, these differences by intervention format were not maintained at follow-up. The inclusion or not of homework
assignments did not significantly affect gains in knowledge immediately or at follow up.

- The knowledge improvements of this type of intervention for carers of people with schizophrenia were also supported by a qualitative evaluation of a similar education programme [67]. The most commonly reported benefit (mentioned by nine of seventeen respondents) was increased understanding of schizophrenia. Some further specifics were also given. Nine carers also said that it had helped them to reattribute a problem behaviour to the illness. Five mentioned that it de-stigmatised schizophrenia for them. Three mentioned increased understanding or knowledge about medication and two that the books helped explain illness to significant others. However, some comments about what had been unhelpful about the intervention suggest some barriers to achieving these outcomes for some carers. Comments from three carers were categorised as indicating that the carer denied the problems of the person with schizophrenia. Three carers had wanted more information; three felt the information provided was too pessimistic; and three that the information was provided too late.

- One trial of a stroke education programme [72] found that the intervention group had significantly higher scores on the knowledge of stroke scale than carers in the control group. The other [73] found no significant difference between intervention and control group at both three and six months follow-up but a slight trend for improved median scores for both groups. As noted in the previous section, users of a written booklet about aphasia found this generally useful, but 42 per cent did state that the booklet had not offered new information [66].

**Behavioural change from carer education programmes**

As well as improving knowledge, it might be expected that recipients of educational programmes use this knowledge to change their behaviour in some way. The studies which reported on this found mixed evidence in relation to this as detailed below.

- The study of an information booklet for carers of people with head injury [71] reported that more than half said they had implemented some of the advice given.

- Another study of written information, but for carers of people with aphasia [66], also reported mixed responses as to whether the following changes had occurred: 'made me want to read more'; and 'made me talk about things more'.

- A study of education groups for carers of people with dementia [70] found some weak evidence of small increases in the use of formal services following the programme. Another study of dementia carer information [69] reported qualitative feedback that the groups had provided coping mechanisms and useful links with other agencies (although sometimes interactions with these were quite negative in contrast to the expectations raised in the groups).

- The qualitative study of an education programme for carers of people with schizophrenia [67] reported that a small number of respondents mentioned that it had helped them to modify their communication with the person they cared for (when asked what had been helpful or unhelpful about the programme).

**Emotional well-being outcomes from carer education programmes**
Many of the studies also considered whether carer education programmes led to improvements in emotional well-being. The findings were mixed and not particularly encouraging about the effects of this type of intervention in this domain.

- The study of written information for carers of people with head injury [71] found some weak, not statistically significant, evidence suggesting improvements in emotional well-being for the carers of people who had more recently had a head injury (two to nine months ago). Consideration of the separate parts of the General Health Questionnaire did show a significant reduction in social dysfunction suggesting increased participation in and enjoyment of everyday activities. For the participants who had been caring for someone who had had a head injury longer ago (a year or more ago), the changes were more mixed and none were significant.
- The study of written information for carers of people with aphasia [66] did not find a clear trend of positive or negative responses to the statement about the booklet: it 'made me feel more optimistic'.
- Both trials of stroke education programmes [72, 73] found no difference in emotional well-being for carers in the intervention and control group (as measured by the General Health Questionnaire).
- A controlled longitudinal study of schizophrenia carer education [65] found significant reductions in reported stress (using the Symptom Rating Test), particularly on the anxiety sub-scale used and also similar trends on the depression and adequacy subscales. There were also significant reductions on a fear sub-scale (using the Family Distress Scale), and similar trends for tolerance and impact on family life. However, these improvements were not maintained at six month follow up except for reductions in anxiety. The qualitative evaluation of an education programme for carers of people with schizophrenia [67] reported that a minority mentioned feeling reassured or encouraged and some stated that it helped them to realise that they were not alone.
- A randomised controlled trial of dementia carer education [68] reported a significant improvement for those in the intervention group immediately following the intervention and at follow up for 'negative feeling' (toward the person with dementia), 'life upset' (as experienced by the carer) and carers' perceived stress from dementia related behaviours. A qualitative study of dementia information groups [69] reported some evidence of emotional support and a reduction of isolation. Some also commented on feeling distressed at the beginning of the course when finding out about the seriousness of the illness, yet others would have liked to know more about potential difficulties.

Wider health and quality of life outcomes from carer education programmes

Two studies reported on wider health and quality of life outcomes.

- One trial of a stroke education programme [72] found that carers in the intervention group had lower social-functioning sub-scale scores than controls but expressed concerns about the validity of this finding. No other significant differences were found between groups on any of the SF-36 parts (physical functioning, role physical, bodily pain, general health, vitality, role emotional, mental health).
One study of schizophrenia carer education [65] found statistically significant evidence of improvements in social functioning, specifically in carer independence and prosocial activity, with similar trends towards improvement in social engagement/withdrawal and recreation.

**Outcomes of carer education programmes for the people receiving care**

A few of the studies evaluated interventions which were designed for both people with specific medical conditions and their carers. Summaries of their findings about outcomes for the person with the condition are given here.

- One trial of a stroke education programme [72] found no significant differences on measures of health, function or anxiety and depression for patients in the intervention group compared to the control group. It did find significantly higher knowledge scores and also higher satisfaction with the information received on stroke amongst patients in the intervention group.
- The other trial of a stroke education programme [73] reported slightly different outcomes for patients. They found no significant difference in knowledge scores although there was a trend for improved scores amongst the intervention group as well as a trend for greater satisfaction. They identified a significantly greater reduction in the anxiety score in the intervention group at both three and six months and fewer cases but no evidence of an effect on depression scores. They found no significant differences in function and disability measurements.
- The evaluation of an education programme for carers of people with schizophrenia [67] asked carers what they had found helpful or unhelpful about the intervention in an open question. A minority said that it had increased the sufferer’s understanding of schizophrenia. However, two conversely reported that the intervention had made the condition of the sufferer worse.

**Explanatory evidence about education programmes for carers**

These studies provided some limited explanatory evidence as discussed below.

**Explanatory mechanisms**

Fairly self-evidently, the explanatory mechanism underlying these interventions is the provision of information (about a condition, coping with this and/or service support) to the carer. There was no clear evidence of other mechanisms operating.

**Explanatory contexts**

The evidence suggested that the following contextual factors may be relevant to the achievement of outcomes from educational interventions: topics covered; delivery format; timing of delivery; and presence of the person receiving care.

**Topics covered in education programmes**

Some studies [66, 69-71] reported findings which suggested that the topics covered in education programmes are relevant to their success as would be expected.
However, the extent of the evidence is so limited that it is not possible to offer conclusions about which particular types of content are helpful.

**Delivery format of educational programmes**

Some studies provided some explanatory evidence about the potential significance of the format through which the education is provided.

As noted previously, a controlled study of an education programme for carers of people with schizophrenia [65] found that individuals receiving education in a group (supported by the provision of information booklets) acquired more knowledge overall and particularly concerning hospital procedures than relatives receiving information in booklet or video and booklet format only immediately following the intervention. However, these differences by intervention format were not maintained at follow-up. (The inclusion or not of homework assignments did not significantly affect gains in knowledge immediately or at follow up.) Another study (of written information for carers of people with aphasia [66]) reported that the respondents were fairly evenly split in terms of preferences for information in written, oral or both formats. However, there is some evidence that whilst face-to-face delivery can be beneficial, the written information supporting this can also be important. Two other studies of face to face education [67, 69] reported comments that carers found it useful to have written information as a useful reference and reminder. The study of written information for carers of people with aphasia [66] also found that the majority of carers (77%) went back to read the information booklet again and found it useful to have it for a long time, whereas the remainder used it just once.

**Timing of delivery of education**

Three studies reported some evidence that the intervention may be most effective if it is provided at a relatively early stage of caring.

- The study of written information for carers of people with head injury [71] found that the majority would have liked it at an early stage of caring when their relative was in hospital. The relevance of timing in this study was also reinforced by the identification of some outcomes for the group who received the booklet at an earlier stage of caring which were not observed for those who received it at a later stage.
- The study of written information for carers of people with aphasia [66] found that 54 per cent felt that upon discharge was the best time whereas 31 per cent felt it would have been more useful in the very early and acute stages of the illness.
- The study of an education programme for carers of people with schizophrenia [67] reported that a few carers felt the information had been provided to them too late. The study does not provide details of the stage of caring at which these carers were, although the mean length of the illness for all those being cared for in the sample was five years.

**Presence of the person receiving care**

One study [60] considered preferences about running the programme separately for patients and carers. When first approached about participation, many people commented negatively about patients and carers taking part in separate groups.
However, once the programme was running, both patients and carers felt able to be more open about feelings such as frustration and guilt when their spouse or partner was not present.

Summary of findings about education programmes for carers

Outcome findings

Studies of education programmes for carers provided relatively good measurement of outcomes as they were based primarily upon randomised controlled trial or uncontrolled longitudinal research designs. Satisfaction was reported with two interventions using a written booklet format. However, there were no or small differences in satisfaction amongst intervention and control groups for trials of stroke education programmes. Only one of these showed improvements to knowledge as well. This may be because usual care and information provision for carers of this type is sufficient. There was quite strong evidence of improvements to knowledge via other education programmes, specifically those for carers of people with dementia and of people with schizophrenia. There was mixed evidence about whether these interventions also led to some behavioural change in carers, for example, in coping strategies and services used. Further evidence would be needed to offer conclusions on this. Some studies showed some improvement to emotional well-being but generally changes were not reported. Thus the evidence on this as an outcome of carer education programmes was not convincing. There was some limited evidence that these interventions could also have benefits for the person receiving care.

Explanatory evidence

The explanatory evidence supplied by studies of education programmes was quite limited in its extent. The explanatory mechanism underlying the intervention implied by the evidence was the provision of information resources. Contextual factors that could influence outcomes suggested by the evidence were: the topics covered by the intervention; the format through which the intervention was delivered; the timing of delivery of the information; and the presence or not of the person receiving care. In particular, it seemed that face-to-face delivery may improve the achievement of knowledge outcomes, although accompanying written material appears to be an important support to this. The evidence also suggested that these interventions may be most beneficial at a relatively early stage of caring rather than when the carer has been in their role for some time.
3e. ii. Training for carers

Training may be provided to carers in a wide range of skills related to caring. These are often offered to particular groups of carers given that different skills are required to care for people with different conditions.

The studies of training which have been identified are quite diverse in terms of the nature of the training provided, the target carer group and study design. The studies have therefore been briefly summarised below.

- Two separate, uncontrolled longitudinal studies of memory skills groups for carers of people with dementia as well as the person with dementia [74, 75]. One also included qualitative feedback from the group [74].
- Two separate studies of communication skills training with very small samples of carers of people with aphasia including uncontrolled longitudinal outcome measurement and qualitative analysis of communication skills [76, 77].
- An uncontrolled longitudinal study of training in giving massage to disabled children [78, 79].
- A randomised controlled trial of communication skills training for carers of people with dementia [80].
- A randomised controlled trial of care skills training for stroke rehabilitation [81].
- A report including qualitative feedback about a series of training events aimed at empowering carers through the maintenance of support or lobbying groups or through the development of carers’ personal and interpersonal skills [82]. This study differs from the others in that it does not focus on training in care skills but on other types of skills.
- Two studies by the same group of authors of providing training in care skills for carers of people with eating disorders in two different formats: workshop delivery [83]; and distance learning via DVDs supported by telephone coaching [84]. These used longitudinal outcome measurement and also some qualitative research tools.
- A randomised controlled trial of reminiscence therapy training for carers of people with dementia [85].
- A cross-sectional survey of carers and practitioners participating in a behavioural management training and health education programme for carers of people with schizophrenia [86].

One study [53] included in section 3d. ii. (Stress management, coping and counselling programmes) included a training element and so some information about this is also included within this section of the report.

These studies and the interventions covered are very diverse and this should be borne in mind when considering the findings and the likely outcomes of future training interventions.

The overall quality ratings for outcome measurement in these studies were weak. However, the designs used included three randomised controlled trials and several uncontrolled longitudinal studies. These offer better outcome measurement than qualitative or cross-sectional studies because there is some analysis of change over time and, in some cases, comparison of intervention and control groups.
About two thirds of the studies also provided some explanatory evidence. The quality ratings of this varied. Three studies [76, 83, 84] provided strong explanatory evidence.

**Outcome findings for training for carers**

The following outcomes are considered by the studies of training: satisfaction; increased knowledge; development and application of skills; perceptions of caring; emotional well-being; social support; and some relating to the condition of the person receiving care.

**Satisfaction with carer training**

A few studies reported on satisfaction with the intervention. The findings were largely positive as detailed below.

- The study of care skills training in stroke rehabilitation [81] found greater satisfaction with rehabilitation and instruction in looking after the patient amongst those who received the intervention compared to a control group (at three and twelve months).
- In the studies of training for carers of people with eating disorders [83, 84], the majority of workshop participants found the content and objectives of the intervention at least satisfactory and there were also high levels of satisfaction with the DVDs amongst distance learning participants.
- The report on carer empowerment training found that carers’ expectations were generally met [82]. The exception for some carers was the workshop on identifying carer needs. This was because some carers had done this previously and wanted to move onto other topics. Other carers (who did not already belong to carer support groups or who had only recently identified themselves as a carer) did find this day useful though.
- The majority of carers of people with schizophrenia who received the behavioural management training and health education [86] reported that they found this very helpful.

**Knowledge outcomes from carer training**

A number of the studies of carer training reported analysis of any change in the knowledge of intervention participants, often particularly about the condition of the person they cared for. These showed that some of these interventions do improve carers’ knowledge base as detailed below.

- One study of communication skills training for carers of people with aphasia [76] found that following the intervention, there was better agreement between carer perceptions of conversation abilities and those evidenced by conversation analysis. Thus this suggested better carer understanding of their relative’s communication difficulties. They also reported qualitative feedback that carers felt they had a greater knowledge of the complex nature of aphasia. (However, the authors suggest that the link between understanding and managing communication difficulties is not necessarily straightforward.) The other study of a communication skills training booklet for carers of people with aphasia [77] found little change in the measures formally assessing knowledge about aphasia before and after the intervention. However,
qualitative carer feedback suggested that they did feel they had learnt new things from the booklet as well as having existing knowledge reinforced and validated.

- Both the studies of care skills training for carers of people with eating disorders also reported qualitative feedback of better understanding of eating disorders and strategies for helping the person with the eating disorder [83, 84].
- The practitioners involved in a behavioural management training and health education programme for carers of people with schizophrenia reported improvements in families’ knowledge of the illness [86].
- The qualitative feedback in a report on carer empowerment training [82] included reference to the gaining and exchanging of information amongst carers.

**Development and application of skills through carer training**

Perhaps the most significant and expected outcome of these interventions is the development and use of the skills which the training is intended to provide. Thus the majority of the studies reported on this. These showed broadly positive outcomes, although some skills were not maintained by all carers over time.

- The study of communication skills training for people with dementia [80] found skills improvements. They also showed that there were significantly greater improvements in skills amongst those who received the training via a workshop involving video examples compared to those who were given a booklet.
- One study of communication skills training for carers of people with aphasia [76] found quantitative evidence of significantly quicker resolution of conversation breakdown for two carers (from a total sample of four). In addition, whilst there was no change for the other two carers, qualitative analysis suggested that there had been a positive change in the way they managed conversation breakdown. The other study of a communication skills advice booklet for carers of people with aphasia [77] found an increase in the use of helpful communication strategies by carers. This finding was not statistically significant but the sample size was very small.
- The majority of the carers of people with schizophrenia participating in the behavioural management training and health education [86] reported that they used the various skills taught (making positive and negative comments and requests, listening skills and problem solving skills). Practitioners also reported improvements in the skills of the majority of participants.
- Participants in both studies of training for carers of people with eating disorders [83, 84] reported qualitative feedback of skills development.
- The report of carer empowerment training [82] reported qualitative feedback of skills improvements amongst those on the training day focused on dealing with calls from carers and from another training day in relation to behaving assertively or advocating effectively.
- One of the studies of memory aid groups [75] found that carers were significantly more likely to use active coping techniques (for example, considering several solutions to a problem) after the group than before, but were less likely to do so at follow-up than immediately after the group. Carers were also significantly more likely to use active behavioural coping techniques (for example, talking a problem over with someone) after the group than at
three month follow-up. This suggests that behavioural changes may sometimes not be maintained once the intervention ceases.

- The twelve month follow-up study of training in providing massage [79] also considered this and found that 44 per cent were still using the massage skills they had learnt.

**Perceptions of caring outcomes from carer training**

Some studies showed evidence that training improved carers’ perceptions of: the difficulties of the condition of the person they cared for; the negative aspects of caring; and of their ability to provide care. The findings are detailed below.

- The study of communication skills training for carers of people with aphasia [76] found an overall decrease (although this was not significant) in the carers’ perceptions of the severity of the communication difficulties of the person with aphasia. However, all carers perceived conversation topic management to be more of a problem post-intervention. The authors also reported qualitative feedback that carers valued the reinforcement of what they were already doing to facilitate conversation (also reported in the other study of this type of training [77]) and felt surer of their aims in conversations following training.

- The study of workshop training for carers of people with eating disorders [83] found that at post intervention and three month follow up, there were significant decreases in carers’ perceptions of the negative aspects of caring. There were no reported changes in perceptions of the positive aspects of caring. This study also reported a significant reduction in carers’ perceptions of the negative impact of the eating disorder between baseline and follow-up.

- The study of carer training in massage for their disabled child [78] found that immediately following the eight week intervention, there were significant improvements in carer scores of self-efficacy both in managing the child’s psychosocial well-being and in giving massage. Those who had continued to use the massage at twelve month follow up [79] also showed better scores at that point in time for the self-efficacy measurements than those who had not continued.

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**Emotional well-being outcomes from carer training**

Many of the studies of training measured emotional well-being albeit in a number of different ways. With one exception, these all reported improvements for intervention participants.

- The study of carer training in giving massage to their disabled child [78] reported a significant reduction in carer anxiety and a non-significant trend towards improvement in depression scores immediately following intervention. In addition, those who had continued to use the massage at twelve month follow up had better scores for anxious and depressive mood than those who had not continued [79].
A randomised controlled trial of care skills training for carers of people who had had a stroke [81] found significantly better outcomes for those who received the intervention compared to a control group (at three and twelve months) for: burden (measured by the caregiver burden score); quality of life (EuroQol visual analogue scale); and anxiety and depression (Hospital Anxiety and Depression Scale).

The study of workshop training for carers of people with eating disorders [83] identified significant improvements in emotional well-being (as measured by the General Health Questionnaire-12) at post intervention and three month follow up. However, sub-analysis showed that was true for carers who lived with the patient but not amongst carers who lived separately (the former group were more distressed at baseline). There was also a (non-significant) reduction in this amongst participants in the distance learning study [84] immediately post-intervention. However, there was qualitative feedback of reduced carer stress and improved coping from carers in both studies.

In relation to memory skills training for carers of people with dementia, one small scale study [74] found improvements, no change and worsening of reported carer stress levels following the intervention. Where stress had worsened, the patient’s memory ability scores had also deteriorated which was not the case for others and so this may be relevant. The other study [75] found a significant reduction in stress levels (using a combined measure of stressors including cognitive status, problematic behaviour, loss, role captivity and family conflict) after the intervention compared to before. However, some of these individual stressors (cognitive status, problematic behaviour and family conflict) worsened at three months. This could either be due to the progression of dementia or because the benefits of the intervention were not sustained. They also found that emotional well-being (as measured by the General Health Questionnaire) was highest at three month follow-up compared to both post and pre-intervention.

The study of communication skills training [80] for carers of people with dementia did not find any significant decrease in carer stress. However, a study of training in dementia reminiscence therapy [85] found that whilst carers' general health remained relatively stable, the stress levels for the carers attending the intervention reduced considerably.

Qualitative feedback on the carer empowerment training [82] suggested some potential improvement to emotional well-being through having a day without the worries of caring and through validation that others were interested in carers and their issues.

Social opportunities from carer training

Two studies [82, 83] reported qualitative evidence that carers valued the opportunity to meet others in similar situations.

Outcomes of carer training for the person receiving care

Some studies of training also reported on outcomes for the person receiving care. These were often neutral which may be because training often focuses more on managing a condition than actually trying to change symptoms. There was one exception where a small number experienced a negative response to the new skills developed which obviously needs further investigation.
A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence

- The study of massage [78] identified that a few children had a negative response to the massage and became hyperactive. This shows that this intervention will only work within the context of certain medical conditions where this does not occur. Further work would be needed to identify when and why this may happen. However, generally whilst some children were wary in the first few sessions of the intervention, children appeared to enjoy the massage.

- The studies of workshop training of carers for people with eating disorders [83] did not find any significant changes in symptoms or treatment amongst patients of the participating carers.

- The study of training in stroke rehabilitation care [81] found no significant difference between the two patient groups in mortality, institutionalisation or functional abilities.

- One study of memory skills training [74] found that the majority of the small sample of patients appeared to be coping better.

- One study of communication skills training for carers of people with aphasia [77] found some weak evidence of improvement in communication abilities, but generally showed little difference arising from the intervention.

- The study of dementia reminiscence therapy training [85] showed improvements in functioning for those in the intervention group but lower quality of life compared to the control group, although qualitative feedback from carers contradicts this finding.

- The study of schizophrenia behavioural management training and health [86] found that the majority of patients thought the programme was helpful and used some of the skills taught. Patients did continue to experience a range of symptoms from their illness.

**Explanatory evidence about training for carers**

*Explanatory mechanisms*

The studies suggest that the following mechanisms may explain the achievement of the outcomes of training interventions.

- Perhaps most obviously there is the provision of the resource of learning about a condition and ways to cope.

- In some cases [76, 77, 80, 82], it was also reported that training could reinforce and/or validate carers’ existing knowledge.

- There was also some evidence that a social support resource was provided through the opportunity to meet and discuss problems with others in similar situations [75, 82, 83].

- One study, of massage training, reported that parents enjoyed spending ‘quality time’ with their children as opposed to carrying out necessary tasks with them [78, 79]. In this way, the training had given them a new element to their caring role. This was particular to this study and reflects the fact that the training was in a non-essential aspect of caring.

*Explanatory contexts*

The studies suggested a number of contexts that may contribute to explaining whether or not or to what degree outcomes are achieved.
Training style

The evidence suggests a number of aspects of training style and content which may be relevant to the achievement of outcomes.

- **Training format.** As noted earlier, the study of dementia communication skills training [80] found greater skills development amongst those who received the training via a workshop featuring video examples compared to those who received it in the form of a written booklet. Another study [53] (reported primarily in section 3dii.) found that written training information was only used when professionals actively encouraged carers to do so.

- **Personalisation.** The studies of communication skills training for carers of people with aphasia [76, 77] reported that participants found the use of personalised written extracts of conversation to analyse helpful. The relevance of tailoring training was also suggested by the study of distance training for carers of people with eating disorders [84]. Some had difficulties applying the general knowledge presented on the DVDs to their own personal circumstances.

- **Interactive content.** This was commented upon positively by participants in the communication skills training for carers of people with aphasia [76]. In the distance training for carers of people with eating disorders [84], the role play was highly valued and perceived as necessary to put knowledge into practice. The report of carer empowerment training [82] found both that role play was seen as useful but that it was sometimes felt to be unsatisfactory because of the performance of the partner.

- **Problem solving with others in a similar situation.** This was commented upon positively by participants in the communication skills training for carers of people with aphasia [76], memory skills training [75] and carer empowerment training [82].

- **Use of example material.** In the dementia communication skills study, the use of the video in the context of the workshop was expressed as very helpful qualitatively and this was also evidenced in the quantitative data [80].

- **Use of light-hearted analogies.** In the study of distance training for carers of people with eating disorders [84], the use of animal analogies of different modes of behaviour and communication between the carer and patient was found helpful as a light-hearted way for carers to understand this.

- **Technical issues.** Some participants using the DVD training [84] experienced technical difficulties which could obviously hinder the achievement of outcomes.

- **Allocation of time.** The report on carer empowerment training reported that some carers found a whole day long session too long and also that some carers felt it was difficult to cover everything in the time available.
Timing of training

It was suggested by recipients of the dementia communication skills training that it would be most helpful to receive this training at an early stage of caring to avoid making mistakes earlier on [80].

Response of the person receiving care

In the study of training in giving massage to disabled children [78, 79], a small number of children did not respond appropriately to the massage. In addition, a small number of carers did not continue with the massage over the 12 month period because the child had got older and did not want massage. Thus the wishes and characteristics of the person receiving care may be important.

Time constraints

One study of training in giving massage [78, 79] found that some carers did not continue with the massage (and enjoy the positive outcomes associated with this) because of time constraints. This suggests that sufficient free time may be a necessary context for the success of some training interventions (particularly those which focus upon a non-essential aspect of caring such as this one) in the longer term.

Revision of skills

Some of the outcome evidence [75, 78, 79] suggested that use of the skills learned in training decreased over time. Follow-up or review sessions might be needed to maintain skills and benefits.

Summary of findings about training for carers

The interventions covered in this section and the study methodologies used were quite diverse and this should be borne in mind when considering the findings.

Outcome findings

The outcome measurement evidence of these studies was rated as weak in quality, although some studies did use randomised controlled trial or longitudinal designs. There were generally high levels of satisfaction with the interventions amongst carers. The studies provided some evidence that carer training could validate existing expertise and provide new knowledge and understanding and lead to the development and application of new skills. However, some evidence suggested that the use of new skills may not be maintained over time. In addition, there was some evidence that carer training could improve perceptions of caring and ability to care, improve emotional well-being and provide social support. In most cases, there were neutral outcomes for the person receiving care.
Explanatory evidence

The evidence suggested that the principal mechanisms explaining the achievement of outcomes were the provision of new (and validation of existing) knowledge about particular medical conditions and ways of managing symptoms and behaviours. There was limited evidence that the provision of social support may also be important. The studies also provided some explanatory evidence about contextual features of the interventions that might influence the achievement of outcomes. Training style was highlighted in particular. Aspects that appeared to be beneficial included: interaction, personalisation, problem-solving with others and the use of examples and light-hearted analogies. It could also be important to have sufficient time to do the training and to apply it. The evidence also suggested that the timing of the delivery of training in terms of stage of caring could be important and that some kind of follow-up might be needed to help carers maintain their newly developed skills. The response of the person receiving care to the new skills could also be important.
3f. Employment-related interventions

Only one study has been identified of an intervention focused upon carer employment [87, 88]. Other literature has considered the experiences of working carers and the policies and support offered by employers to carers. However, this has not been included here as it did not fit the criteria of this review.

The study [87, 88] evaluated a project to support non-working carers into employment (as well as people with disabilities). The project was delivered through one project development worker overseen and supported by a partnership of private, public and voluntary sector agencies in Sunderland. It offered clients: identification of suitable job opportunities and work related training courses and/or placements; guaranteed interviews; help with application forms and interview techniques; transport and accompaniment to interviews; benefits advice; training; and a central link with other agencies or providers. Attempts were made to tailor support to the individual.

The quality of this evidence in terms of outcome measurement has been given a weak rating because there was no comparison group or consideration of confounding factors. The evaluation provided a considerable amount of explanatory evidence. However, the findings are mainly presented together for carers and disabled people who used the programme. Unfortunately therefore little can be reported specifically about explanatory mechanisms or contexts in relation to carers.

**Outcome findings for employment-related interventions**

The evaluation reported that fifteen out of twenty-eight carers who were supported by the programme secured employment over the two year project. This was fewer than the project targets but was judged a success nevertheless as clients had been less work-ready than anticipated when support was provided. This initial limited evidence suggests that this type of intervention may be worth exploring further.

**Explanatory evidence about employment-related interventions**

Qualitative feedback from the project development officer delivering the project included the following points specifically relating to carer participation.

- She found that the participating carers often lacked confidence and self-esteem, and had emotional problems. It was therefore important not to put carers forward for interviews too early since apparent failure at an interview could then reinforce these issues.
- Carers could also be quite restricted in the hours they could work which limited available job opportunities. In addition, she felt that if carers returned to work on a part-time basis or within an organisation with flexible working arrangements they were more likely to be able to balance employment and caring responsibilities and thus for it to be a success.
- Carers also sometimes had difficulty returning to employment if there were problems in securing appropriate services and support for the person receiving care when they were at work.
Summary of findings about employment-related interventions

Outcome findings

There was outcome measurement evidence (of weak quality) that this type of intervention may help carers to gain employment suggesting that it may be worth exploring this further.

Explanatory evidence

There was limited evidence (of weak quality) that the following may influence the achievement of outcomes via carer employment projects: sensitivity to the emotional needs and situation of participating carers; the local availability of work on a part-time basis, for certain hours or on a flexible basis; and the appropriate provision of support services for the person receiving care.
3g. Carer breaks

This section covers evidence on interventions designed to give carers a break from caring [89-113]. These interventions achieve this through the provision of alternative forms of care for the person the carer supports. They may take various forms and may be targeted at people with specific conditions. Interventions were only included if one of their primary aims was to provide a break for the carer (rather than doing this incidentally, for example, when the person receiving care received specialist rehabilitation services). However, they may also have had other accompanying primary aims concerned with the services directly provided for the person receiving care.

- Some studies provided evidence about a range of forms of breaks. Some were focused upon carers of any type [89] and others upon carers of people with dementia [91, 97, 101, 111] or carers of adults with learning disabilities [95].

Others focused upon the following specific forms of alternative care provision.

- **Short stay residential care** (typically periods of one to two weeks). In the studies included, these were all provided by the health sector, commonly a hospital. These were targeted either at people with dementia [96], elderly people with other conditions requiring care [90, 94, 102, 109] or palliative care users [107]. One study considered carer breaks achieved through holidays for adults with learning disabilities [99].

- **Short stays in family-based care.** These were typically of one to three days. The studies identified of these were focused upon the placement of adults with learning disabilities [98] and children with learning disabilities [108]. Another study considered short breaks with families for children with autism but did not specify the length of these breaks [105].

- **Overnight care.** Two studies evaluated interventions providing overnight care for people with dementia [110, 113]. Care was provided from one evening to the following morning for up to four nights a week.

- **Day care.** Two studies evaluated the use of day care centres. One focused specifically on a centre for younger people (aged under 65) with dementia [106] and the other on the use of a number of local day hospitals for elderly people [112].

- **Sitting services.** Four studies evaluated the use of a sitting service where a care worker provided care within the home for a period of a few hours, effectively replacing the carer during this time. Two were provided for elderly people with various care needs [93, 100] and two specifically for people with dementia [103, 104]. Three of these were provided by voluntary sector organisations [100, 103, 104]; the provider of the other is not specified [93].

- **Carer holidays.** One study evaluated a one week holiday for carers at a holiday centre with or without the person they supported [92].

Sixteen of these studies are based upon either a cross-sectional survey or qualitative interviews. These are therefore classed as weak in quality in terms of measuring
outcomes across a carer population. Seven used an uncontrolled longitudinal study design and thus offered some analysis of change in outcomes over time. An additional two studies also used a control group. These thus offer a better indication of outcomes, although their overall quality ratings were still weak.

Some of the studies provided some interesting explanatory evidence, although the quality of this is also variable. Certain studies offered high quality explanatory evidence [89, 97, 98, 102, 106].

**Outcome findings for carer breaks**

The studies of carer breaks included assessment of outcomes for carers covering: satisfaction; the achievement of a break, rest or relief; emotional well-being; physical health; social inclusion; and the ability to continue caring. They also often reported upon outcomes for the person receiving care which was important given that this type of intervention necessarily involves direct support for this person as well as the carer.

**Satisfaction with carer breaks**

Generally studies which reported on satisfaction found that the majority of carers were satisfied with breaks provision [92, 98, 100, 101, 103, 107, 108, 110]. These covered some sitting services, day care, residential care, night care and carer holidays. Satisfaction was expressed both with the organisation of services and with the provision for the person receiving care. However, some dissatisfaction was expressed (or at least, suggestions for improvements were made) with respect to a number of factors in some cases, for example, the flexibility of the service and quality of the care provided. These factors are detailed in the explanatory evidence discussed at the end of this section about carer breaks. Some evidence about relative satisfaction with different types of breaks service, for example, sitting services or short-stay residential care is also given in the explanatory evidence.

Some studies [92, 97, 98, 101] reported carers' general views of whether the service had been beneficial to them. These found that the majority of carers felt the service had provided some benefit to them.

A number of studies reported findings that satisfaction levels varied according to particular characteristics of the carer or the person they were caring for as detailed below.

- One study [95] found that mean satisfaction scores with the expertise of staff and standard of care received in short-stay residential care were above satisfied for carers of people with mental health difficulties and physical disabilities but not for those caring for people with behavioural problems. For satisfaction with admission and discharge procedures, carers of people with mental health problems were satisfied but the mean score of the other two groups was between ‘unsure’ and ‘satisfied’. The study's findings on day care found that mean satisfaction levels for the expertise of day care staff and also the input of other professionals within the adult centre (speech and language therapist, occupational therapist and physiotherapist) were also consistently slightly lower for those with behavioural problems than for those with physical disabilities or mental health difficulties.
Another study [108] of family placements for children with learning disabilities noted that carers of children with low physical capacities were significantly more likely than carers of more able children to perceive the services as useful. In addition, carers who reported their children as having frequent challenging behaviour were less likely than others to see the service as accessible or available at short notice.

A study of breaks for carers of people with dementia [97] noted that daughter carers, in particular, had very positive reactions to residential care breaks.

One study [101] found high satisfaction levels and perceived benefit for a range of breaks services amongst carers of people with dementia. This study also explored the relationship between this and social support. It found that the number of people in a carer’s support network and the amount of ‘affectionate support’ (representing the availability of others to offer the carer affection) explained 19 per cent of the variance in overall satisfaction with breaks services. Greater social support of this kind led to higher satisfaction. The number of people in the carer’s support network was also related to the degree of perceived benefit of breaks services for both the carer and the person receiving care (a higher number led to greater perceived benefit).

**Outcomes concerning the achievement of a carer break**

Most studies reported on the achievement of a break itself for the carer. In addition, the evidence showed that a break could enable carers to achieve a number of different things including having a rest from caring, having time for themselves, doing everyday jobs, enjoying social activities and going to work as discussed below. These outcomes were generally reported across the studies of the various different types of break. However, going on holiday and better sleep were unsurprisingly reported on predominantly by studies that involved breaks including overnight care. The limited evidence of support for employment was only mentioned in studies of either regular day or overnight care.

- **Rest and relief.** Many studies reported that the intervention enabled carers to have some rest and some relief from caring [89, 90, 92, 98, 102, 105-110, 113]. This included reference to notions of ‘batteries being recharged’, emotional or physical energy reserves being topped up and achieving relaxation. One study [97] reported that the benefits of day care often lasted beyond the immediate break. The elderly people were often tired on return so the carer had a peaceful evening or even a full night’s sleep.

- **Sleep.** The two studies of overnight care [110, 113] both reported qualitative evidence that a majority of carers said the break enabled them to have a good night’s sleep. One [113] suggested that the positive impact on sleep was also felt on nights when the person with dementia was at home. Studies of residential care also reported qualitatively that this provided an opportunity to get a good night’s sleep [102, 109]. Another study used quantitative outcome measurement to look in more detail at the effect of residential care on carers’ sleep [96]. This showed that carers’ total sleep time per night increased significantly and subjective sleep quality improved during the break. Both outcomes returned to levels not significantly different from baseline at follow up after the break. These effects were only found for carers who normally did not share a bedroom with the person with dementia. However, carer sleep efficiency (the percentage of time in bed spent asleep) showed no
significant change between baseline and during the break but showed a significant reduction at follow-up. It seems likely that this was due to subsequent deterioration in the person with dementia's sleep patterns as a result of the break (discussed later in the outcomes for the person receiving care section). Thus potential benefits during the break need to be considered in light of possible deterioration afterwards. The study does not come to a definitive conclusion about the overall impact of the break on sleep.

- **Time for themselves.** A number of studies reported the benefit carers felt of generally having some time for themselves during the break [99, 103, 105, 109, 113].

- **Everyday jobs.** Several studies reported that carers were able to do everyday household jobs, for example, cleaning, cooking, shopping and gardening during breaks that were difficult to fit in at other times [89, 97, 98, 102, 107, 111, 113]. One study [97] also noted that some carers undertook more substantial tasks, for example, decorating or spring cleaning whilst the person receiving care stayed in residential care for a short period. Time for these tasks could be perceived by carers as equally or more helpful than taking part in more seemingly enjoyable activities such as holidays [107].

- **Social activities and interests.** Breaks were also found to offer carers the benefit of time to pursue social activities and interests [97, 102, 104, 108, 110, 111]. This included spending time with other family and friends [98, 105, 107-110], going out [102, 109], going on holiday [98, 102, 107, 109] and generally having fun [92].

- **Support to maintain paid employment.** There was a little evidence that breaks could play a role in enabling carers to maintain paid employment. In a study of night care [110], some carers reported using the break to enable them to go to work on a night shift. A study of day care [106] also reported that this service helped some carers to continue working.

- One study [107] reported that in a few cases, expectations of a break were not met because the time spent was not enjoyable, involved other commitments or the carer was worrying about their situation.

**Emotional well-being outcomes from carer breaks**

The studies provided some measurement of outcomes concerning emotional well-being. Details of this evidence by type of break are given below. There is very little robust quantitative evidence of improvements to emotional well-being over time. However, it may be that deterioration in the condition of the person receiving care and other factors may influence this. The studies included here do not adequately control for these factors. The evidence also indicates that changes in emotional well-being are quite mixed amongst carers again suggesting that other factors may influence this. Qualitative evidence does suggest that carers perceive that breaks have a beneficial impact in terms of their emotional well-being though and so this intervention should not be dismissed in this outcome domain. Particular themes elucidated in qualitative evidence included facilitation of a sense of normality, freedom, peace of mind and relief. However, there is also quite consistent evidence of some negative feelings related to the use of breaks services including anxiety about the experience of the person receiving care during the break and particularly guilt.
Mixed breaks services. One study of breaks for carers of people with dementia [97] found that irrespective of service use, emotional well-being (as measured by the GHQ) remained stable and occasionally worsened over a period of a year. The authors commented that this is not that surprising given that the condition of many of the people receiving care deteriorated over the year and the amount of services used did not change substantially.

Short stay residential care. A study of residential care for elderly people [94] also found no change in carers’ emotional well-being (as measured by the GHQ) before and after the break. However, they did find a small but significant reduction in depression but also a similarly significant increase in social dysfunction between the measurements. Another study of residential care but for palliative care users [107] reported mixed findings on carer stress (Relative Stress Scale Inventory) with some carers showing improvements, some no change and some deteriorating. A study of short stay residential care for people with dementia [109] found that all carers except for one thought the admission was helping them to relax. However, the quantitative outcome measurement did not show any significant difference before and towards the end of the break on depression levels or morale levels. Yet, there were various weaknesses in the study design that made it difficult to detect a statistical effect, for example, small sample size. Other studies suggest that even if quantitative outcome improvements are not apparent over time, qualitatively carers feel they have benefited. One study [90] reported that about two-thirds (67%) of the sample felt the break had helped their psychological well-being. Another [102] found that the majority of carers thought that without the service they would have experienced more stress and lower quality of life.

Carer holiday. A majority of those on the carer holiday [92] retrospectively reported positive benefits to emotional well-being include stress relief and feeling appreciated.

Overnight care. A study of night care [110] found that the majority (89%) reported feeling better the day after their relative had attended the night centre. A much smaller proportion (38%) said that the benefit persisted after three days. This study also analysed quantitative measures of emotional well-being (using the GHQ, Relative Stress Scale and Beck Depression Inventory) and found that mean scores improved for carers of new attendees during the first month of use. In addition, there was evidence of greater change amongst this group than a control group of carers of regular attendees. The other study of overnight care [113] found no significant differences on the carers’ ratings of anxiety levels between any of the time periods assessed (within first week of attendance, after six weeks, twelve weeks and six months). However, qualitatively the majority expressed positive feelings about their relative or friend attending the service including feeling relief, happiness and being comforted.

Day care. A cross-sectional survey evaluating day care [112] found that the majority (88%) felt less anxious and/or more happy and relaxed. A very small number (2%) said that their anxiety had worsened.

Sitting services. One study of a sitting service [93] found that overall scores for emotional well-being (as measured by the GHQ) improved significantly after three months of service use. However, the authors noted that there was a lot of variability in change and that for eleven of the forty five carers in the sample emotional well-being deteriorated. As with other studies though, this could also relate to deterioration in the condition of the person receiving care. Another study [100] found that the strain felt by carers using the service decreased over time whilst that of those
who had chosen not to use the service increased. However, the difference was not statistically significant. Another study [104] reported qualitative findings of peace of mind, ability to relax and the lack of worry when they went out. Another cross-sectional survey of a sitting service [103] found that the majority strongly agreed that the service had given them peace of mind because they knew there was someone they could turn to for help.

The evidence also provides some qualitative evidence of particular themes relating to emotional well-being. Some studies [89, 105, 108] referred to carers enjoying a return to normality and leading a more normal life style during the break. One qualitative study [89] of a mix of types of break reported that a sense of freedom (and similarly independence) during a break seemed to be the most important benefit. This was reported by another study [97]. Other themes reported included relaxation or stress relief [92, 109, 112, 113], happiness [112, 113] and lack of worry or peace of mind [103, 104].

However, there was evidence of carers having both positive and negative feelings about breaks [91, 113]. For example, one study [111] noted that some felt relief at their freedom during the break, but sadness for the spouse who had to use alternative care. Other negative emotions reported included pangs of anxiety [111] including about the care received [107], frustration [111] and most notably, guilt [90, 97, 107, 111, 113] about using breaks provision. One study reported that some carers missed the other person whilst on a break [90]. Some studies found that in a minority of cases, these negative feelings could outweigh any positive impact [102, 107]. One study [102] reported that over half of the sample experienced guilt.

However, this study [102] also noted that this was less likely amongst carers who felt that the person they cared for benefited themselves in some way from the break or who recognised that their ability to continue caring might be negatively affected if they did not have a break. Another study [113] found that different reasons were given for feeling guilty. These included because: the carer felt they could no longer cope on their own; their relative or friend had not wanted to attend the alternative provision; the carer felt relieved; and that they felt they had disengaged themselves from the person they cared for. One study [112] related increased carer anxiety (for a minority) to reluctance on the part of the person receiving care to attend day care provision.

**Physical health outcomes from carer breaks**

Two studies reported on physical health outcomes from carer breaks. One cross-sectional survey about experiences of short stay residential care [90] found that a majority (71%) of carers reported that the break had benefited their physical well-being. A cross-sectional survey of carers using day care [112] found that just over half (56%) reported improvements to their physical health following use of the service.

**Social inclusion outcomes from carer breaks**

It has already been noted that a benefit of breaks is that this can give carers time to pursue social activities and interests. Three studies [103, 104, 112] also specifically reported that breaks had led to some carers feeling less socially isolated. The study of a holiday for carers [92] also noted that this provided an opportunity for some to meet other carers and to make new friends.
Information and advice gained via carer breaks

Two studies [102, 103] also noted that some carers received and appreciated information and advice from the staff they came into contact with through breaks provision.

Impact of carer breaks upon ability to continue caring

Quite a few studies considered whether having a break helped the carer to care and specifically to continue in this role. This evidence is mixed. It suggests that breaks can be critical to maintaining caring situations. However, for some, they may also be the first step towards permanent use of residential care but it is not clear that the use of breaks actually influences this entirely separately from other factors.

Several cross-sectional survey or qualitative studies [89, 90, 102, 109] reported that many carers felt that having a break was critical to enabling them to continue to provide care. Without this, carers thought that the caring situation was likely to have broken down. Two studies of carers of frail elderly people quantified the proportions who felt this as: 76 per cent [90] and 64 per cent [102]. Some studies reported a general feeling amongst carers of being better able to cope with caring due to breaks provision [97, 104, 105]. This was also reported specifically of overnight care [110, 113]. However, quantitative measurement of coping in one of these studies [113] showed no significant differences over time through use of the service.

Some studies considered any relationship between the use of breaks services and the likelihood of the person receiving care entering full-time residential care. One [97] found that this was more likely amongst those who used short-stay residential care to provide a carer break. However, it was clear that this service was targeted upon those caring for the most dependent elderly people for whom this outcome might have been expected anyway. In fact, a regression analysis showed that use of short stay residential care was not significant in explaining entry to long-term care once other factors were taken into account as well. This study usefully highlights that there may be different types of breaks users: those for whom the break enables them to continue caring; and those where the move to long-term residential care is likely anyway and this is a step on the path towards this. A study of family placement schemes for adults with learning disabilities [98] found that the families using the scheme did appear to be more active in exploring future accommodation options for the person receiving care such as residential homes compared to non-service users. However, the proportions doing so were small and the differences were not statistically significant. Again there may also have been confounding factors in operation. A study of overnight care [113] found that consideration of individual cases showed that for some carers, using the service was a first step in enabling them to make the decision to give up the caring role. However, as noted previously, use of the service had enabled others in the sample to continue caring.

Some studies reported that the break could help improve the carer’s ability to care. For example, one [89] suggested that carers sometimes found it useful to learn about different ways of caring from the people providing the alternative care during the break. A cross-sectional survey about day care breaks [112] reported that through use of the service most carers stated that they: understood their relative's problems better (88%); found their relatives' physical problems easier to manage (65%); found their social problems easier to deal with (60%); and found behavioural problems
A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence

Easier to manage (51%). This study also noted that a significantly higher proportion of male carers (75%) found their dependant's social problems easier to manage while only 55 per cent of female carers reported this. A study of family placement schemes for adults with learning disabilities [98] noted some limited evidence from host families that participation could enable carers to see what their child could achieve and to allow them more independence. One specific benefit reported from another study of breaks for carers of people with dementia was feelings of increased patience with the person requiring care [97].

However, the break could cause difficulties in providing care. One study [107] found that this could be because relatives had greater expectations of care after the break or routines had been disrupted. Further evidence which implies that this might be the case is suggested below in consideration of the outcomes of breaks upon the condition of the person receiving care.

**Outcomes of carer breaks for the person receiving care**

The included studies included data on outcomes of alternative care provision for the person receiving care during a carer break covering: satisfaction; change in their condition; emotional well-being and social inclusion; and sleep. The findings suggest that outcomes are quite varied and can be negative and/or positive. It is also worth noting that some carers may not be using these services in the first place because of resistance or concern on the part of the person receiving care. It might therefore be expected that responses tend towards the positive.

**Satisfaction and enjoyment of breaks amongst the people receiving care**

Some studies reported satisfaction on the part of the person receiving care [90, 111]. This was particularly high in the study of holidays for adults with learning disabilities [99] and the study of family placements for adults with learning disabilities [98]. However, some studies reported poor experiences or dissatisfaction with particular elements of care amongst some of those receiving care [90, 97, 102].

One study of short-stay residential care [102] described three main distinct groups of attendees in terms of their perceptions of the service. For about a quarter, it was a positive experience: they enjoyed it. Most had been attending for some time and had built relationships with staff and other users. They also tended to see the admission as an opportunity for medical treatment or re-assessment. A second group (about half of the sample) tolerated the admission as a time-limited experience. They did not feel it benefited them but felt it was helpful for their carers. For the remaining minority, the break seemed to be a very negative experience often causing a reduction in self-esteem. They did not see a reason for admission, resisted this and this often resulted in a deterioration in their relationship with their carer.

**The impact of breaks upon the condition of the person receiving care**

A variety of findings about the impact of breaks upon the condition of the person receiving care were reported as follows.

- Some studies reported worsening in the person’s condition as a result of the alternative care provision. This included: worsening of incontinence [97, 102, 111]; increased confusion [89, 97, 102, 111]; deskillling in activities of daily living [111]; and deterioration in mobility [97, 102]. Evidence from one study
[111] suggested that these effects were more likely following longer admissions (of more than three nights) to short stay residential care. In addition, it found that these effects did not occur for those who had more severe dementia.

- The studies of overnight care [110, 113] did not find any evidence of the stay causing deterioration in the condition of the person with dementia. In fact, nearly a third [110] in one study were reported to have improved behaviour following service use. Other studies reported improved physical well-being for a majority [90, 94] or a minority [102]. This was sometimes enabled through access to health care staff during admission [90]. Greater use of these health care services was associated in this study with greater satisfaction. Some carers saw the opportunity for medical assessment and care as a benefit of the provision [102].

- One study [97] attempted to quantify the proportions who observed improvements or deterioration to conditions. This reported that 30 per cent of carers felt that the elderly person with dementia benefited from short-stay residential care. This was generally if action had been taken to alter medication or to improve the person's sleeping pattern. A slightly higher proportion felt the stays made no difference. One tenth identified that there were advantages and disadvantages. Just over a tenth (11%) reported deterioration in the elderly person’s condition.

Emotional well-being and social inclusion outcomes of breaks for the person receiving care

There was some limited evidence about the impact of alternative care provision on the emotional well-being of the person receiving care. There was more extensive evidence about the potential benefits in terms of social inclusion for the person receiving care as detailed below.

- Some studies reported improved emotional well-being through meeting and forming relationships with other people during the break [90, 102]. However, a minority reported greater depression following admission [90]. This was also reported in another study [102] and was explained as a result of seeing other more dependent patients.

- Explorations of sitting services [97, 104] found that the elderly person often enjoyed the company and social stimulation received from the care attendant. One study [97] reported these types of benefits to 60 per cent of the sample.

- Two studies reported on benefits from day care. One study of day care for younger people with dementia [106] found that all users reported some things they liked about the centre. Some carers felt that the service improved the self-confidence of the person with dementia. Another [97] reported that most carers (about 80%) thought day care benefited their relatives. Benefits included: a change of scene; some company and stimulation; and a small improvement in the person with dementia's mood.

- The studies of holidays for adults with learning disabilities, family placements for adults with learning disabilities, family placements for children with disabilities and short breaks for children with autism [98, 99, 105, 108] all noted a number of benefits to those attending the provision. These included opportunities: to meet and spend time with other people; to take part in different, and often more stimulating, activities than usual; to spend time in different surroundings; to enjoy themselves; and to develop personal and interpersonal skills and confidence. However, a small number of families reported difficulties encountered by their children with learning disabilities on
family placements, for example, relating to the child's difficulty adjusting to a different environment or concerns about the child's health problems [108].

Sleep outcomes of breaks for the person receiving care

One study [96] focused particularly upon outcomes concerning sleep for people with dementia admitted to short-stay hospital residential care. They found deterioration in sleep (in terms of time taken to get to sleep, total sleep per night and night-time activity relative to day-time activity) during the period of admission. These changes were reversed in the follow-up period after admission with one exception. The time taken to get to sleep per night increased further after admission for those who shared a bedroom with their carer.

Explanatory evidence about carer breaks

The studies identified provided quite a lot of explanatory evidence about carer breaks. As noted previously, this was of variable quality with a few studies providing high quality evidence [89, 97, 98, 102, 106].

Explanatory mechanisms

The evidence suggested that there were three main mechanisms underlying the success of carer breaks.

- **Rest.** A break could provide an opportunity for a rest. This could be both emotional (through allowing the carer to experience a sense of normality, freedom and a lack of stress) and physical (through not having to undertake physical caring tasks and through relaxation during the break).

- **Management of daily life.** The evidence suggests that breaks allowed carers to keep on top of things or to manage their every day lives, for example, by giving them time to do household tasks that caring made difficult. There was also limited evidence that they could allow carers to maintain employment.

- **Maintenance and/or development of social interests and networks.** Breaks also benefited carers by giving them time to pursue their own interests and social activities and to maintain and develop social networks including important relationships with other family and friends.

The evidence also suggested some mechanisms which could occur through a carer break which could hinder the achievement of outcomes. In particular, it highlighted the potential for carers to feel guilty or worried about using breaks services because of the reaction or experience of the person they cared for. Another mechanism, reassurance and support from the staff involved (as well as a growth of confidence in the service gained through time and experience) could help to counteract this [89, 97].
Explanatory contexts

The studies included here provided quite a wealth of evidence about contextual factors which could influence satisfaction with and the success of breaks services. However, as two of the more comprehensive studies [97, 102] point out, whilst carers had preferences concerning many of the factors discussed below, they may still have been gaining considerable benefits from less than ideal breaks services. At the same time, the evidence considered here only relates to breaks users and it may be that some of these factors may have stopped others from using these services in the first place.

The explanatory contextual factors are divided into those relating to: the overall type of breaks service; the nature and quality of the provision of alternative care; and organisational factors.

The overall type of breaks service

Preferences between different types of breaks service. A number of studies considered carers’ preferences for different types of breaks services and the reasons for this. These give varied reports of preferences (see below) indicating that it is unlikely that any one service will suit all carers but that a range of services will be needed to meet individual needs and preferences.

- One [89] found the most positive comments for home sitting services because of its flexibility, the fact that the person receiving care did not have to go elsewhere and it was managed in a friendly way. Another study [94] showed a preference generally amongst carers for day care or sitting rather than residential care. One study [91] of carers of people with dementia noted that respondents who had access to night time help found this especially helpful. Another study of views of sitting services, short-stay residential care and day care for people with dementia [97] reported that day care could give the carer more choice about whether to stay at home or go out and it generally gave them a longer break than a sitting service. In addition, some carers felt uncomfortable about having a stranger in their house in the case of sitting services.

- A study [108] of family placements for children with learning disabilities also considered the use and views of other types of breaks service amongst the sample. Short period sitting services were valued for giving short breaks during the day and playschemes for help during school holidays. Some had used short-stay residential care and had valued this if they had been let down by host families or had not been able to get emergency support from them. The study explicitly notes that carers tended to view the different types of break service as complementary rather than as substitutes for each other. However, the family placement scheme was seen as “the most ‘important’, ‘available’, ‘flexible’ and ‘personal’ form of respite for children and their families” [108] (p113).

- Privately organised services. One study [97] noted that issues of timing and introductions were less important to carers who used private sitters as the arrangements had evolved to their specification. The studies in this systematic review include no other references to the distinctive experiences of those who arrange and use breaks services on a private basis but this could be an interesting area for future research.
• **Service location.** Two studies [95, 108] noted that some carers would have liked a more local service. Another study [102] reported that the rural nature of the area they were studying made it difficult for some carers to visit their relative during the break.

The nature and quality of the alternative care provided

A number of studies reported generally that the quality and nature of the alternative care provided was very important to carers (and users) [90, 91, 97, 103, 105-108]. Reassurance and confidence about this could allow carers to relax and enjoy their breaks. This could also prevent feelings of guilt about breaks [102]. Conversely, one of the studies [97] noted that some of the sample had stopped using a breaks service because of concerns about the quality of the care provided. This could be the carer’s own concerns or equally, as noted previously, negative reactions on the part of the person receiving care to the alternative provision. This could have a negative impact on the carer’s enjoyment of and feelings about the break [97, 102]. Another study [102] noted that care quality might be judged both by the local reputation of services as well as actual experience including visits to and observation of the service.

A number of specific factors relating to the nature of the alternative care provided were noted as potentially significant by studies as follows.

• **Provision of care for people with particular condition.** Some studies reported some criticism from carers where provision was not adequate for people with particular conditions including particularly those with behavioural problems [95, 97]. This may be one factor explaining the different satisfaction levels reported earlier amongst carers of people with different conditions. A study of family placements found some dissatisfaction amongst those who had to wait quite a long time for a match. This was generally for specific groups who were harder to place including: those with older children, those with children whose behaviour was difficult to manage or where there were two children in a family requiring placement.

• **Activities and stimulation.** Some studies reported that carers would have liked more or different activities to be available during the break for the person receiving care [89, 91, 95]. In particular, more stimulation was often called for [89, 97]. This could be both mental stimulation and physical activity [91]. In addition, some carers of people with learning disabilities wanted provision for them to be more integrated with others who were more able [95]. One study [97] reporting on day care found that carers were particularly pleased with provision where each elderly person was a member of a small group and had a key worker responsible for them and was busy most of the day, participated in a wide range of activities and was taken out regularly.

• **Personalisation of care.** Some studies reported particular preferences which suggest that carers like care to be personalised in some way. Some carers expressed a desire for continuity in how care was provided on the break compared to at home [107]. This included ensuring that activities such as mobilising the patient continued [107]. One study [89] noted that Black African/Caribbean carers were particularly concerned that care should be appropriate to their specific ethnic and cultural needs. Another study [97] noted that carers expressed greater satisfaction with the quality of care provided through family-based short stays where considerable time had been
spent matching the elderly people and host families. In another study [91] carers generally expressed a preference for specialist rather than generalist care.

- **Provision of health care.** Some studies showed that some carers appreciated care that offered new opportunities for medical care [102, 107] including rehabilitative and complementary therapies [107]. However, this varied and one study [102] found that other carers would have preferred more of a holiday feel to the provision and others were not concerned either way.

- **General environmental factors.** Carer preferences were noted in relation to general environmental factors in terms of: units not being too noisy [95]; providing enough space [95]; having a good atmosphere [89, 107]; offering single rooms [91]; single sex facilities [91]; an accessible layout [91]; and a pleasant environment [91].

- **Staff.** The nature of the staff providing the alternative care was reported as potentially significant in several studies. Carers wanted to feel there were sufficient staff [91, 95, 97] and would also prefer fewer changes in staff and greater continuity [95, 97, 104, 108]. Continuity in staff was seen to be important in order that a relationship could be built between the staff and the person receiving care and to help ensure that appropriate, tailored care was provided [91]. Specific attributes desired included: reliability [97]; personal qualities such as being helpful, approachable, friendly, caring, understanding and sympathetic [91, 98, 112]; and being well-qualified and trained and having expertise [91, 95, 97, 103]. One study mentioned the need for more male staff [95].

- The importance of sufficient and helpful communication with staff was also mentioned [95, 107, 112]. One study [102] noted that carer relationships with staff varied and that carers who did not like or were shy about making contact with staff may have missed out on information and communication that would have been useful. One study mentioned that carers wanted greater clarification about the role of the care attendant and what it was acceptable to ask them to do or not [104]. A study of a family placement scheme for children with a learning disability [108] found that carers valued the information given to them about the family beforehand. They also appreciated that time was allowed to meet and get to know each other and to make the child feel comfortable with the family before the service began properly.

- **Involvement of the carer.** A few studies found that positive involvement of the carer in the service provided to the person receiving care could be beneficial and equally that exclusion or disregard from staff could be unhelpful [91, 97, 102]. Positive involvement included being recognised as the carer [91] and their expert knowledge being recognised and listened to in relation to the provision of care and the preferences of the person receiving care [102]. One study [91] noted that examples of helpful involvement included being given a copy of the care plan, being invited to care reviews and the keeping of a diary for the carer. Some carers still wanted to be involved during the break through visiting [91, 102]. However, some carers also visited out of a sense of obligation and for these, it could be helpful if staff ‘gave permission’ not to visit [102]. This depended on individual preferences.
Support services. There were some brief comments in studies about support services. There was some dissatisfaction about food [90] and lost possessions [95, 97].

Organisational factors

Studies noted a number of factors relating to the organisation of services which could be important to carers.

- **Extent of provision.** It was quite commonly found that some carers would have liked a longer break and or more frequent breaks [90, 94, 95, 97, 98, 102, 104, 107, 109]. Some studies gave estimated proportions who expressed this view including 25 per cent [98], over a third [104] to about half [97]. There were specific reasons for desired extensions in some cases. These included, for example, to have 14 rather than 13 nights to allow the carer to take a package holiday for a fortnight [102], to have a few days after the return from holiday to prepare things [97] and, in the case of a sitting service, to have occasional irregular cover for an evening or family celebration [97]. Some studies [102, 104] noted that carers were often reluctant to make additional requests because they did not want to seem too demanding.

- **Timing of provision.** Studies also often found that the timing of provision was significant to carers. Some would have preferred a break at alternative times to those provided [95, 97, 102]. Some would have accepted fewer breaks if they could have been on more suitable dates [102]. Some expressed concern at the lack of emergency provision [95, 98, 102, 108] and similarly availability at short notice [97, 108]. Sometimes carers just lacked information about emergency provision which could have been available to them [102]. A specific wish for flexibility was sometimes voiced [106]. One study reported a specific demand amongst day care users for weekend cover, particularly for daughters or sons caring for parents [97]. Some services (notably sitting services) which were available on a more flexible, quick response basis and not necessarily nine to five basis were particularly appreciated [103, 104].

- **Organisational service support.** The two studies of family placement breaks found that the practical and personal support offered by the co-ordinators of the schemes was important to carers [98, 108]. One [108] noted particularly that it was helpful that this support was informal but professional.

- **Another supporting service which could be of significance was transport.** Some studies reported dissatisfaction with and anxiety caused by problems with transport provision, for example, unreliability in timing or cancellations [89, 90, 108]. Conversely, appropriate provision could be particularly important to carers [91, 97].

- **Service restrictions.** One study [97] noted that some carers using sitting schemes mentioned they had to go out when the sitter came but would have preferred to stay at home.

- **Tailoring of the service.** Some studies reported that the tailoring, responsiveness and personalisation of a service was beneficial [97, 108] and conversely that inflexibility was unhelpful [95]. A study of a family placement
scheme [108] found that families particularly valued the control the project allowed families in deciding when and under what circumstances to use a host family and also the lack of administration involved in the day to day arrangements. However, this did mean that some less confident or assertive families felt their arrangements were not as ideal as they could have been.

Summary of findings about carer breaks

Outcome findings

Most of the carer breaks studies identified were based upon cross-sectional surveys or qualitative evidence and so offered weak findings in terms of outcome measurement. Some longitudinal studies were included which tended to concentrate upon measuring emotional well-being, with one focusing explicitly and exclusively upon sleep.

Overall, studies generally reported carer satisfaction with breaks. There was also strong evidence that breaks allowed carers to have a rest and experience physical and emotional relief. They also enabled carers to do everyday jobs, pursue social activities and interests and to a lesser extent, employment.

There was little robust quantitative evidence of improvements to emotional well-being achieved through carer breaks. However, several of the studies focused upon carers of people with dementia where the progressive nature of the condition might mean that carers’ emotional well-being might be expected to worsen over time. The studies did not adequately control for confounding factors such as these. There was some qualitative evidence that carers felt breaks benefited their emotional well-being particularly in terms of facilitating a sense of normality, freedom, peace of mind and relief. However, there was also evidence that breaks could cause carers to experience negative emotions including anxiety about the person receiving care, sadness at being separated or leaving the person receiving care and most notably, guilt about using such services. These feelings could be related to the acceptability of the alternative care provision to the relative or friend receiving care.

There was some limited evidence of improvements to physical health achieved through carer breaks and of improved social inclusion.

There was also qualitative evidence that breaks enabled some carers to continue in their caring role who would otherwise have sought other options. Other studies looked specifically at whether there was a relationship between service use and subsequent institutionalisation of the person receiving care. The evidence on this was mixed and inconclusive. However, it seems that in some cases a breaks service is able to sustain a caring situation, whilst in others it is a step on a fairly inevitable journey towards permanent residential care.

Studies also reported upon the outcomes for the person receiving care. There were mixed findings with some very much enjoying the break and others finding it a very negative experience. Satisfaction was particularly high in two studies, one of family placements and one of holidays both for adults with learning disabilities. Some studies relating to care for a person with dementia reported some worsening in the person's condition, particularly for longer stays in residential care. However, other studies found that some breaks services offered useful opportunities for additional medical care. For some, the service offered an opportunity to meet other people and to access stimulating activities. In particular, the services for people with learning
disabilities evaluated offered these types of benefits and in addition, personal and social skills development.

Explanatory evidence

The studies identified provided a considerable amount of explanatory evidence. This was of variable quality but included a few high quality studies. The evidence suggested that the following mechanisms contributed to outcomes: experiencing emotional and physical relief from caring; management of other activities of daily life; and time to maintain and develop other social interests and networks.

A number of explanatory contextual factors which could influence the perceived use of services were identified. There was some evidence of preferences between the different types of breaks services. However, this was not conclusive and suggested that a range of types of breaks service are likely to be needed to meet different needs and preferences. A key factor in the success of the services was confidence about the nature and quality of the alternative care that the carer’s relative or friend received during the break. The following particular factors relating to this were identified as potentially significant: the amount and nature of the activities provided; personalisation of the care; the opportunity for additional medical care; and general environmental factors. The qualities of the staff providing care were also considered to be significant. These included: their training and expertise; personal qualities such as warmth and empathy; continuity; and simply having a sufficient number as well. Studies also indicated that involvement of the carer through recognition of their knowledge and relationship to the person receiving care could also be beneficial.

Two important organisational factors potentially influencing the benefits of the service were the extent and timing of provision. In addition, the wider organisational support for the service could improve service satisfaction. There was also some evidence that the tailoring of services and service flexibility could be beneficial.
4. CONCLUSIONS AND RECOMMENDATIONS

The conclusions and recommendations of this review are divided into: those related to the nature of the research evidence included; those concerned with specific types of intervention for carers; and those which cut across the various interventions for carers.

4a. Future research

4a. i. Gaps in the evidence base

Little evidence was identified (within the boundaries of the review: post-1990, UK based research) about the following interventions for carers.

- Support to access services in personalised forms such as direct payments which give control to the person receiving support.
- Interventions targeted at carers’ physical health.
- Interventions aimed at helping carers to maintain or access employment. (There is, however, a body of evidence which was not included within the criteria of this review about how employers can help carers to maintain employment.)
- Befriending schemes.
- Complementary therapies. (There may, however, be relevant evidence about the use of these interventions with other client groups which might be useful.)

Whilst more evidence was identified within the other intervention categories, this was sometimes concentrated upon support for particular types of carer according to the condition of the person receiving care. Studies of interventions focused upon emotional and social support were quite heavily concentrated upon services specifically for carers of people with mental health difficulties or dementia. Studies of education and training for carers often evaluated services for carers of people with dementia. Studies of carer breaks particularly focused upon services for carers of people with dementia or of older people.

In contrast, there was very little evidence which focused upon carers of a particular type according to their own specific characteristics (for example, by ethnicity, age, gender or relationship to the person receiving care). Study samples tended to include a range of types of carer in terms of their own characteristics. Some studies did consider the relevance of carer characteristics within their findings but this type of analysis was fairly limited.

There was relatively little evidence about voluntary sector carer services despite the fact that there is substantial provision by this sector. The review also includes little evidence about preferences between and the value of services provided by different sectors, namely, the public sector (which can be divided generally into either health service or local authority social services provision), the voluntary sector (which includes generic carer provision and provision by condition specific organisations such as the Alzheimer’s Society) and the commercial sector (upon which there is little evidence). This is largely because studies have concentrated upon a particular service or group of services delivered by one sector. There was also very little evidence about the use of services which carers have arranged and funded on a private basis.
Whilst this review has identified these gaps in the evidence base, this is specifically within the context of the UK since 1990. The use of international research about carer interventions may go some way towards filling these.

This review does not consider evidence relating to the cost-benefit of carer interventions and so cannot comment on the need for research of this type.

Recommendations:

- Further research should be carried out to address the gaps identified above.
- Priority areas for research should be interventions about which there is currently very little evidence, yet which are highlighted as important in current policy debates. These include: personalised approaches to support, for example, individual budgets; interventions designed to support carer employment; and interventions focused upon carers’ physical health.
- Further research about carer services provided by the voluntary sector would also be useful.
- Research about the different types of interventions should cover all types of carers. However, it should also include analysis of how findings differ according to specific carer characteristics. Whilst the condition of the person receiving care is often likely to be important, other carer characteristics such as ethnicity, age, gender and relationship to the person receiving care should also be considered.
- Generally further comparative research on carer interventions considering the relative value of different forms of intervention would be useful.

4a. ii. The value of outcome measurement and explanatory evidence

Two types of research evidence were included in this review: outcomes and explanatory. Most of the evidence which measured outcomes was relatively weak in quality. This is unsurprising given the practical and ethical difficulties which may be encountered in using methods such as randomised controlled trials in social research. Whilst these approaches can be used in some cases, it is also worth considering what can be learnt from other forms of evidence.

Interestingly in some cases, quantitative studies recorded little or no effect upon specific outcomes in contrast to qualitative studies of similar interventions in which carers did report benefits of this kind. This raises questions about the validity and sensitivity of the outcome measurements used. The standardised measures used in quantitative studies may not adequately cover all the dimensions of complex outcomes such as emotional well-being. Qualitative work is helpful in identifying particular benefits, for example, feeling recognised and valued that can be missed in standardised quantitative outcome measurement. However, it may be that carers retrospectively overstate the benefits of interventions through gratitude in qualitative research. In addition, the changes may, in fact, be very small and therefore difficult to detect quantitatively.

Explanatory evidence has helped to provide an understanding of the mechanisms at work in carer interventions. It has also suggested many interesting contextual factors which appear to contribute to the success or otherwise of interventions. However, this is unfortunately not very often clearly linked to outcomes.
Within each category of intervention, there was often a tendency for the evidence base to be either predominantly based upon cross-sectional survey and qualitative research or upon controlled and/or longitudinal quantitative designs focused upon outcome measurement. This often related to the type of intervention. Those developed in the health care field were more likely to take the latter approach and those based in social care or the voluntary sector were more likely to have been evaluated using the former approach. A relatively small number of research studies combined both quantitative outcome measurement and explanatory qualitative work. Consideration of the two elements together could offer useful insight.

Recommendations:

- **Evidence measuring outcomes using research designs other than the ideal of randomised controlled trials should not be quickly dismissed given the difficulties of the ideal format. Researchers should continue to try to use designs involving comparison of outcomes either longitudinally and/or amongst an intervention and control group. A range of designs should be used whilst recognising their potential limitations.**

- **The validity and sensitivity of the way in which carer outcomes are measured should be carefully considered in future research. Qualitative research may be particularly useful to identify the range of outcomes which may be produced through an intervention. Quantitative research may then be needed to assess the size and extent of outcomes.**

- **Future research into carer services should both measure outcomes and consider the explanatory mechanisms underlying these and the contextual factors which may influence these. Analysis should link these together to provide a holistic understanding of whether and how carer interventions work.**

### 4b. Learning about specific carer interventions

#### 4b. i. Interventions supporting access to services

The review suggests that statutory carer assessment can be very helpful to carers. It can be of practical benefit through linking carers into other direct support services. However, the evidence suggests that this only occurs for a proportion of carers, often less than half. Perhaps less intentionally but nonetheless importantly, assessment can also constitute a useful cathartic, emotional process. It can allow carers to express themselves, reflect upon their situation, receive recognition and validation from others and to feel supported.

The review found that many factors potentially influence the success or otherwise of assessment. The qualities and approach of the staff conducting the assessment were potentially very significant. Assessments may be more helpful if they are provided by staff who: have good interpersonal skills; provide active assistance; are skilled and knowledgeable in carer support; and who follow up actions and maintain contact. The centring of the assessment upon the individual carer, their preferences and expertise is also likely to be important. Following on from this, a broad approach which focuses specifically on the outcomes the carer wishes to achieve has shown particular promise. Carers may have individual preferences about the extent of the information they want prior to assessment and whether or not it is held in private, separately from the person receiving care. The subsequent availability and nature of resources to meet needs identified in assessment and follow up on these is also important.
The evidence suggested that other interventions (notably support workers, but also potentially information services) may achieve similar outcomes to statutory carer assessment in terms of emotional support and access to services. Similar factors may also influence their success.

Recommendations:
- There is currently a focus amongst local authorities on meeting performance targets for the number of carer assessments achieved. This should be matched by a focus upon the quality of these assessments.
- Attention to staff training and approaches in this area is particularly important.
- The availability and adequacy of resources to meet needs identified in assessment has to be addressed.
- It would be interesting to consider how statutory assessment and support worker models of interventions to help carers to access services compare. In some areas, new ways of working are now being piloted where voluntary sector carer support workers conduct assessment. Further research is needed to consider the value of these different models of support.

4b. ii. Carer support groups

Whilst the outcome measurement evidence on carer support groups was generally weak in quality, it suggested that these may lead to a wide range of significant outcomes. These included: receipt of information and advice on a range of topics and issues; emotional support from other group members and through the development of confidence and a carer identity; social inclusion through meeting others, developing friendships and participating in social activities and outings; and sometimes facilitation of access to other services.

It was clear that the specific nature of individual support groups could be quite influential in terms of the outcomes achieved. In particular, the following could be significant, whether a group: was linked to a service; had more narrowly defined criteria for membership; or was led by a professional or run by peers.

Recommendations:
- The evidence suggests it is worth supporting and researching carer support groups further. This is particularly the case given that these may offer a relatively inexpensive form of support as they can be delivered to several carers at a time and generally have relatively limited overhead costs.
- Given the potential significance of different types of support group, those organising and running groups should consider the aims, activities, membership, leadership and evaluation of individual groups carefully.
- Within local areas, it might be helpful to review the number and range of different groups available and to consider whether there are gaps in provision or whether some provision might benefit from changes.

4b. iii. Stress management, coping and counselling programmes

Studies of these programmes (often located in the health sector) often used relatively robust longitudinal and control group designs to consider outcomes. They identified improvements in knowledge in relation to the medical condition, ways of caring, management of stress and coping techniques. There was more mixed evidence as to whether improvements in emotional well-being (generally their principal objective)
were also achieved. There was some evidence of behavioural change amongst carers participating in these interventions, for example, in the ways that they managed their role. However, it was difficult to distinguish whether this was due to the intervention or just a natural change occurring over time.

The extent of the explanatory evidence reported on these types of intervention was quite limited.

Recommendations:
- These types of programme are worth exploring further. It may be particularly useful to carry out some qualitative research into how these interventions work and the contextual factors which may influence this.

4b. iv. Education and training for carers

Studies reported quite consistently that education and training programmes for carers can add to knowledge and skills as they are intended to. This was found for a range of types of education and skills training aimed at carers of people with various specific medical conditions. Improvements could also be fairly substantial in size. As well as building new knowledge and skills, it was reported as useful that these programmes sometimes validated existing knowledge amongst carers. In relation to training, however, there was some evidence that skills may not be maintained over time. There was some evidence that training could also have a beneficial impact upon emotional well-being including improved perceptions of the difficulties of caring and the carer’s ability to manage.

Relevant contextual factors that could influence the outcomes of these interventions included: the topics covered; format of delivery; timing of delivery (the stage of caring participants were at); and the presence or not of the person receiving care. The delivery of education programmes in a face-to-face format but supported by written information appeared to be most useful. Provision of these interventions at earlier stages of the caring journey seemed to be beneficial, although further research would be needed to establish the extent of this. Particular aspects of training style noted as important included: the use of interaction; personalisation of the content; and the use of problem-solving approaches with others.

Most of the studies of these interventions were about condition-specific programmes (often developed within the health sector). However, some more generic programmes, for example, the Caring with Confidence government funded programme (www.caringwithconfidence.net – accessed January 2009), are now being developed. It will be important to evaluate these carefully.

Recommendations:
- Education and training should continue to be provided to fulfill specific carer needs for knowledge and skills development.
- Those developing and running these types of intervention should consider structural aspects of the intervention likely to influence its success, particularly the timing and the format of delivery.
4b. v. Employment-related interventions

Little evidence was found about interventions concerned with carer employment. However, one study suggested that the following may influence success: the need to consider carers’ confidence in relation to accessing employment; potential difficulties in finding employment offering suitable hours and flexibility in these; and the potential need for additional support services for the person receiving care to support the carer’s return to work.

Recommendations:
- Those developing and running carer employment projects should consider the points made above.

4b. vi. Carer breaks

The review found evidence that breaks offer carers a rest (emotionally and physically) and also allow carers to do things including catch up with everyday household tasks, social activities and sometimes employment. There was evidence that this type of intervention can be critical to the ability of some carers to continue caring. This was not apparent in the reports about other types of intervention suggesting the particular potential importance of this service. (This may also partly reflect the interest of studies of these services in this outcome domain.) However, the service may also constitute a first step on a fairly inevitable journey to stop caring for some carers. There is complexity in the influence of carer breaks upon carers’ emotional well-being. They may offer relief, a sense of normality and freedom but also often lead to feelings of guilt and anxiety.

There was variation in preferences for different types of breaks service (for example, day care, short stay residential care or sitting services). There was some quite consistent evidence about factors which influenced satisfaction with and the potential benefits of breaks services. The nature and quality of the alternative care provided to the relative or friend of the carer was very important. This included its acceptability to the person receiving care, staff characteristics, the activities on offer and general environmental factors. The extent and timing of provision was also important to carers and tailoring and flexibility in services were valued.

Recommendations:
- Carer breaks should continue to be a priority in carer service development.
- Those planning breaks services across a local area should consider whether they are offering an adequate supply and range of types of carer breaks.
- Those planning and running specific breaks services should consider, in particular, the flexibility of their provision and the nature and quality of the alternative care provided.
- It would also be useful for service providers to consider what they can do to address or ameliorate the sometimes difficult emotions experienced by carers using breaks services.

4c. Overarching considerations for carer interventions

4c. i. Considerations regarding the person receiving care
Some evidence about the outcomes of carer interventions for the person receiving care was recorded. These were generally neutral or positive. There was some limited evidence of potentially negative outcomes in two studies of a stroke support worker which needs further investigation. There was also an example of negative outcomes for a minority in a study of carer training. Carer breaks were the one intervention type where there was stronger and more consistent evidence of negative outcomes for a proportion of those receiving care. These included dislike and dissatisfaction with the experience and also some deterioration in people’s health and functional abilities. However, equally, in some cases, breaks provision could be very positive for the person receiving care. For example, this was the case where stimulating activities and new opportunities were provided for people with learning disabilities during breaks.

Recommendations:

- Future research must continue to consider any outcomes of carer interventions for the person receiving care.
- In some cases, provision may need to be stopped or altered in order to avoid negative outcomes for the person receiving care.
- The outcomes for the person receiving care are likely to influence carers’ perceptions and feelings about services and their potential take-up of services. These factors need to be considered in service design.

4c. ii. Intervention delivery themes

The review identified some contextual factors relating to the delivery of interventions which cut across a number of types of interventions. These included the following.

- The approach and qualities of the staff delivering interventions could be very significant. This was apparent particularly in the evidence on services to support access to services and also for breaks, where it specifically related to the characteristics of the staff providing the alternative care.
- The potential value of flexibility, tailoring and personalisation of services was apparent for a number of types of intervention. Control of services was noted as important a few times as a way of achieving this. However, overall the more dominant theme was that flexibility and personalisation were valued whether this was considered by the provider or driven by the carer’s own actions.
- Evidence on a number of types of intervention reported that recognition by service providers of a carer’s role, knowledge and expertise could be beneficial.
- The evidence throughout the review showed that various structural aspects of interventions can be significant and need to be considered. Broadly, these include: timing of delivery; content; characteristics of the target group; and the format of delivery. In relation to the timing of delivery, generally it was reported that it was more helpful for carers to receive interventions at a relatively early stage in their caring role.

There was an interesting contrast between the interventions researched in terms of the extent to which they were structured and pre-defined. Some, for example, fairly unstructured, ongoing support groups and in contrast, group coping programmes with very defined content and structure, appeared to lead to some similar outcomes, for example, improved knowledge and social support. It was not clear from the evidence how these types of characteristics might influence outcomes.
Recommendations:

- The common factors listed above which came through particularly consistently as potentially significant need to be considered in the planning and delivery of carer services.
- It would be interesting to research further the relative role and value of more organic, self-determining interventions and those which are more closely designed and structured prior to delivery.

4c. iii. The significance of carer characteristics

Many of the studies focused upon interventions for specific types of carer, commonly in relation to the condition of the person they were caring for, for example, dementia or stroke. This was sometimes self-evidently important. For example, education programmes focused upon caring for people with a particular condition might include condition specific knowledge. Evidence also suggested that a stronger support bond might be developed in carer support groups where members had more in common with each other, for example, in relation to the condition of the person they cared for. Evidence on breaks suggested that dissatisfaction was higher amongst carers of people with certain conditions, for example, behavioural problems, where it was harder to access adequate care because of the specific nature of these conditions.

Most studies included little information about outcomes for black and minority ethnic carers. However, where this group was considered it was apparent that services need to consider their specific cultural needs and preferences.

The review also reported some evidence that carers who were more assertive, confident and knowledgeable about their rights and support were more likely than others to receive the support they wanted. In contrast, some carers were reluctant to criticise support (for fear of losing it or seeming ungrateful) or to initiate contact with practitioners to request support.

Recommendations:

- In some cases, it will be beneficial to develop services for specific groups of carers (according to either their own characteristics or those of the person they care for).
- Service providers should consider the needs of less assertive carers and consider proactive approaches to supporting these carers.

4c. iv. Distinctions and complementarity in service provision

As noted elsewhere, it was quite difficult to categorise carer interventions neatly. There is considerable overlap in the functions and provision of interventions. Similarly the review shows that various outcomes, particularly emotional well-being, might be achieved through a variety of interventions. Particular structural aspects of interventions may also lead to specific secondary outcomes. For example, the evidence suggests that interventions of any kind delivered in a group format will potentially provide some opportunity for carers to provide mutual emotional and social support to each other.

Recommendations:

- Planners and commissioners in local areas may need to consider if there are any obvious gaps or overlap in provision that need reviewing. Overlap may be
necessary where different types of provision meets the various preferences of individual carers.
- Further comparative research on carer interventions may be useful.

4c. v. The role of carer interventions

This review has not considered the outcomes for carers of interventions specifically aimed at the person receiving care. It has been suggested that these can offer the most significant benefit to the carer’s well-being because they can reduce or share caring tasks and responsibilities.

The evidence presented in this review suggests that carer specific services also have a particular role to play. They can address specific carer needs including emotional support, stress management, social support and knowledge and skills development.

Across the various types of interventions for carers, there were generally high levels of satisfaction. However, there were also various suggestions for improvements.

Recommendations:
- Policy makers, commissioners and service providers should continue to consider carer specific needs as well as those of the person receiving care and their shared needs and preferences.
- Service providers should not be complacent about high levels of carer satisfaction but should continue to consider how services can better meet the needs of carers.
BIBLIOGRAPHY

a. Studies included within the review


82. Poole B. *Carers together: the report of a training programme organised by Carers National Association and Contact a Family*. London: Contact a Family in conjunction with Carers National Association; 1993.


A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence


b. Other references


## APPENDIX 1: TABLES OF STUDY DETAILS

### Table 6: Studies of statutory carer assessments (discussed in section 3b. i., page 28)

<table>
<thead>
<tr>
<th>Reference and design</th>
<th>Sample characteristics</th>
<th>Intervention</th>
<th>Outcome measures</th>
<th>Quality appraisal ratings</th>
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</thead>
<tbody>
<tr>
<td>1. Arksey et al 2000</td>
<td>Longitudinal qualitative interviews with carers and single qualitative interviews with staff. n=51 carers (49 at follow up) Mix of relationships to people receiving care and of their conditions. 71% female; age range 32-87. 51% 61+ years. 96% caring for 20+ hours per week; 14% in their first year of caring, 53% caring for 5 years+. All carers being assessed in 4 sample areas (selected purposively) were invited to participate until sufficient numbers accessed. n=20 staff (4 senior managers and 16 practitioners involved in carer assessment in 4 social services)</td>
<td>Statutory carer assessment (theoretically as per statutory guidance in effect in 1998).</td>
<td>Qualitative feedback from carers after assessment and 6 months after the first interview.</td>
<td>Overall: weak for outcome measurement. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:n; 7:y.</td>
</tr>
<tr>
<td>2. Becker et al 2005</td>
<td>Documentary analysis plus qualitative interviews with practitioners and carers. n=10 carers Mix of relationships to care recipients and conditions. 80% female; mix of ethnicity Selected on basis of assessment records to cover a mix of thorough and brief records. n=271 assessment records analysed. n=13 assessors.</td>
<td>Statutory carer assessment – conducted by community care officers and social workers, predominantly within adult social care, but 2 located within mental health teams and 1 in a physical disability team.</td>
<td>Analysis of carer assessment forms to judge whether there was sufficient evidence to construct an action plan and to judge whether action plans would meet the carer needs identified on the form. Qualitative feedback from practitioners and carers.</td>
<td>Overall: weak for outcome measurement. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:n; 7:y.</td>
</tr>
<tr>
<td>3. Becker et al 2007</td>
<td>Quantitative analysis of assessment forms and qualitative interviews with carers and assessors. n=11 carers Mix of relationships to people receiving care and of their conditions. 66% female; 64% white; mix of ages. Mix of caring responsibilities and length of time spent caring. Selected purposively. n=16 staff (mix of social services staff who carried out carer assessments.) n=260 assessment forms completed in the local authority in one year analysed.</td>
<td>Statutory carer assessment (theoretically as per statutory guidance in effect at the time).</td>
<td>Retrospective qualitative feedback.</td>
<td>Overall: weak for outcome measurement. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:n; 7:y.</td>
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## A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence

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<thead>
<tr>
<th>Reference and design</th>
<th>Sample characteristics</th>
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<tbody>
<tr>
<td>Cross-sectional postal survey of carers.</td>
<td>Mix of relationships with person receiving care and condition of person receiving care. 76% female; 1% aged 17-25, 19% 26-44, 49% 45-65, 31% 66+. 90% provided 20+ hours of care per week; 69% had been caring for 5 years+, 44% for 10 years+. Approx. 10,000 questionnaires sent to organisations in the Wales Carer Alliance to distribute (response rate 13%). Responses from across all 22 local authorities in Wales.</td>
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<td>Cross-sectional postal and telephone surveys.</td>
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<tr>
<td>Cross-sectional survey plus qualitative interviews with carers.</td>
<td>Mix of carers in terms of relationship with person receiving care and their condition. 70% female; 97% white; 10% aged 30-44, 54% 45-64, 35% 65+. 95% care for more than 20 hours per week; 46% had been caring for more than 10 years.</td>
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<tr>
<td>7. Nicholas 2003</td>
<td>n=12 carers n=37 assessments reviewed representing a mix of the wider caseload and ethnic mix of the area. n=14 practitioners: 5 home care organisers and 9 social workers/care managers conducting assessments.</td>
<td>Statutory carer assessment using newly developed outcomes focused tools including: a carer’s needs form to gather initial details; 3 detailed questionnaires covering difficulties and satisfactions in caring and coping strategies; a summary of carer outcomes and needs form to inform plans; a carer feedback form to evaluate change. Staff were given training in this approach.</td>
<td>Retrospective qualitative feedback from assessors and carers.</td>
<td>Overall: weak for outcome measurement. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:n; 6;y; 7:y.</td>
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<tr>
<td>Documentary analysis plus qualitative interviews with practitioners and carers.</td>
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# A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence

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<tbody>
<tr>
<td>8. Orrell et al 2006 Cross-sectional postal survey of carers.</td>
<td>n=5,391 carers. Carers of older people with mental health problems. Carers identified via local statutory services and the Alzheimer’s Society in 70 areas of England. Response rate not given.</td>
<td>Statutory carer assessment (theoretically as per statutory guidance in effect in 2001-2). The study compares areas where carer assessments were said to be available (68.6% of areas) and those where they were not said to be available (despite the fact that there was a legal duty to provide these in all areas of England at this time).</td>
<td>Carers’ self report of: whether they were asked if they needed any help; told what help was available and whether it would be paid for; told about benefits; told how to complain; introduced to someone whom they could contact if they were worried; and whether they were currently receiving all the help they needed to have a break.</td>
<td>Overall: weak for outcome measurement.</td>
</tr>
<tr>
<td>11. Seddon &amp; Robinson 2001 Qualitative interviews with carers and practitioners.</td>
<td>n=64 carers All spouses or adult children of older people with dementia. 61% female; mean age 61, range 33-83. Carers of people requiring a high level of assistance with activities of daily living; mean length of time caring 4.5 years. Carers identified for inclusion by the participating practitioners within 4 unitary authorities in Wales. n=32 care managers within social services depts.</td>
<td>Statutory carer assessment (theoretically as per statutory guidance in effect at the various times at which primary data collection was undertaken).</td>
<td>Retrospective qualitative feedback.</td>
<td>Overall: weak for outcome measurement. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:n; 7:y.</td>
</tr>
<tr>
<td>12. Seddon et al 2007 Secondary analysis of 9 previous studies including data from surveys, qualitative interviews and focus groups and documentary analysis.</td>
<td>n=2,000+ carers across the 9 included studies. Mix of relationships to care recipients, condition of care recipients, gender and age. Limited participation of BME carers and also of varied sexualities. n=376 professionals across the 9 studies. At strategic and operational level, in a variety of types of organisation.</td>
<td>Statutory carer assessment covering the period 1993-2006.</td>
<td>Retrospective qualitative feedback.</td>
<td>Overall: weak for outcome measurement. A:s; B:w; C:s; D:m; E:m; F:w; G:s; H:m. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:y; 7:n.</td>
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Table 7: Studies of information services (discussed in section 3b. ii., page 40)

<table>
<thead>
<tr>
<th>Reference and design</th>
<th>Sample characteristics</th>
<th>Intervention</th>
<th>Outcome measures</th>
<th>Quality appraisal</th>
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</thead>
<tbody>
<tr>
<td>13. Carers UK 2006 Cross-sectional survey.</td>
<td>n=265 carers Relationship with person receiving care and their condition not given. 75% female; 95% white; 53% aged over 60. 5% caring for less than a year, 65% for 5+ years, 16% for 16+ years. All service users invited to respond by questionnaire; response rate not given.</td>
<td>Special helpline set up by Carers UK for a nationwide carer awareness day in 2005.</td>
<td>Post-intervention knowledge of and applications for various benefits and carer assessment.</td>
<td>Overall: weak for outcome measurement. Overall: weak for explanatory findings. 1:y; 2:y; 3:n; 4:n; 5:n; 6:n; 7:n.</td>
</tr>
<tr>
<td>14. Clarke 2001 Uncontrolled longitudinal outcome measurement.</td>
<td>n=18 carers Details of relationship with care recipient and their condition not given. 61% female; mean age 65. Mean length of time caring was 15 years.</td>
<td>1 day joint training workshop for carers and care professionals providing information on opportunities for involvement, services available and setting goals for participation in decision making. Provided by trainers associated with social services. Open to any carers in the area.</td>
<td>Psychological empowerment broken down into: perceived control at individual, organisational and community level (scales used); self-efficacy (unstandardised, carer specific scale used); self-esteem (Rosenberg’s 1965 instrument) and self-perceived knowledge of involvement methods, services and rights. Measures at 2 weeks prior to the intervention and on completion.</td>
<td>Weak for outcome measurement. A:w; B:m; C:w; D:w; E:w; F:s; G:s; H:s.</td>
</tr>
<tr>
<td>15. Jarvis &amp; Worth 2005 Cross-sectional survey.</td>
<td>The intervention targeted any type of carer. 12 carers evaluated the information pack.</td>
<td>Distribution of a screening questionnaire to a GP’s register of patients to identify carers and offer them information, followed (where requested) by a pack of information about services for carers, benefits and advocacy.</td>
<td>Number of carers identified and proportion of carers who identified the information pack as useful.</td>
<td>Weak for outcome measurement. Strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:n; 7:y.</td>
</tr>
<tr>
<td>16. Reeve &amp; Baker 2005 Cross-sectional survey.</td>
<td>n=63 carers Mix of carers in terms of relationship with the person receiving care and their condition. 71% female; 8% aged 20-44, 44% 45-64, 35% 65-84, 5% over 85, remainder n/k.</td>
<td>Identification as a carer by 4 GP practices and signposting to a local voluntary sector carers centre.</td>
<td>Number of referrals, satisfaction, knowledge, use of services and feelings.</td>
<td>Week for outcome measurement. Weak for explanatory findings. 1:n; 2:y; 3:y; 4:y; 5:y; 6:n; 7:y.</td>
</tr>
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</table>
### Table 8: Studies of direct payment schemes (discussed in section 3b. iii., page 43)

<table>
<thead>
<tr>
<th>Reference and design</th>
<th>Sample characteristics</th>
<th>Intervention</th>
<th>Outcome measures</th>
<th>Quality appraisal</th>
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<tbody>
<tr>
<td>18. Blyth &amp; Gardner 2007</td>
<td>Mixed methods including qualitative interviews with carers and practitioners, a carer survey and documentary analysis.</td>
<td>n=37 carer questionnaire respondents (self-selected). n=24 carer qualitative interview participants (selected from questionnaire respondents). All parents/carers of disabled children. Other carer characteristics not given. From 1 local authority area. Manager and support workers from the direct payment support service and a senior local authority manager and a number of specialist social workers from the disabled children’s team were interviewed.</td>
<td>Direct payments supported by an independent direct payment support service. The latter offered payroll/accounts, recruitment advice, employment advice and emotional support.</td>
<td>Retrospective qualitative feedback including coverage of emotional health and satisfaction with support. Overall: weak for outcome measurement. Overall: moderate for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:y; 6:n; 7:y.</td>
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</table>
A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence

Table 9: Studies of support workers (discussed in section 3b. iv., page 45)

<table>
<thead>
<tr>
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<th>Outcome measures</th>
<th>Quality appraisal</th>
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<tbody>
<tr>
<td>19. Lankshear et al 1999</td>
<td>n=47 carers (30 in the pilot surgery and 17 in a control surgery with no carers register) Carer characteristics not given. In pilot surgery, carers sampled from the carers register; in control surgery, carers suggested from practitioner memory. All in East Sussex.</td>
<td>Comparison of a pilot GP surgery employing a carer support worker with 2 control GP surgeries. Pilot surgery: attached carer support worker to: identify carers; develop existing support networks; provide a drop-in service, home visits and a telephone service; set up a carer support group; develop care plans for carers; educate the practice team on carers’ needs; run a carers’ open day; develop a carers’ information pack; educate other agencies on carers’ issues. 2 control GP surgeries with no carers’ register or specialist provision for carers.</td>
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<tr>
<td>Mixed methods comparative study including qualitative interviews with carers and practitioners, carer survey and documentary analysis.</td>
<td>n= all 10 staff from pilot surgery; all GPs from control surgeries.</td>
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<tr>
<td>20. Manchester PSSRU 2002</td>
<td>n=68 (GHQ measures, although some non-response, data not given) n=191 (satisfaction survey) Mix of relationships to person receiving care and their condition. 100% white; 60% retired. 28% caring for less than 4 years; 44% 4-10 years; 28% over 10 years.</td>
<td>Carer support workers based in GP practices providing: information about services; support/ liaison with other agencies (including social services and the benefits agency); advocacy; counselling; referral to carers group; referral to specialist providers (including social services, occupational therapy and Age Concern); referral to practice staff.</td>
<td>Psychological well-being (General Health Questionnaire (GHQ)-12). Assessed an average of 9 months apart. Satisfaction (by cross-sectional survey).</td>
<td>Overall: weak for outcome measurement. A:m; B:m; C:w; D:w; E:s; F:w; G:m; H:s.</td>
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<tr>
<td>Uncontrolled longitudinal plus cross-sectional survey.</td>
<td>n=5 voluntary advocates</td>
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<td>21. Fazil et al 2004</td>
<td>n=19 families Parents of children with severe disabilities. Mothers participated primarily; 14 Pakistani, 5 Bangladeshi; mean age of mothers 35 years. Amount of care per week; length of time caring. 20 of 35 families were selected on basis of greatest needs following assessment, 1 family moved out of the area. East Birmingham.</td>
<td>Advocacy service for Asian families with children with severe disabilities. Advocates were recruited from ethnic minority communities and spoke a range of relevant languages. A mutual support group for mothers was also set up. The role of the advocates was to befriend the families, link them into services they were not accessing and to aid communication with services which were not being accessed effectively. The aim was also to empower families to access and negotiate with services when the advocacy service ceased after 9 months.</td>
<td>Retrospective qualitative feedback including coverage of service access and uptake, empowerment and emotional support.</td>
<td>Overall: weak for outcome measurement. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:n; 7:y.</td>
</tr>
<tr>
<td>Qualitative action research including longitudinal qualitative interviews with carers and qualitative interviews with practitioners.</td>
<td>n=5 voluntary advocates</td>
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<td><strong>With a mental health specialism</strong></td>
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<td>22. Dack et al 2006 Qualitative interviews with carers.</td>
<td>n=11 carers 6 spouse/partner and 7 parent carers (1 had multiple roles) of people with mental health difficulties. 10 female; 6 aged 35-54, 4 aged 55-64, 1 aged 65+. 5 had been caring for &lt;5 years, 3 for 5-15 years, 3 for 15+ years. All service users from the past 6 months invited to participate; refusals not reported. Northumberland.</td>
<td>Carer support workers based in the community mental health team. Service provided if need identified at a carer assessment. Support is tailored individually and could include: accompaniment to social activities; listening and emotional support; introduction to and representation with services; practical support; and consideration of coping strategies.</td>
<td>Retrospective qualitative feedback covering emotional health and social inclusion.</td>
<td>Overall: weak for outcome measurement. Overall: moderate for explanatory findings. 1:y; 2:y; 3:n; 4:y; 5:y; 6:n; 7:y.</td>
</tr>
<tr>
<td>23. Weinberg &amp; Huxley 2000 Non-randomised controlled design plus qualitative interviews.</td>
<td>n=62 carers. Comparison of those who were new cases for the FSW (n=25) and those who had been supported for at least 6 months (n=37). Carers of people with long-term mental health problems, mainly schizophrenia. 84% parents, 8% spouse, 8% other. 64% women only, 8% men only.</td>
<td>Voluntary sector carer-focused family support workers (15 with various backgrounds). They provided: emotional support for family and patients (23% of time) including counselling, listening, befriending, assessing and motivating patients; practical support for the families (18% of their time) eg information and advice about the condition, crisis intervention, accompaniment on appointments or trips, advocacy and visits to the patient in hospital; liaison with health and social care agencies (10% of their time).</td>
<td>Quality of life (Lancashire Quality of Life profile); burden (objective burden scale from the Social and Behavioural Assessment Schedule); and satisfaction.</td>
<td>Overall: weak for outcome measurement. Overall: weak for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:n; 6:n; 7:n.</td>
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<tr>
<td><strong>For carers of older people with dementia or psychiatric problems</strong></td>
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<td>24. Greenwood &amp; Walsh 1995 Uncontrolled longitudinal outcome measurement.</td>
<td>n=20 carers of people with dementia. No other sample details given.</td>
<td>The Admiral Nurse Service for carers of people with dementia (a pilot in London). The aim was to help carers continue to care through the provision of information, support to access practical help and emotional support. Based upon a problem-solving approach. Work with individual carers was open-ended and tailored to the individual. Delivered by nurse specialists.</td>
<td>Carer needs assessment. Measures at first meeting and 3 months later.</td>
<td>Overall: weak for outcome measurement. 1:w; 2:m; 3:w; 4:m; 5:s; 6:w; G:w; H:m.</td>
</tr>
<tr>
<td>25. Murray et al 1997 RCT.</td>
<td>n=44 carers (26 intervention and 18 in a waiting list control group; 39 completed the 6 month follow up) Spouse carers of older people: 29 with dementia, 12 with depression, 2 with anxiety and 1 with schizophrenia. 29 female. Participants recruited to use the service via a previous research study, local GPs, day centre staff, sheltered housing and recently discharged mental health patients.</td>
<td>Key worker intervention for the couple based upon an initial needs assessment. The workers provided social support, information and advice about the relevant medical condition and financial and social problems. Referrals were made to psychiatric and psychological services where necessary. Mean of 6 hours 7 minutes spent by the keyworker with each couple.</td>
<td>Psychological morbidity (GHQ-28, Geriatric Mental State for those over the age of 65 or the Clinical Interview Schedule plus additional questions for those under the age of 65); and severity of difficulties in housing, finance, marriage and social life (shortened Social Problems Questionnaire). Measures at baseline, 12-14 weeks later (the control group were then offered the intervention) and then final assessment another 12-14 weeks later.</td>
<td>Overall: weak for outcome measurement. 1:w; 2:s; 3:w; 4:w; 5:w; 6:s; G:w; H:m.</td>
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## A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence

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<tr>
<td>26. Woods et al 2003</td>
<td>n=128 carers of people with dementia (55 intervention and 73 control groups; 43 intervention and 61 control followed up.) Intervention group: 19 spouse, 19 adult child, 5 other carers; 32 female, 11 male; mean age 62; mean time caring 3.7 years; 33 co-resident. Control group: 21 spouse, 31 adult child, 9 other carers; 43 female, 18 male; mean age 59; mean time caring 2.7 years; 34 co-resident. All new referrals of carers of people with a probable diagnosis of dementia invited to use the service and participate in the study.</td>
<td>Admiral Nurse Service, a specialist mental health nursing service for carers of people with dementia. Provided information, emotional support encouraging coping skills and co-ordination of practical support. Delivered by specialist mental health nurses. Open-ended support. Those in the control group were in areas where they received usual care involving potential support from community mental health teams. There were two types of support. Firstly, assessment and then referral back to the GP and/or social services. Secondly, key worker support over time for the person with dementia and often the carer over an extended period.</td>
<td>Emotional well-being (GHQ). Measures at baseline and 8 months later.</td>
<td>Overall: weak for outcome measurement. A:m; B:m; C:s; D:m; E:s; F:s; G:w; H:m.</td>
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<td>27. Richardson et al 2007</td>
<td>n=25 carers of people with lung cancer (of 21 patients; 19 carers declined to take part) 14 daughter/step-daughter and 7 wife carers. Sample taken through consecutive, convenience recruitment.</td>
<td>Individualised carer support programme. Firstly, a hospital support nurse undertook a systematic assessment of needs interview. A tailored, individualised plan of 12 weeks ongoing support was then offered. Targeted at or near to diagnosis of condition. Intervention logs showed the following were provided: information/advice giving (on 48% of contact episodes); monitoring well-being/maintaining continuity of relationship (19%); listening (37%); helping carer navigate the system (15%); exploring patient’s condition (13%); acknowledging and reassuring about carer role (12%); benefits (3%); help with decision making (1%).</td>
<td>Emotional well-being (GHQ-12); quality of life (Quality of Life Family Version Instrument); and meeting of needs (Family Inventory of Needs). Measures at pre-intervention and after 12 weeks.</td>
<td>Overall: weak for outcome measurement. A:w; B:m; C:w; D:w; E:s; F:s; G:m; H:m. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:y; 6:y; 7:y.</td>
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<td>28. Dennis et al 1997</td>
<td>n=246 carers (119 intervention and 127 control groups; 102 and 110 at follow up) Carers of people who had had a stroke in the last 30 days at recruitment. No other carer characteristics given. Randomisation stratified by patient characteristics. Edinburgh.</td>
<td>A stroke family care worker (from a social care background). She tried to identify unmet needs and meet these through accessing health services, social services and voluntary agencies as well as offering some counselling herself. Mean number of contacts was 3 (decided according to assessment of needs). Control group: usual care from a well organised stroke service for carers of people with dementia. Provided Admiral Nurse Service, a specialist mental health nursing service. Two types of support. Firstly, assessment and then referral back to the GP and/or social services. Secondly, key worker support over time for the person with dementia and often the carer over an extended period.</td>
<td>Social activities (Frenchay activities index); emotional health (GHQ and HADS); social adjustment scale; caregiving hassles scale; and carer satisfaction questionnaire. Follow-up measures taken at 6 months.</td>
<td>Overall: moderate for outcome measurement. A:s; B:s; C:w; D:s; E:s; F:s; G:s; H:s.</td>
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<tr>
<td>29. Dowswell et al 1997</td>
<td>n=15 carers (8 intervention, 7 control) Carers of people who had had a stroke and been discharged from hospital 13-15 months previously. No other carer characteristics given. Purposive sampling based upon level of patient disability and support worker. Bradford.</td>
<td>Specialist nurse stroke support worker. Intervention individually tailored but to include at minimum: provision of information about services and stroke; consideration of any problems focused upon maximising patient social activities and carer relief; delivered over a 6 month period with review at 12 months. Usual care for control group. Considers the same intervention as study 30.</td>
<td>Retrospective qualitative feedback on use of services and satisfaction.</td>
<td>Overall: weak for outcome measurement. Overall: moderate for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:y; 6:n; 7:y.</td>
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### Reference and design

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<th>Reference and design</th>
<th>Sample characteristics</th>
<th>Intervention</th>
<th>Outcome measures</th>
<th>Quality appraisal</th>
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<tr>
<td>30. Forster &amp; Young 1996 RCT.</td>
<td>Carers of people who had a stroke. Numbers and characteristics only given for patients (n=240), not for carers. Patients recruited via medical institutions, 93% participation. Bradford.</td>
<td>Specialist nurse stroke support worker. Intervention individually tailored but to include at minimum; provision of information about services and stroke; consideration of any problems focused upon maximising patient social activities and carer relief; delivered over a 6 month period with review at 12 months.</td>
<td>Emotional well-being (GHQ-28). Measures taken at recruitment and 3, 6 and 12 month follow-up.</td>
<td>Overall: weak for outcome measurement. A:m; B:s; C:w; D:m; E:s; F:w; G:m; H:s.</td>
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<tr>
<td>31. Lilley et al 2003 Qualitative interviews with carers.</td>
<td>n=14 carers (8 intervention, 6 control) Carers of people who had a stroke 9-24 months previously. No other carer characteristics given. Carers of purposively sampled patients within Nottinghamshire.</td>
<td>A stroke family organiser over a period of 9 months. The service aimed to fulfil unmet patient and carer needs by the provision of stroke information, liaison with other services such as social services and benefits agencies and the provision of emotional support (not formal counselling). Control group received standard care. Considers the same intervention as study 32.</td>
<td>Retrospective qualitative feedback on the services received in the previous 9 months.</td>
<td>Overall: weak for outcome measurement. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:y; 6:y; 7:y.</td>
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<tr>
<td>32. Lincoln et al 2003 RCT.</td>
<td>n=159 carers at 4 month follow up, 146 at 9 month follow up. Carers of people who had a stroke within last 4 weeks at recruitment. Other carer characteristics not given. Recruitment of patients through medical referrals, 85% participation. North Nottinghamshire.</td>
<td>A stroke family organiser over a period of 9 months. The service aims to fulfil unmet patient and carer needs by the provision of stroke information, liaison with other services such as social services and benefits agencies and the provision of emotional support (not formal counselling). Mean number of patient contacts 6. Control group received standard care. Considers the same intervention as study 31.</td>
<td>Emotional health (GHQ-12); strain (Caregiver Strain Index); tailored questionnaires covering knowledge of condition and services and satisfaction with information and services. Follow up measures at 4 and 9 months.</td>
<td>Overall: weak for outcome measurement. A:m; B:s; C:w; D:w; E:w; F:w; G:m; H:m.</td>
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<tr>
<td>33. Mant et al 2000 RCT.</td>
<td>n=267 carers (130 intervention group, 137 control group) 65% spouse, 24% adult child, 11% other carer of person who had a stroke in previous 6 weeks. 67% female; mean age 64 years. 25% not co-resident with patient. All carers of patients on the Oxford stroke register invited to participate within certain eligibility criteria; 90% patient consent rate.</td>
<td>Stroke Association family support worker for patients and carers. The worker provided information, emotional support and liaison with other services via home and hospital visits, telephone, information leaflets and setting up local stroke clubs. Frequency and nature of interaction at discretion of worker. On average, 1 hospital visit, 1 home visit, 3 telephone calls, liaison with 1 service in first 6 months of service.</td>
<td>Knowledge about stroke and use of services (tailored questionnaire); social activities (Frenchay Activities index); emotional health (HADS, GHQ-28 and the Caregiver Strain Index); quality of life (Dartmouth co-op charts and SF-36); satisfaction with services (existing questionnaires). Measures taken at 6 months.</td>
<td>Overall: strong for outcome measurement. A:s; B:s; C:s; D:s; E:s; F:s; G:s; H:s.</td>
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<tr>
<td>34. Tilling et al 2005 RCT.</td>
<td>Carers of stroke patients. Numbers and characteristics given for patients but not for carers. 96% patient participation rate.</td>
<td>An FSO (family support organiser) employed by the Stroke Association charity. Offered information, emotional support and prevention advice to families. Aimed at assisting the transition from hospital to home and could include facilitating access to local statutory and voluntary services; providing advice about ongoing physiotherapy. Support decided following an initial assessment. Mean of 15 contacts per patient. Little evidence of targeting the intervention to need. Caregiver Strain Index; emotional health (HADS); also questions about social life and life after stroke; and satisfaction with stroke care (the carer version of the Pound Satisfaction Scale). Follow-up measures at 3 months and 1 year.</td>
<td>Caregiver Strain Index; emotional health (HADS); also questions about social life and life after stroke; and satisfaction with stroke care (the carer version of the Pound Satisfaction Scale). Follow-up measures at 3 months and 1 year.</td>
<td>Overall: weak for outcome measurement. A:m; B:s; C:w; D:m; E:s; F:w; G:m; H:m.</td>
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### Table 10: Studies of interventions focused upon carers’ health

(discussed in section 3c., page 57)

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<tr>
<th>Reference and design</th>
<th>Sample characteristics</th>
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<th>Quality appraisal</th>
</tr>
</thead>
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| 35. Jarvis and McIntosh 2007  
Cross-sectional survey plus qualitative interviews. | n=31 carers participating in the intervention (12 evaluation forms returned from 31 distributed; 11 of 15 randomly selected participants took part in a semi-structured interview.) Range of relationships with and conditions of the person receiving care. Mix of ages. | Pilot Carers Health Clinic. Run weekly in 4 general practices. Staffed rotationally by nurses. Carers were offered: an assessment of their health needs including blood pressure, urinalysis; a carer assessment; information on a range of support services; and referral to an independent stress management therapist in some cases (22). Open referral system from the PHCT, social care staff, voluntary sector and self-referrals. | Identification of health needs, retrospective satisfaction. | Overall: weak for outcome measurement. Overall: weak for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:n; 6:n; 7:y. |
| 36. Rogers 2000  
Outcome measurement plus qualitative feedback. | n=6 carers 5 female, 1 male. Other sample details not given. | Nursing support service. Carers of patients at a general practice offered an opportunity to speak to a nurse for listening support and to have their weight, blood pressure and urine checked. The opportunity to meet other carers was also offered and appropriate information was available on request. | Identification of health needs, retrospective qualitative feedback. | Overall: weak for outcome measurement. Overall: weak for explanatory findings. 1:n; 2:n; 3:y; 4:n; 5:n; 6:n; 7:n. |
### Table 11: Studies of carer support groups (discussed in section 3d. i., page 59)

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<tr>
<th>Reference and design</th>
<th>Sample characteristics</th>
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<th>Quality appraisal</th>
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<tr>
<td>37. Arshad &amp; Johal 1999</td>
<td>Asian carers of people with mental health difficulties in Coventry. No further sample numbers or details given. Feedback was also given by the group facilitators, no further sample details on these are given.</td>
<td>A support group for Asian carers of people with mental health difficulties. Group facilitators were fluent in a number of Asian languages and printed information was also provided in a number of languages. Information was provided about services and speakers from outside agencies were invited. The emphasis was upon preventing ill-health in carers.</td>
<td>Retrospective reports of knowledge and understanding of condition and emotional well-being.</td>
<td>Overall: weak for outcome measurement. Overall: weak for explanatory findings. 1:n; 2:n; 3:n; 4:n; 5:n; 6:n; 7:n.</td>
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<td>38. Carson and Manchershaw 1992</td>
<td>n=10 carers of people with chronic mental illness, principally spouses and parents. Age range: 18 - late 70s. Questionnaire sent to all 12 carers who had attended the group regularly for more than 6 months, 10 responses received. n=1 facilitator feedback.</td>
<td>An ongoing open support group in Redbridge for relatives of people with chronic mental illness. 2 hours once a month. Set up by the voluntary services co-ordinator in the health authority, after 6 months she was joined by the community-based clinical psychologist. Focused primarily upon emotional support rather than practical support, information or education. Respondents’ attendance at the group varied from 6 months to 3 years; 6 were still attending, 4 had stopped.</td>
<td>Retrospective satisfaction plus facilitator’s qualitative feedback.</td>
<td>Overall: weak for outcome measurement. Overall: weak for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:n; 6:n; 7:n.</td>
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<td>40. Larkin 2007</td>
<td>n=37 former carers 24 partners; 10 adult children; 2 adult children in law; 1 neighbour. Conditions of people receiving care not specified. 26 female, 11 male; 12 under the age of 60, 25 over 60s. Mean time caring 9 years. Carers recruited via self-referral from intermediaries such as carer organisations. Other informants were staff from carers’ organisations, academics and district nurses.</td>
<td>A number of voluntary sector carer support groups. 1 group referred to was solely for former carers. No further details are given.</td>
<td>Retrospective qualitative feedback on emotional, instrumental, appraisal and informational support.</td>
<td>Overall: weak for outcome measurement. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:y; 7:y.</td>
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<td>41. Mitchell 1996a</td>
<td>n=18 carers (3 from each of the 6 groups) Caring for people with a range of conditions (no mental health difficulties). 9 parents, 3 spouses, 1 adult child, 1 friend. 16 female, 2 male; 15 white, 3 Indian/Pakistani; 5 aged 31-45, 4 aged 46-60, 7 aged 61-70, 2 aged 70+. 3 had attended the group for 1-6 months, 3 for 12-24 months, 12 for 24+ months. The sample was selected randomly from carers who volunteered to take part.</td>
<td>6 separate local carer support groups, all supported by a professional worker from the Social Work department. 2 groups were off-shoots of day centres/service facilities, 1 of a centre for adults with learning disabilities and 1 of a centre for adults with a physical disability. 2 groups were free-standing, generic groups open to all carers. 2 groups were free-standing but for specific groups of carers: 1 for carers of stroke patients and 1 for carers from ethnic minorities caring for children and young adults with special needs, mainly with a learning disability.</td>
<td>Retrospective qualitative feedback.</td>
<td>Overall: weak for outcome measurement. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:n; 7:y.</td>
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<tr>
<td>42. Mitchell 1996b</td>
<td>n=6 group leaders (2 social workers, 2 day care officers, 1 social work assistant, 1 home care organiser).</td>
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<td>43. Morton &amp; Mackenzie 1994 Qualitative interviews with carers.</td>
<td>n=12 carers (5 from the 6 month group, 7 from the 8 year group). No other carer characteristics given.</td>
<td>2 carer support groups based in a health unit: 1 had been meeting for 6 months and the other for 8 years.</td>
<td>Retrospective qualitative feedback.</td>
<td>Overall: weak for outcome measurement. Overall: weak for explanatory findings. 1:y; 2:y; 3:n; 4:n; 5:y; 6:n; 7:n.</td>
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<td>44. Munn Giddings &amp; McVicar 2007 Observation plus qualitative interviews with carers.</td>
<td>n=15 carers (8 from support group 1, 7 from support group 2). Condition of people receiving care not given. Group 1: 4 spouses/partners, 0 sons/daughters, 4 other; 6 female, 2 male; all white; mean age 55; mean years of group membership 3.5. Group 2: 2 spouses/partners, 2 sons/daughters, 0 other; 3 female, 4 male; all white; mean age 51; mean years of group membership 3. All carers from the 2 selected groups in the South East of England participated; the groups were purposively chosen.</td>
<td>2 self-help carer support groups, operating for over 5 years, met monthly on a face-to-face basis. Group 1 was set up by the carers themselves without professional input from within a single locality, a small town. Group 2 was initiated by a professional who drew membership from across the organisation’s county catchment area but who had withdrawn from the group.</td>
<td>Retrospective qualitative feedback.</td>
<td>Overall: weak for outcome measurement. Overall: strong for explanatory findings. 1:y; 2:y; 3:n; 4:n; 5:y; 6:y; 7:y.</td>
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<td>45. Slowik et al 2004 Qualitative analysis of records of group meetings.</td>
<td>Group facilitators’ feedback.</td>
<td>An open support group for parents and carers of children with mental health difficulties on 2 in-patient mental health hospital units. 1 hour every 2 weeks during family visiting time. The group ran for 9 months. 3-7 carers participated in each group meeting. The aim was for the facilitators to be empathetic and reflective rather than experts with answers and solutions.</td>
<td>Group facilitators’ qualitative feedback of participant outcomes.</td>
<td>Overall: weak for outcome measurement. Overall: moderate for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:y; 6:n; 7:n.</td>
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A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence

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<td>46. Barrowclough et al 1999 (6 month outcomes)</td>
<td>n=77 carers (28 received the intervention at the threshold of 10 sessions or more). Carers of a patient with schizophrenia, schizoaffective disorder or delusional disorder with a minimum 2 year history and at least one relapse requiring hospital admission in the previous 2 years. 71% female; mean carer age 53. Minimum 10 hours contact per week between carer and patient; mean face to face contact 44 hours per week.</td>
<td>A needs-based psychosocial intervention service including family support compared to family support alone (control group). The family support worker offered: information, benefits advice, advocacy, emotional support and practical help. The focus, content and quantity of the psychosocial interventions were determined through a systematic assessment of needs. Areas that could be covered included: support information and liaison; coping with symptoms; relationships; hardship; and negative emotions associated with the illness. 3 types of intervention could be provided: problem-solving techniques; cognitive behavioural interventions with families; individual cognitive behavioural interventions with the patient. Delivered by a clinical psychologist. Median number of carer sessions 14 (range 10-19). Participation from 15 patient keyworkers.</td>
<td>Number of cardinal needs; psychological morbidity (GHQ); depression (Beck Depression Inventory); and Social Behaviour Assessment Schedule section D. Measures at baseline, 6 and 12 months.</td>
<td>Overall: moderate for outcome measurement. A:w; B:s; C:m; D:m; E:s; F:s; G:w; H:s.</td>
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<td>47. Sellwood et al 2001 (12 month follow up) RCT.</td>
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<td>48. Shore &amp; Holmshaw 1998 Uncontrolled longitudinal outcome measurement plus cross-sectional survey.</td>
<td>n=23 carers started the programme, 18 completed it. Carers of people with mental health difficulties, principally schizophrenia. 19 parents, 3 partners, 1 sibling. Other sample details and recruitment process not given.</td>
<td>Psychosocial group training course to consider communication, problem-solving, goal-setting, stress management and assertiveness. Aimed at ‘first episode’ and more recent carers. 10 sessions of 3 hours in 2 periods of 5 weeks with a 3 week break in between plus a follow up session 3 months later. 10-12 carers per group.</td>
<td>Emotional well-being (GHQ, Family Distress Scale); the Understanding Schizophrenia Scale; and satisfaction measures. Measures 1-2 weeks before and after intervention and at 3 month follow-up.</td>
<td>Overall: weak for outcome measurement. A:w; B:m; C:w; D:w; E:s; F:m; G:m; H:m. Overall: weak for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:n; 6:n; 7:n.</td>
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<td>49. Szmukler et al 2003 RCT.</td>
<td>n=61 carers (49 followed up). Carers of people with schizophrenia or another diagnosis of psychosis. 62% parents, remainder a variety of relationships. 82% female; 66% white. 26% had more than 35 hours per week contact with the patient, 28% 10-35 hours, 46% less than 10 hours.</td>
<td>6 individual family sessions followed by 12 fortnightly relatives’ groups. The 6 initial sessions were conducted without the patient and covered: discussion of main problems of carers; education in relation to the mental health condition and available service support; scrutiny of coping strategies. Delivered by a community psychiatric nurse. The 12 relatives’ groups included informal chat, a half hour talk by a speaker with special knowledge followed by directed discussion.</td>
<td>Psychological morbidity (Clinical Interview Schedule Revised); appraisal of caregiving (Experience of Caregiving Inventory); coping (2 summary scales from the Coping with Life Events and Difficulties Index). Social support (2 summary scales from the Self Evaluation and Social Support Schedule).</td>
<td>Overall: strong for outcome measurement. A:w; B:s; C:s; D:m; E:s; F:s; G:m; H:s.</td>
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<td>Marriott et al 2000</td>
<td>n=42 carers invited to participate (14 allocated to each of the 3 groups; 56 originally invited to participate but 14 refusals, also 1 later drop out). Carers of people with Alzheimer’s type dementia. Intervention group: 9 spouse, 3 adult children, 2 sibling carers; 9 female; mean age 70; mean duration of dementia in months: 58. Control group A: 8 spouse, 6 adult children carers; 9 female; mean age 63; mean duration of dementia in months: 63. Control group B: 5 spouse, 8 adult children, 1 sibling carer; 11 female; mean age 58; mean duration of dementia in months: 38. Patients and carers recruited via health services.</td>
<td>Individually based intervention for carers of people with dementia with 3 components: carer education (3 sessions); stress management (6 sessions); and coping skills training (5 sessions). Principal aim to reduce carer stress rather than modification of the disease. 14 fortnightly sessions plus 4 booklets. Delivered by a clinical psychologist in Manchester. Control groups received usual care. Control group A was also given an in-depth interview to identify any cathartic effect from this.</td>
<td>Emotional well-being (GHQ and Beck Depression Inventory). Measures at pre-intervention, post intervention (9 months after trial entry) and 3 month follow up (12 months after trial entry).</td>
<td>Overall: moderate for outcome measurement. A:m; B:s; C:m; D:m; E:s; F:s; G:m; H:m.</td>
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<td>Mason et al 2006 Qualitative feedback from a cross-sectional survey.</td>
<td>n=9 carers of people with the early stages of dementia. Relationships not specified. 8 female, 1 male; mean age 68 years. All participants in 2 groups invited to respond.</td>
<td>Psychoeducational groups for people with early stage dementia and their carers. Aims: to improve understanding of dementia, memory problems and the role of medication; and to facilitate client and carer coping practically and emotionally. Once a week for 1.5 hours for 7 weeks. Held in a day hospital in Worcestershire. Led by a clinical psychologist.</td>
<td>Retrospective qualitative feedback. (Outcome measurement data is not included here because it is not broken down for carers and people with dementia.)</td>
<td>Overall: weak for outcome measurement. Overall: weak for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:n; 6:n; 7:y.</td>
</tr>
<tr>
<td>Mitchell 2000 Uncontrolled longitudinal outcome measurement.</td>
<td>n=7 carers (6 completed post intervention measures). 6 spouse carers and 1 daughter carer of an elderly person with dementia/confusion. 5 female, 2 male. 6 caring at home, 1 for someone in a nursing home (outside scope of review). All group participants invited to participate in study.</td>
<td>Structured stress management support group for carers of people with dementia. 4 sessions of 1.5 hours weekly. Content: 1 – what is stress and anxiety, breathing; 2 – dealing with panic/anxiety; 3 – problem solving, assertiveness solutions, relaxation options, deep muscle relaxation; 4 – assertiveness. Weekly handouts provided. 7 group members, attendance always a minimum of 5, only 1 carer missed 2 sessions. Held in a hospital.</td>
<td>10 questions covering self-ratings of awareness and understanding of stress and its management; and the Carer’s Checklist covering dementia related problems and associated burden. Measures pre-intervention and 1 month after intervention completion.</td>
<td>Overall: weak for outcome measurement. A:m; B:m; C:w; D:w; E:w; F:s; G:m; H:w.</td>
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### A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence

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<tr>
<th>Reference and design</th>
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<td>53. Moniz-Cook et al 1998. RCT plus qualitative interviews.</td>
<td>n=30 carers of people with dementia (15 intervention, 15 control group; 10 from each group assessed at 6 months and follow-up.) Other sample details not given.</td>
<td>All received: 45 minute feedback interview upon diagnosis; 3 advice pamphlets covering information on dementia, crisis prevention advice and everyday memory games; usual care from elderly mentally infirm support team in Hull. Intervention consisted firstly of psychoeducation followed by active training in memory management for patient and carer. Psychoeducation: home-based, 6-12 hours over 4-14 weeks, provided by a clinical psychologist. Content: structured information on diagnosis; role of carer and patient well-being in crisis prevention; counselling; emphasis on maintenance of social activities. Memory management: individualised memory rehabilitation with carer to act as therapist, up to 10 further contacts. Advice reinforced at 6 month interview and by health service contacts on ongoing basis.</td>
<td>Emotional well-being (GHQ-30, Beck Depression Inventory, Hospital Anxiety and Depression Scale). Measures at 6 months and 18 months after diagnosis.</td>
<td>Overall: weak for outcome measurement. A:w; B:s; C:w; D:m; E:s; F:m; G:m; H:m. Overall: weak for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:n; 6:n; 7:n.</td>
</tr>
<tr>
<td>54. Morris et al 1992 Controlled longitudinal outcome measurement.</td>
<td>n=31 carers of people with dementia (13 in ways of coping group, 18 in information group; additional 4 had refused to participate.) Ways of coping group: 31% spouse, 62% adult child; mean age 57. Information group: 28% spouse, 61% adult child; mean age 57. Patient eligibility: only included if there had been a progressive decline in intellectual functioning in previous 6 months.</td>
<td>Comparison of 2 carer support groups: ways of coping; and information-based. 5 weekly sessions of each run with 3 groups with a maximum of 8 group members each. Ways of coping group. Content: understanding dementia and related problems; management of behavioural problems; coping with stress; ways of involving other people; using formal services. Overall a problem-solving approach. Information group. Seminar format with presented information and facilitated discussion of issues related to personal experience. Invited speakers typically including a psychogeriatrician, a clinical psychologist, a community psychiatric nurse, a social worker and a worker from a voluntary organisation for dementia sufferers.</td>
<td>Coping (Coping Strategies questionnaire); emotional well-being (Beck Depression Inventory and a strain scale); Knowledge of Dementia questionnaire; and consumer satisfaction questionnaire. Measures at pre and post intervention and 3 month follow-up.</td>
<td>Overall: moderate for outcome measurement. A:w; B:m; C:m; D:m; E:m; F:s; G:m; H:m.</td>
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<td>55. Nathwani 2006 Cross-sectional survey.</td>
<td>n=7 spouse carers of people with dementia at various stages. (2 patients in residential care – excluded from this review.) No other sample details given. All 7 group members invited to participate.</td>
<td>Psychoeducation group for carers of people with dementia. 1.5 hours weekly for 7 weeks. Content: 1 – introductions and programme; 2 – causes of memory problems, diagnosis and medication; 3 – understanding unusual behaviour and dealing with problems; 4 – break services and benefits; 5 – social services and voluntary sector support; 6 – stress and coping with caring; 7 – further support, information leaflets. Individual sessions run by relevant professionals. Referrals from the older adults community mental health team.</td>
<td>Retrospective perceptions of knowledge and other benefits gained.</td>
<td>Overall: weak for outcome measurement. Overall: moderate for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:y; 6:n; 7:y.</td>
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A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence

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<tr>
<td>56. Harding et al 2002</td>
<td>n=73 carers (36 received the intervention, 37 control who chose not to take up the intervention) Carers of people receiving a home care palliative service: 63 with cancer, 4 HIV, 2 motor neuron disease, 1 Bechet’s disease, 1 congestive heart failure, 1 Leigh’s syndrome, 1 Parkinson’s. 86% partner; 18% adult child; 11% parent. 69% female; 80% white, 8% black, 7% Asian, 6% other; mean age 59, range 26-88. Mean of 15.4 hours care provided per week, range 1-24; mean duration in caring role 27 months.</td>
<td>Closed multi-professional group ‘the 90 minute group’ (for carers but deliberately not labelled in this way) in London. Aim: to promote self-care by combining information teaching with group support. 6 weekly sessions of 90 minutes with a maximum of 12 carers per group. Weekly speaker (welfare benefits advice, occupational and physical therapy, clinical nurse specialist and aromatherapy) followed by facilitated group discussion. Initial focus on patient issues to provide legitimacy for attendance. Transport and a sitting service were provided. Usual care for control group.</td>
<td>Burden (Zarit Burden Inventory); coping (Coping Responses Inventory); emotional well-being (GHQ-12 and State Anxiety Scale). Measures at pre-intervention, post-intervention and follow up (5 months from baseline).</td>
<td>Overall: weak for outcome measurement. A:w; B:m; C:s; D:w; E:n; F:w; G:s; H:m.</td>
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<tr>
<td>57. Harding et al 2004</td>
<td>Controlled longitudinal outcome measurement plus qualitative interviews.</td>
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<td>58. Robinson et al 2005</td>
<td>n=12 carers of people who had had a stroke. Other sample details not given. All group attendees invited to participate in study. 2 groups were run: the first (5 carers) gave qualitative feedback; the second (7 carers) completed a satisfaction questionnaire.</td>
<td>Small group course for carers of stroke patients based upon coping theory and cognitive behavioural therapy. In North Tyneside. Content: individualised provision of information; emotional adjustment; stress management; enhancing self-efficacy and self-worth. Jointly facilitated by a clinical psychologist and specialist stroke nurse. 6 sessions. Participants recruited through advertising in health service settings, invited to join 6 months after patient discharge from hospital as this is often a time of difficulty.</td>
<td>Retrospective qualitative feedback and satisfaction reports.</td>
<td>Overall: weak for outcome measurement. Overall: weak for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:y; 7:y.</td>
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<td>59. Secker &amp; Brown 2005</td>
<td>n=30 (15 intervention, 15 control) Primary carer of an individual with Parkinson’s Disease; 87% spouse. 90% female; mean age 59 years; 43% in employment. All with a score of 5 or more (indicating a case of psychological morbidity) on the GHQ-28.</td>
<td>Cognitive behavioural therapy in an individualised format. Range of 11-19 therapy sessions (mean 14.7) typically at one week intervals. 8 modules covering: education and introduction to CBT; accessing community resources and supports; pleasant activity scheduling; relaxation training; sleep improvement; identifying and challenging negative thoughts and feelings; challenging maladaptive rules and core beliefs; review, planning for the future and ending of treatment. The choice and order of the modules was based upon collaborative prioritisation of needs with the carer. Delivered by a clinical psychologist.</td>
<td>Emotional well-being (GHQ-28, Geriatric Depression Scale, Caregiver Strain Index and Caregiver Burden Inventory). Measures at baseline, at the end of treatment (3 months later) and at 6 months.</td>
<td>Overall: weak for outcome measurement. A:w; B:m; C:w; D:w; E:s; F:m; G:m; H:m. Overall: weak for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:n; 6:n; 7:n.</td>
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<tr>
<td>60. Simons et al 2006</td>
<td>n=14 carers of people with Parkinson’s Disease at different stages of the disease. 13 spouse, 1 relationship not specified. 8 female, 6 men; mean age 65. Recruited via local branches of the British Parkinson’s Disease Society and local newspaper articles. 4 completed less than 5 of the 8 sessions, data from these carers is not included here.</td>
<td>Education programme for people with Parkinson’s Disease and their carers. Separate sessions for patients and carers. 8 sessions of 90 minutes each. Aim: to empower participants to deal with psychosocial problems. Content covered: information; self-monitoring; health empowerment through pleasant activities; stress management; anxiety and depression; the carer’s challenge; social competence; and social support. Located in a day hospital.</td>
<td>Rating of current mood on 100 point visual analogue scale; health related quality of life (Euro-Qol-5D statements on anxiety and depression and performance of usual activities); depression (self-rating depression scale); and psychosocial problems in Parkinson’s Disease carer specific questionnaire. Measures before and after intervention.</td>
<td>Overall: weak for outcome measurement. A:w; B:m; C:w; D:w; E:m; F:m; G:m; H:m.</td>
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A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence

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<th>Reference and design</th>
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<th>Quality appraisal</th>
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<tr>
<td>61. Sinnakaruppan et al 2005 RCT.</td>
<td>n=45 carers of people with head injury (25 intervention and 20 control; 23 intervention and 19 control followed up). Intervention group: 8 parents, 15 partners; 18 female, 5 male. Control group: 8 parents, 10 partners; 15 female, 4 male. Recruited as patient-carer pairs from a rehabilitation centre in Ayrshire.</td>
<td>Educational group training programme for people with head injury and their carers. Separate patient and carer groups. Addressed 3 main problems arising from head injury: memory; executive functions; and emotions, especially anxiety, depression and anger. 8 sessions each of 2.5 hours. On average, 7 participants per group. Run by a neuropsychologist. Format: didactic presentations, group discussions and role play. Handouts provided.</td>
<td>Emotional health (Hospital Anxiety and Depression Scale, the GHQ-28); the Rosenberg Self-Esteem Scale; coping (the COPE scale); and the Functional Independence Measure. Measures before and after intervention and at 3 month follow-up.</td>
<td>Overall: weak for outcome measurement. A:m; B:s; C:w; D:w; E:s; F:s; G:w; H:w.</td>
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# A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence

## Table 13: Studies of befriending schemes (discussed in section 3d. iii., page 76)

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<tr>
<td>62. Charlesworth et al 2008 RCT.</td>
<td>n=136 carers of people with dementia (at allocation: 116 intervention group, 120 control; follow up 1: 101 intervention group, 111 control group; follow up 2: 93 intervention group, 104 control group; follow up 3: 90 intervention, 95 control)</td>
<td>Access to a befriender facilitator and the offer of contact with a trained volunteer befriender (compared to usual care). Expectation that befriending visits would be weekly home visits for at least 6 months, but individual variation as appropriate. Befrienders to provide companionship, conversation, a listening ear and emotional support plus some informal 'signposting' or support, but not giving advice or carrying out practical tasks.</td>
<td>Primary measures: depression (Hospital Anxiety and Depression Scale); health related quality of life (Euro-Qol 5D). Others: anxiety (HADS); loneliness (2 item Stroebe measure); positive affectivity (Positive and Negative Affect Schedule); and global health. Measures at baseline, 6, 15 and 24 months (main end point 15 months).</td>
<td>Overall: strong for outcome measurement. A:m; B:s; C:s; D:m; E:s; F:s; G:m; H:s.</td>
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**Table 14: Studies of complementary therapies** (discussed in section 3d. iv., page 77)

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<tr>
<th>Reference and design</th>
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<th>Outcome measures</th>
<th>Quality appraisal</th>
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| **63. Mackereth et al 2005**  
Mixed methods: uncontrolled longitudinal and qualitative interviews. | n=182 pre and post-intervention carer records analysed, plus:  
n=34 carers in pre and post intervention assessment, plus n=23 self-completion questionnaires.  
Carers of people with cancer, mix of relationships.  
Approx. 75% female.  
All those who chose to have the intervention were invited to participate within 1 hospital site.  
Some qualitative feedback from the therapists also included. | Massage resting on a chair either by the bedside of the patient or in a day room, given over clothes, focusing on the back, shoulders, arms, neck and head. Lasting 15 minutes. Delivered individually by one of six therapists. | 'Feeling Good thermometer' visual analogue scale and 2 Likert scales (physical and psychological) from 0 to 10 for well-being, reported worry and sleep quality.  
Measures taken prior to massage, post massage and next day. | Overall: weak for outcome measurement.  
A:w; B:m; C:w; D:w; E:w; F:m; G:s; H:m  
Overall: strong for explanatory findings.  
| **64. Papadoulos et al 1999**  
Qualitative interviews with carers. | n=4 carers.  
2 caring for their spouse, 2 caring for their mother.  
All female. Other details not given.  
Study undertaken in Birmingham. | Aromatherapy. All participants had received aromatherapy from the same aromatherapist for the past year. | Open qualitative feedback on perceived benefits. | Overall: weak for outcome measurement.  
Overall: moderate for explanatory findings.  
### Table 15: Studies of education programmes for carers (discussed in section 3e. i., page 80)

<table>
<thead>
<tr>
<th>Reference and design</th>
<th>Sample characteristics</th>
<th>Intervention</th>
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<th>Quality appraisal</th>
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<tr>
<td>65. Birchwood et al 1992 Controlled longitudinal outcome measurement.</td>
<td>n=94 carers of people with schizophrenia. (47 group intervention, 30 postal intervention, 17 video intervention; 62 completed the follow up questionnaire). Initially 157 invited to participate, 23 dropped out, 40 who scored above the 75th percentile on the knowledge measure were excluded. No detail on sample recruitment procedures.</td>
<td>Education programme for carers of people with schizophrenia. 4 components covering: the nature, aetiology and outcome of schizophrenia; explanation and examples of symptoms; benefits of medication, side effects and the role of the family; and professional resources available, need for family to consider own needs and residual symptom management. An information booklet covered each component. Information was provided weekly. Delivered in 3 different ways to the 3 groups: 1: via small group education led by 2 therapists, oral presentation with audiovisual aids and question and answer discussion, information booklets supplied. 2: information booklets sent through the post, no opportunity for discussion of material. 3: information provided on 4 videos corresponding to the booklets of 15-20 minutes each, booklets also supplied, no opportunity for discussion of material. Approximately half of each of the 3 groups were also allocated homework to examine the effect of this.</td>
<td>Knowledge questionnaire; scales covering beliefs and expectations of the family’s role in treatment, medication and patient control over symptoms; Family Distress Scale; and the Social Functioning Scale. Measures at pre and post intervention and at 6 month follow-up.</td>
<td>Overall: weak for outcome measurement. A:w; B:m; C:w; D:m; E:s; F:m; G:w; H:m.</td>
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<tr>
<td>66. Brumfitt et al 1994 Cross-sectional survey.</td>
<td>n=14 carers of people with aphasia. No other carer characteristics given. Recruited via the speech and language therapy departments in 2 areas: South Yorkshire and North Derbyshire.</td>
<td>A booklet giving information about stroke and communication problems. 20 pages, large print. Included specific information about strokes; case histories with samples of comments from carers about how they felt; and other problems following stroke such as changes to emotions and sexual feelings. It did not include guidelines for helping the patient with communication but made suggestions about where the carer could seek support. Given to carers at the time of hospital discharge. Carers were asked to keep the booklet for at least 3 months.</td>
<td>Evaluation questionnaire about use of booklet. Completed post-intervention.</td>
<td>Overall: weak for outcome measurement. Overall: moderate for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:y; 6:n; 7:y.</td>
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<tr>
<td>67. Budd &amp; Hughes 1997 Qualitative interviews with carers.</td>
<td>n=20 carers of people with schizophrenia. 15 parents, 4 spouses, 1 sister. 16 female, 4 male; mean age 50. All intervention recipients invited to participate sequentially until target sample of 20 reached.</td>
<td>Family educational intervention, typically 4-5 sessions of about an hour in the family’s home delivered by 2 therapists. Programme content: 1 – understanding schizophrenia as an illness; 2 – main symptoms of schizophrenia; 3 – role of medication and family in improving patient’s life; 4 – information about local services, strategies for managing symptoms and encouragement of patients and carers to address their own needs. Delivered in South Wales.</td>
<td>Retrospective qualitative feedback.</td>
<td>Overall: weak for outcome measurement. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:y; 7:y.</td>
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<tr>
<td>68. Kempenaar et al 2002 RCT plus qualitative interviews with carers.</td>
<td>n=105 carers of people with dementia (split into an intervention and two control groups). No other sample details given.</td>
<td>6 week structured education programme. Aim to promote empowerment and a sense of mastery regarding the caring role. Sessions covered areas of biomedical knowledge, coping skills and service provision. Control group 1 received a single psychosocial intervention: a needs led intervention offering people support or information as requested. Control group 2 entered a waiting list for 18 weeks.</td>
<td>Unspecified measures of depression, stress, knowledge of dementia and service use. Measures pre and post intervention and at 3 month follow-up.</td>
<td>Overall: weak for outcome measurement. A:w; B:s; C:w; D:m; E:w; F:w; G:w; H:w. Overall: weak for explanatory findings. 1:n; 2:y; 3:y; 4:n; 5:n; 6:n; 7:n.</td>
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## A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence

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<tr>
<td>69. Mendham 2007</td>
<td>n=8 carers of people with dementia. Other sample details not given.</td>
<td>Information groups for carers of people with dementia. 9 weekly sessions of 2 hours each covering: what is dementia; understanding behaviour; communication; legal and financial issues/welfare rights; accessing services; caring for yourself; continence; moving and handling; activities and stimulation. Delivered by different professionals according to the topic. Attendees encouraged to ask questions and to contribute. Information provided to take away. Transport and a sitting service provided. Self-referrals plus referrals from statutory services.</td>
<td>Retrospective qualitative feedback. Reliability is questionable as participants had attended the intervention a long time ago – 4-5 years previously.</td>
<td>Overall: weak for outcome measurement. Overall: weak for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:n; 6:n; 7:n.</td>
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<td>70. Moniz et al 1991</td>
<td>n=10 carers of people with dementia. Other carer characteristics not given. Participants invited from those caring for a person receiving substantial input from a hospital in Hull.</td>
<td>Closed educational group with the aims of increasing awareness of services and facilities locally, providing information about dementia and offering social contact. Facilitated by 2 nurses from the day hospital and a social work assistant. Six sessions covering: introduction and aims; nature of dementia; coping with dementia; social services provision; coping with incontinence; and carers rights and benefits. 1.5 hours weekly.</td>
<td>Dementia knowledge questionnaire. Measures before and after intervention.</td>
<td>Overall: weak for outcome measurement. A:w; B:m; C:w; D:w; E:w; F:s; G:m; H:w.</td>
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<tr>
<td>71. Morris 2001</td>
<td>n=33 carers 11 carers of someone who had had a head injury 2-9 months ago, all were followed up. 4 partners, 7 parents; 10 female, 1 male. 22 carers of someone who had had a head injury 1 year or more ago, 16 completed the second questionnaire. 8 partners, 13 parents, 1 sibling; 17 female, 5 male. Self-selection of participants notified of study through range of medical organisations.</td>
<td>An information booklet for carers of people with head injury (mild, moderate or severe). Four sections covering: about head injury; effects and coping with cognitive impairment; effects and coping with emotional and behavioural change; ways for the carer to look after themselves.</td>
<td>Emotional health (GHQ-28, Hospital Anxiety and Depression Scale); and Symptom Checklist covering physical, emotional and behavioural changes frequently occurring following head injury. Measures taken before and after intervention. Also a booklet questionnaire covering readability, interest and style etc completed post-intervention.</td>
<td>Overall: weak for outcome measurement. A:m; B:m; C:w; D:w; E:m; F:m; G:s; H:m. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:n; 7:y.</td>
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<td>72. Rodgers et al 1999</td>
<td>n=176 carers of stroke patients (107 recruited to intervention and 69 to control group; 20 attended 3 sessions or more of the intervention; 65 intervention group completed follow up measures, 41 control group completed follow up measures) Intervention group: 44% spouse; 70% female; median age 58. Control group: 43% spouse; 67% female; median age 60. Recruitment via a stroke unit in North Tyneside; 51% patient participation rate.</td>
<td>Stroke education programme. Rolling programme of one 1 hour small group educational session for in-patients and their carer followed by six 1 hour educational sessions following discharge. Aims: to improve knowledge of stroke and treatments; to give advice about prevention; provide an opportunity for questions; and social support. Content of 6 follow-up sessions: the nature of stroke; the role of physiotherapy and occupational therapy in care; the psychological effects of stroke; caring for a stroke patient; communication and swallowing problems; reducing the risk of stroke, the Stroke Club. Sessions were led by various professionals depending on the topic. Routine care and information provided for all.</td>
<td>Health (Short Form-36); tailored knowledge of stroke questionnaire; satisfaction with services; emotional health (GHQ-30). Measures before and after intervention and at 6 month follow-up.</td>
<td>Overall: moderate for outcome measurement. A:w; B:s; C:s; D:m; E:m; F:m; G:w; H:s.</td>
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<td>73. Smith et al 2004 RCT.</td>
<td>n=97 carers of people who have had a stroke (49 intervention, 48 control; at 3 months follow up: 43 intervention, 37 control; at 6 month follow up: 40 intervention, 36 control). Intervention group: 73% partner; 65% female; median age 65. Control group: 71% partner; 50% female; median age 67. All patients admitted to a stroke rehabilitation unit in a city in the North of England were invited to participate with a carer.</td>
<td>An education programme for patients and carers recovering from stroke focused around the process of rehabilitation goal setting. A copy of the Stroke Recovery Programme manual was given to participants covering: causes and consequences of stroke; stroke recovery; financial benefits; relevant services; and information for carers. Participants were also invited to attend specifically convened meetings every 2 weeks of about 20 minutes with members of their multi-disciplinary team. All received usual care and information as well.</td>
<td>Stroke knowledge questionnaire; emotional health (GHQ-28); and satisfaction. Measures before intervention, after 3 months and after 6 months.</td>
<td>Overall: moderate for outcome measurement. A:m; B:s; C:m; D:m; E:w; F:m; G:w; H:m.</td>
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A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence

### Table 16: Studies of training for carers (discussed in section 3e. ii., page 87)

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<tr>
<td>74. Allen &amp; Brown 1996 Uncontrolled longitudinal outcome measurement plus qualitative feedback comments.</td>
<td>n=4 carers of people with dementia (not at severe stage); 3 partners, 1 daughter. All female. All 4 members of one memory aid group in Aylesbury recruited.</td>
<td>A memory aid group based at a GP practice for clients and carers. Once a week for 1.5 hours for 6 weeks. Covered: understanding memory difficulties; external memory aids; internal memory aids; physical health, activity and memory; cognitive strategies and review of approaches. Sessions included suggestions from group leaders, discussion of coping strategies, sharing of experiences, tea breaks, handouts and weekly homework. Co-run by a clinical psychologist, nurse and health adviser for the elderly.</td>
<td>Relative stress scale and behaviour and disturbance scale. Measures pre and post intervention.</td>
<td>Overall: weak for outcome measurement. A:w; B:m; C:w; D:w; E:s; F:s; G:w; H:s. Overall: weak for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:y; 6:n; 7:n.</td>
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<tr>
<td>75. James and Sabin 2005 Uncontrolled longitudinal outcome assessment.</td>
<td>n=14 carers (12 post-intervention responses, 6 follow-up responses) Carers of people with dementia at the stage of mild memory problems. 10 spouses, 3 daughters, 1 nephew. 9 female, 5 male. Patients were invited to participate based on their diagnosis and interest in participating in a group.</td>
<td>Two memory groups. Covered a range of issues relating to memory and aimed to assist clients and carers to develop a prosthetic home environment by educating them about various external memory aids. Aimed to develop supportive, therapeutic relationships with the presenters and other members of the group. Newcastle.</td>
<td>Memory Awareness Rating Scale to measure carer perceptions of relative’s memory abilities; Carer’s Stress Scale; General Health Questionnaire for emotional well-being; and Coping Response Inventory to assess coping strategies. Measures taken pre-group, post-group and at 3 month follow-up.</td>
<td>Overall: weak for outcome measurement. A:w; B:m; C:w; D:w; E:s; F:w; G:w; H:m.</td>
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<td>76. Booth and Swabey 1999 Uncontrolled longitudinal quantitative outcome measurement.</td>
<td>n=4 carers of people with aphasia. 1 brother, 1 wife, 1 husband and 1 niece of the person receiving care. 2 female, 2 male. Selection influenced by the clinical availability of clients with carers when the study started.</td>
<td>A communication skills group programme for carers of people with aphasia. Once a week for 2 hours for 6 consecutive weeks. Conversation analysis was used to guide individualised advice that was incorporated into the group through written advice sheets. The course included lectures, discussions and workshops in which carers analysed conversation extracts.</td>
<td>The Conversation Analysis Profile for People with Aphasia and a quantitative and qualitative analysis of the carer’s collaborative repair of conversation breakdown. Measures pre and post intervention.</td>
<td>Overall: weak for outcome measurement. A:w; B:m; C:w; D:w; E:w; F:s; G:w; H:s. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:y; 7:y.</td>
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<td>77. Lesser &amp; Algar 1995 Uncontrolled longitudinal outcome measurement plus qualitative interviews.</td>
<td>n=3 carers of people with aphasia. A comparison is made of carer of person A, a sister carer, age 73, retired and carers of person B, 2 friend carers, 1 male, 1 female, age 44 and 26, 1 employed, 1 student. Method of sample selection not given.</td>
<td>Compilation of individually tailored communication advice booklets for carers. Developed based on analysis of a 90 minute conversation extract. About 20 pages. Content: brief introduction of nature of patient’s type of stroke and aphasia; account of specific word-finding difficulties; main part – advice on recommended communication strategies. Carers were encouraged to apply the strategies.</td>
<td>Analysis of naming tasks and conversation samples for successful use of strategies; knowledge questionnaire; plus qualitative feedback. Measures at baseline, given booklet at 3 weeks, then repeat measures taken a further 2 months later.</td>
<td>Overall: weak for outcome measurement. A:w; B:m; C:w; D:w; E:m; F:s; G:m; H:s. Overall: weak for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:n; 6:n; 7:n.</td>
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<td>78. Cullen et al 2004 (pre and post intervention measurements)</td>
<td>n=99 (82 completed the follow up)</td>
<td>Carer training in giving simple massage to the child. 8 weekly sessions of 1 hour by a trained therapist working one-to-one, supported by a training information pack.</td>
<td>Carer perceived health status (visual analogue scale); psychological well-being (Hospital Anxiety and Depression Scale); self-confidence in managing child’s well-being (Psychosocial sub-scale of the Parent’s Self-Efficacy Scale); carer self-efficacy in massage. Measures at baseline, immediately after the intervention at 8 weeks and 12 months later comparing those who had and had not continued to use massage.</td>
<td>Overall: weak for outcome measurement. A:m; B:m; C:w; D:w; E:w; F:s; G:s; H:s. Overall: moderate for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:n; 7:n.</td>
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<tr>
<td>79. Williams et al 2005 (12 month follow up) Uncontrolled longitudinal outcome measurement.</td>
<td>n=99 (82 completed the follow up)</td>
<td>Carers of children with a range of disabilities including cerebral palsy and autism spectrum disorders. 85% mothers, 11% fathers, 4% grandmothers (this varied slightly at the second follow up point). 91% white European (as recorded at first follow up); 46% working full or part-time (as recorded at first follow up).</td>
<td>Carer training in giving simple massage to the child. 8 weekly sessions of 1 hour by a trained therapist working one-to-one, supported by a training information pack.</td>
<td>Overall: weak for outcome measurement. A:m; B:m; C:w; D:w; E:w; F:s; G:s; H:s. Overall: moderate for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:n; 7:n.</td>
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<td>80. Done &amp; Thomas 2001 RCT.</td>
<td>n=45 carers (30 workshop, 15 booklet).</td>
<td>Comparison of training in communication skills for carers of people with dementia via: i) a short workshop – 2 sessions of 1 hour separated by a week using video examples discussed by a therapist. ii) a booklet presenting similar information and advice in an interesting format.</td>
<td>Assessment of Awareness about Communication Strategies (AACS); stress (relatives stress scale); 10 communication and 10 behavioural problems (The Thomas Assessment of Communication Inadequacy). (The behaviour assessments provided a within subjects control.) Consumer evaluation (based upon Likert scales). Measures pre-intervention and at 6 weeks post intervention.</td>
<td>Overall: weak for outcome measurement. A:m; B:s; C:w; D:m; E:w; F:w; G:m; H:s. Overall: weak for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:y; 6:n; 7:n.</td>
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<td>81. Kalra et al 2004 RCT.</td>
<td>Carers of people with stroke; 66% spouse carers. (Numbers and other characteristics not given.) Recruited via n=300 stroke patients from a stroke rehabilitation unit.</td>
<td>Stroke carer training. Covered instruction on common stroke related problems and their prevention, advice on local benefits and services, ‘hands-on’ training in lifting and handling, moving and transfers, continence, assistance with personal activities of daily living and communication. Tailored to the needs of individual patients. 3-5 sessions depending on need of 30-45 minutes. Training began when discharge was contemplated. 1 follow through session at home. Study undertaken in a largely middle class suburban area. All (including controls) received usual care. 75 patients in each group also received a family support worker.</td>
<td>Function and social activities (Frenchay activities index); anxiety and depression (Hospital Anxiety and Depression Scale); emotional health (Caregiver burden scale); and quality of life (EuroQol visual analogue scale). Measures were taken at 3 and 12 months after stroke onset.</td>
<td>Overall: moderate for outcome measurement. A:m; B:s; C:m; D:m; E:s; F:m; G:m; H:s.</td>
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A Systematic Review of Interventions for Carers: Outcomes and Explanatory Evidence

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<tr>
<td>82. Poole 1993 Qualitative feedback.</td>
<td>Feedback on 2 different specific training events was given by a sample of 7 carers in each case. Sample details for carers and staff who gave feedback on the programme as a whole are not given.</td>
<td>A programme of carer training with 5 components delivered separately as 1 day courses. These covered: identifying the carer’s own needs; maintaining self-help groups; developing self-help groups effectively; listening and responding effectively; and assertiveness/carers speaking up for themselves. The overall aim was to empower carers through the maintenance of support or lobbying groups or through the development of personal and interpersonal skills. Delivered across England and Wales.</td>
<td>Retrospective qualitative feedback.</td>
<td>Overall: weak for outcome measurement. Overall: weak for explanatory findings. 1:n; 2:n; 3:n; 4:n; 5:n; 6:n; 7:n.</td>
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<tr>
<td>83. Sepulveda 2008 Uncontrolled longitudinal outcome measurement plus qualitative carer feedback.</td>
<td>n=35 carers (28 used in analysis as 2 dropped out of follow-up and 5 couples were included). Carers of people with eating disorders (22 anorexia nervosa, 6 bulimia nervosa); 26 parents, 1 spouse and 1 sibling. 23 female, 5 male; mean age 53, range 28-68. Study participants invited via a support group, hospital, website and newsletter. Study undertaken in London.</td>
<td>The Maudsley eating disorder collaborative care skills workshops for family members of individuals with eating disorders. 6 workshops of 2 hours each over 3 months with an additional follow-up workshop 3 months after completion. Taught how to moderate expressed emotion and match goals and expectations with the patient’s stage of change and motivational interviewing to improve communication and readiness for change. Used strategies of problem solving, behavioural experiments and goal setting to foster change.</td>
<td>Emotional well-being (GHQ); Experience of Care-giving Inventory; Eating Disorder Impact Scale; attendance monitored for acceptability; visual analogue scales covering interest, utility and helpfulness. Measures taken at baseline, post-intervention and 3 months after the last workshop.</td>
<td>Overall: weak for outcome measurement. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:n; 7:y.</td>
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<tr>
<td>84. Sepulveda et al 2008 b Uncontrolled longitudinal outcome measurement plus qualitative carer feedback.</td>
<td>n=16 carers (14 completed the follow-up assessments). Carers of people with eating disorders. Relationships with person receiving care not explicitly stated but appear to be parents. 13 female, 3 male; mean age 52, range 41-66. Sampled carers from four sources who had varying levels of other support.</td>
<td>DVD based skills training supplemented with telephone coaching. The content was the same as for Sepulveda et al 2008 a. Five DVDs were delivered in two packs of two DVDs and then the final DVD. Supplementary telephone coaching (30 minute session) following a semi-structured format was given after each DVD pack was received.</td>
<td>Emotional well-being (General Health Questionnaire and Hospital Anxiety and Depression Scale); Experience of Care-giving Inventory; Family Questionnaire to assess the emotional climate in the family; tailored questionnaire to assess acceptability using visual analogue scales covering feasibility, interest, utility and helpfulness. Measures taken at baseline and after each of the 3 packs of DVDs were received.</td>
<td>Overall: weak for outcome measurement. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:n; 7:y.</td>
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<td>85. Thorgrimsen et al 2003 RCT.</td>
<td>n=11 carers of people with dementia. Further sample details not given.</td>
<td>‘Remembering Yesterday, Caring Today’ reminiscence programme. 18 weekly group sessions, 11 attended only by carers and volunteers to train them in using reminiscence with the people they cared for. Participants were referred to the programme by local health service staff.</td>
<td>Emotional well-being (GHQ-12, Relative Stress Scale). Measures at pre and post intervention.</td>
<td>Overall: weak for outcome measurement. Overall: weak for explanatory findings. 1:w; 2:s; 3:w; 4:w; 5:w; 6:w; 7:w.</td>
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<th>Sample characteristics</th>
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<td>Whitfield &amp; Acton 1992</td>
<td>n=13 carers of people with schizophrenia. Majority parent carers but also spouses, siblings and an adult child carer. Other sample details not given. All those on the programme were invited to participate in the study (20). n=16 staff involved with the programme including 1 psychiatrist, 6 nurses, 7 social workers, 2 occupational therapists.</td>
<td>‘Family Care in Schizophrenia Programme’ involving behavioural family management and health education. 3 major components. 1: a health education programme covering ‘what is schizophrenia?’: symptoms, probable cause(s), medication, abuse of drugs/alcohol, stress. 2: communication skills training covering: positive and negative comments and requests. 3: problem solving skills.</td>
<td>Retrospective satisfaction, knowledge and use of skills.</td>
<td>Overall: weak for outcome measurement.</td>
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Table 17: Studies of employment-related interventions (discussed in section 3f., page 96)

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<td>87. Arksey 2002</td>
<td>n=28 carers. No other sample details given. All those recruited to the project which was open to current carers receiving benefits, ex-carers and current or former ‘hidden’ carers not in contact with statutory services.</td>
<td>People into Employment project to support people with disabilities and carers into employment (findings for carers only reported here). Based in Sunderland. Provided by 1 Project Development Officer, although the project was overseen and supported by a partnership of just under 20 private, public and voluntary sector organisations. Services offered: identification of suitable job opportunities and work related training courses and/or placements; guaranteed interviews; help with application forms and interview techniques; transport and accompaniment to interviews; benefit advice; training; and a central link with other agencies/providers. Attempts were made to tailor support to the individual.</td>
<td>Number in employment.</td>
<td>Overall: weak for outcome measurement. A:w; B:m; C:w; D:w; E:s; F:w; G:w; H:m. Overall: weak for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:y; 6:n; 7:n.</td>
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88. Arksey 2003
Uncontrolled longitudinal outcome measurement plus qualitative interviews.
### Table 18: Studies of carer breaks (discussed in section 3g., page 98)

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<td>89. Ashworth &amp; Baker 2000 Qualitative carer interviews.</td>
<td>n=23 carers Mix of relationships with the person receiving care and of their conditions. 14 female; 17 white, 6 black African/Caribbean; mean age 65. Average number of years caring 12; 22 co-resident. Recruited via a day centre and residential home run by social services, a day centre and a residential home run by the NHS and a voluntary sector sitting service. 23 of 25 agreed to participate.</td>
<td>Carer breaks provided through the use by the person receiving care of a day centre and residential home run by social services, a day centre and a residential home run by the NHS and a voluntary sector sitting service.</td>
<td>Retrospective qualitative feedback.</td>
<td>Overall: weak for outcome measurement. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:y; 7:y.</td>
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<tr>
<td>90. Ashworth et al 1996 Cross-sectional survey.</td>
<td>n=21 carers of people with high dependency disability due to old age. 12 female; mean age 56, range 22-72. All carers of users of the service invited to participate. 50% response rate. Lambeth.</td>
<td>Carer breaks provided through the use by the person receiving care of an intermediate care centre (run by the health service). This offered 20 in-patient beds, 4 of which were dedicated to short stays. A full multi-disciplinary health team were based there and the ward was run by nurses. Individualised nursing using a care plan was offered. Mean duration of use was 4.5 years with a mean usage of 1 week in every 8 weeks.</td>
<td>Retrospective satisfaction and self-reports of physical and psychological well-being and ability to continue caring.</td>
<td>Overall: weak for outcome measurement. Overall: moderate for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:n; 7:n.</td>
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<tr>
<td>92. Eastwood 2007 Cross-sectional survey.</td>
<td>n=247 carers. No other sample details given. Questionnaire sent to all carers who went on the break.</td>
<td>A week’s break specifically for carers at a holiday centre on a free half-board basis (with or without the person receiving care). A variety of activities and events were on offer during the week.</td>
<td>Retrospective qualitative feedback plus satisfaction ratings.</td>
<td>Overall: weak for outcome measurement. Overall: weak for explanatory findings. 1:n; 2:y; 3:y; 4:n; 5:n; 6:n; 7:y.</td>
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<tr>
<td>93. Harper et al 1993 Uncontrolled longitudinal outcome measurement.</td>
<td>n=82 carers (45 followed up at 3 months) Carers of elderly people, predominantly with cognitive impairment. 45% spouses, 43% adult children carers. 43% female. Recruitment method not specified.</td>
<td>Carer breaks through use of a home-based care aide scheme (a sitting service) in Merseyside. Where possible, the same care aide provided the service over time. There were few formal guidelines in order to allow for flexibility and pragmatism in the service. Services provided included personal care, domestic help and social activities. Over the first 2 years of the scheme, the average number of hours provided per month rose from 4 to 16. There was flexibility in the amount and frequency of support provided. Referrals taken from health, social care and directly from carers themselves.</td>
<td>Emotional well-being (GHQ-30). Measures at baseline and 3 months later.</td>
<td>Overall: weak for outcome measurement. A:m; B:m; C:w; D:w; E:s; F:w; G:m; H:m.</td>
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<td>94. Homer &amp; Gilleard 1994 Uncontrolled longitudinal outcome measurement plus qualitative feedback.</td>
<td>n=77 carers of elderly people (54 were followed up successfully) Mean age 66, range 37-91. Recruited through geriatric services in 2 areas of London.</td>
<td>Carer break achieved through admission of elderly person to hospital in-patient short stay care.</td>
<td>Emotional well-being (GHQ-28) plus qualitative feedback. Measures prior to and during break.</td>
<td>Overall: weak for outcome measurement. A:m; B:m; C:w; D:w; E:s; F:s; G:s; H:s.</td>
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<tr>
<td>95. Johnston 1994 Cross-sectional survey.</td>
<td>n=25 carers of adults with learning disabilities (some also had physical disabilities or behavioural problems). Other carer details not given. All those eligible to use the services were invited to take part in the study; 25 of 33 did so.</td>
<td>Carer breaks achieved through the use by the person receiving care of either residential care or day care in Northern Ireland. 23 received day care at one of three units. 13 used social services residential care, 2 hospital-based residential care and 2 private residential care.</td>
<td>Retrospective measures of satisfaction.</td>
<td>Overall: weak for outcome measurement. Overall: weak for explanatory findings. 1:n; 2:y; 3:y; 4:n; 5:y; 6:n; 7:y.</td>
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<tr>
<td>96. Lee et al 2007 Uncontrolled longitudinal outcome measurement.</td>
<td>n=39 carers (33 were followed up) 31 spouse and 8 adult child carers of people with dementia. 26 female; mean age 67, range 34-87. All co-resident. Consecutive recruitment from 4 community hospital units providing the service in the East Midlands.</td>
<td>Carer breaks achieved through use by the person with dementia of 2 weeks of non-emergency care in one of four community hospital units.</td>
<td>Sleep assessment through wrist actigraphy plus questionnaires (The Pittsburgh Sleep Quality Index, the Medical Outcomes Study Short Form 36 and the Epworth Sleepiness Scale) and diary records. Measures collected continuously for 2 week periods prior to admission, during admission and immediately afterwards.</td>
<td>Overall: weak for outcome measurement. A:m; B:m; C:w; D:w; E:s; F:s; G:m; H:m. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:n; 7:y.</td>
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<tr>
<td>97. Levin et al 1994 Uncontrolled longitudinal outcome measurement plus qualitative interviews.</td>
<td>n=287 carers of people with dementia (243 followed up at 1 year) 57% spouse carers, 34% adult child (or child in law), 5% sibling, 4% other. 70% female; 100% white; mean age 66, range 23-92, 2/3 aged over 65. Sample recruited by asking service providers to provide details of elderly confused people living with at least 1 other; 89% participation.</td>
<td>Carer breaks via either day care, short-stay residential care or sitting services by any providers in the study areas. Mix of health, social services and voluntary sector provision. Mean amount of day care received by users was 14 hours per week. Mean amount of sitting services received by users was 3.5 hours per week, generally during weekdays. Amongst short-stay residential care users: 27% took very regular breaks every 6 weeks; a similar number every 8-12 weeks; 24% used the service occasionally, on average 3 weeks per year; the remainder had only just begun to use the service or did not intend to continue. Most stays were for a fortnight. Study undertaken in 3 areas of England: part of a city in a southern county; small towns and villages in a county in the Midlands; and part of a city in a northern Metropolitan district.</td>
<td>Satisfaction; psychological well-being (GHQ and SELFCARE Depression). Measures at baseline (carers were already using the services at this point) and 1 year later.</td>
<td>Overall: weak for outcome measurement. A:m; B:m; C:w; D:w; E:s; F:s; G:m; H:m. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:n; 7:y.</td>
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<td>98. McConkey et al 2004. Qualitative interviews.</td>
<td>n=25 carers of adults with learning disabilities. 15 parent, 9 sibling (including 2 in-laws) and 1 spouse carer(s). 8 aged 55-59, 10 aged 60-69, 6 aged 70-79, 1 aged 80-89. All scheme users invited to take part; 25 of 30 did so. n=30 (of 35) host family placement providers.</td>
<td>Carer breaks achieved through a family placement scheme for the person receiving care. 4 separate schemes in Northern Ireland covered: 2 organised by a voluntary sector organisation and 2 by a statutory sector provider. The individual with care needs would be matched to a host family. A host family would normally care for 1 or 2 people at a time and no more than 3. Average of 20 overnight stays per year (range 2-70) usually taken in the form of 2-3 day stays every 4-6 weeks, although there were also some week long stays. 5 received day placements. Referrals made mainly by social workers.</td>
<td>Retrospective qualitative feedback.</td>
<td>Overall: weak for outcome measurement. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:y; 7:n.</td>
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<td>99. McConkey &amp; McCullough 2006 Cross-sectional survey.</td>
<td>n=209 carers of adults with learning disabilities. No other carer details given. All carers using the service were invited to participate in the study.</td>
<td>Carer breaks achieved through the take-up of a holiday by the adult with a learning disability. Holidays organised by a training and resource centre for adults with learning disabilities in Belfast. Activities were tailored to the people on the holiday. In the first two years of the project, holidays took place in one specialist facility for people with learning disabilities. After this, a variety of mainstream locations and centres were used. Weekend or week long breaks; day breaks were also provided for those with more profound disabilities who could not be accommodated on the longer breaks.</td>
<td>Retrospective qualitative feedback.</td>
<td>Overall: weak for outcome measurement. Overall: weak for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:n; 6:n; 7:y.</td>
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<td>100. Milne et al 1993 Controlled longitudinal outcome measurement.</td>
<td>n=78 carers (63 intervention group, 15 control group) Carers of elderly people, most frequently with dementia or stroke. Intervention group: spouse carer 48%, adult child 48%; 68% female; mean age 57; mean length of time caring 1.6 years. Control group: spouse carer 73%, adult child 27%; 73% female; mean age 62; mean length of time caring 1.9 years. All carers referred to the scheme were invited to take part (136), 57% did so; those who did not take up the scheme formed the control group.</td>
<td>Carer breaks achieved through an Age Concern (voluntary sector) care attendant service. The care attendant replaces the carer for agreed periods of up to a few hours in the home undertaking all the carer’s tasks. Scheme based in Northumberland.</td>
<td>Stress (recognised scale used), Coping Responses Questionnaire, emotional well-being (GHQ); and satisfaction ratings. Measures at baseline and 3 months later.</td>
<td>Overall: weak for outcome measurement. A:w; B:m; C:w; D:m; E:m; F:w; G:w; H:m.</td>
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<td>101. Nicoll et al 2002 Cross sectional survey.</td>
<td>n=31 carers of people with dementia. 16 female; mean age 61, range 28-81. Surveys distributed via carer support groups, nursing homes, day centres and district nursing services in an inner city London borough to 140 carers; 22% response rate.</td>
<td>Carer breaks through use of any residential short stay care, day care or sitting service in the area. 65% of the sample had used residential care, 65% day care and 15% a sitting service. There was some overlap in service use.</td>
<td>Retrospective satisfaction ratings.</td>
<td>Overall: weak for outcome measurement.</td>
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<td>102. Nolan &amp; Grant 1992 Qualitative interviews with carers and staff plus service observation.</td>
<td>n=50 carers of elderly people, main disabilities were: results of cerebrovascular accidents, musculo-skeletal disorders, Parkinson’s Disease and mental frailty. 21 spouse carers, 22 adult children (or in law), 7 other. 43 female; mean age 67, range 46-87. Mean length of time caring 8.6 years, range 8 months to 60 years. All but 1 co-resident. Sample randomly selected; level of participation not given.</td>
<td>Carer breaks via short-stay hospital care for frail elderly people. Repeated and regular admission usually on a 2 weeks in, 6 weeks out basis. 5 units in a geographical area were included in the study. Three units had 30 beds, one had 28 and one had 40. 2 units were observed: 1 had a day hospital attached and regular input from therapy staff, while the other had limited staff input from any group other than nurses. Activity at the 2 units was largely informal and initiated by patients. Many carers were new to the service but some had been using it for 5 years or more.</td>
<td>Retrospective qualitative feedback.</td>
<td>Overall: weak for outcome measurement. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:n; 7:y.</td>
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<tr>
<td>103. O'Donovan 1992 Cross-sectional survey.</td>
<td>n=25 carers of people with dementia. 15 spouse carers. 18 female; 17 aged over 60, 4 aged over 80. Average time spent caring was 3.5 years.</td>
<td>Carer breaks through use of the Crossroads (voluntary sector) care attendant scheme. No further details given.</td>
<td>Retrospective satisfaction ratings and agreement with various statements of outcomes.</td>
<td>Overall: weak for outcome measurement. Overall: weak for explanatory findings. 1:n; 2:y; 3:n; 4:y; 5:n; 6:n; 7:n.</td>
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<td>104. Reid 1992 Qualitative interviews.</td>
<td>n=34 carers of people with dementia. 9 spouses, 2 sons, 19 daughters in law, 4 other carers. 28 female; 12 aged 25-44, 13 aged 45-64, 9 aged 65+. Length of time caring: 8 less than a year, 9 1-2 years, 16 more than 3 years.</td>
<td>Carer breaks through a sitting service in the home offered between 7am and 10pm. 7 days a week. Provided by a voluntary sector organisation in north and west Belfast. Provision was flexible including regular breaks, extra relief at times of crisis or for particular social occasions. The care worker provided: personal care; supervision; and stimulation/activities for the person with dementia. The sample had been receiving the service for at least 3 months. Almost a quarter of the carers received 5 or more hours per week and about half had 2 or more breaks per week.</td>
<td>Retrospective qualitative feedback.</td>
<td>Overall: weak for outcome measurement. Overall: moderate for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:n; 6:n; 7:y.</td>
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<td>106. Shlosberg et al 2004 Qualitative interviews.</td>
<td>n=5 spouse/partner carers of younger people with dementia (aged 42-64). 4 female; all white; mean age 57, range 52-60.</td>
<td>Carer breaks through the provision of day care up to 4 times weekly at a resource centre for younger people with dementia.</td>
<td>Retrospective qualitative feedback.</td>
<td>Overall: weak for outcome measurement. Overall: strong for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:y; 6:y; 7:y.</td>
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<td>107. Skilbeck et al 2005 Uncontrolled longitudinal outcome measurement plus qualitative interviews.</td>
<td>n=25 carers completed qualitative interviews; 14 completed pre and post intervention outcome measurements. Carers of people receiving palliative care in the last year of life, 15 with cancer and 12 with neurological conditions; 16 spouse carers. 23 female; mean age 61, range 38-78. Length of time caring range 6 months to 20 years, mean 6.5 years. First time and previous service users were invited to participate in the study.</td>
<td>Carer breaks through patient use of an independent hospice. A two week break provided twice a year, although some were also admitted to provide emergency breaks. Referrals predominantly from GPs and other health professionals.</td>
<td>The Relative Stress Scale Inventory. Measures taken before and after the break.</td>
<td>Overall: weak for outcome measurement. A:w; B:m; C:w; D:w; E:m; F:s; G:s; H:s.</td>
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<td>108. Swift et al 1991 Cross-sectional survey plus qualitative interviews.</td>
<td>n=257 carers returned a postal questionnaire for another research project but included data about this service. n=26 carers returned a postal questionnaire about this service specifically (self-selection). n=26 carers completed an in-depth interview (from 28 randomly invited to participate, not necessarily the same carers who responded to the postal survey). Carers of children with learning disabilities (aged 4-18). No other carer sample details given. n=11 host families were interviewed at home and 13 submitted written evidence.</td>
<td>Carer breaks achieved through placement of child with learning disabilities in a host family. Service run by Barnados voluntary organisation in Dyfed, Wales. For all users: average length of visit 30 hours 30 minutes; in a year, 34% had used the service on 10 occasions or less, 37% 11-30 visits and 29% more than 30 visits. Average length of family matches varied by area from 14 to 34 months. The service was demand-led, no-one was turned away but there could be a waiting period for a match.</td>
<td>Retrospective qualitative feedback.</td>
<td>Overall: weak for outcome measurement. Overall: weak for explanatory findings. 1:y; 2:y; 3:y; 4:n; 5:n; 6:n; 7:y.</td>
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<td>109. Tomlinson 1998 Uncontrolled longitudinal outcome measurement.</td>
<td>n=15 carers of frail elderly people (generally not with dementia) 11 spouse, 2 sister and 2 daughter carers. 13 female; mean age 73, range 45-90. Relatively high incidence of indicators of depression in this sample compared to other samples of this group. 45 users of the service invited to participate, 15 (33%) completed all parts.</td>
<td>Carers breaks achieved through the elderly person’s use of respite care beds at a community hospital in Birmingham. Mean duration of stay was 7.3 days, range 5-14. For this sample, all except one had previously used the service. The shortest regimen was for 1 week break, 4 weeks at home and the longest was 1 week break 3 times per year.</td>
<td>Geriatric Depression Scale, Philadelphia Geriatric Centre Morale Scale plus questions on carers’ views of the service. Measures taken before the break and a few days before the end of the break.</td>
<td>Overall: weak for outcome measurement. A:w; B:m; C:w; D:m; E:m; F:w; G:m; H:m. Overall: weak for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:n; 6:n; 7:n.</td>
</tr>
<tr>
<td>110. Treloar et al 2001 Controlled longitudinal outcome measurement plus a cross-sectional survey.</td>
<td>n=17 carers of people with dementia. Other carer characteristics not given.</td>
<td>Carer breaks achieved through the use by the person with dementia of a statutory service night centre in Bexley, London. Service used for 3 nights a week. Users collected at 8pm and returned home at 8am the next day. A group of regular users of the service were used as a control group and compared with a group of new users.</td>
<td>Emotional health (Relative Stress Scale, Beck Depression Inventory and GHQ-12). Measures taken before service use and 4 weeks later.</td>
<td>Overall: weak for outcome measurement. A:w; B:m; C:w; D:m; E:m; F:w; G:m; H:w.</td>
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<td>112. Walder 1995 Cross-sectional survey.</td>
<td>Sample number not given. Carers of people with dementia; 50% spouse carers. 72% female; over 60% aged 60+. Survey distributed to all carers of people attending day care in the Cornwall area; response rate not given.</td>
<td>Carer breaks achieved through day care of an elderly person with dementia in local day hospitals for this group.</td>
<td>Retrospective self-report of physical and emotional health, understanding of and management of dementia-related problems and satisfaction.</td>
<td>Overall: weak for outcome measurement.</td>
</tr>
<tr>
<td>113. Watkins &amp; Redfern 1997 Uncontrolled longitudinal outcome measurement plus qualitative interviews.</td>
<td>n=27 carers completed qualitative interviews; 26 completed the outcome measurements. 16 spouse, 8 adult children, 1 sibling, 2 other carers of people with dementia. 21 female. All carers of those using the service in a certain period invited to participate.</td>
<td>Carer breaks achieved through the person with dementia attending a night nursing hospital. They were collected between 8 and 9pm and taken back the following day between 8 and 9.30am. Attendance varied from 1 to 4 nights per week. Each patient was allocated a primary nurse. Carer’s ability to cope with and anxiety about the person with dementia (the Crichton Visual Analogue Scale). Measures at 4 points: within 1 week of first attendance, after 6 weeks, 12 weeks and 6 months.</td>
<td></td>
<td>Overall: weak for outcome measurement. A:w; B:m; C:w; D:w; E:s; F:s; G:m; H:m. Overall: weak for explanatory findings. 1:y; 2:y; 3:y; 4:y; 5:n; 6:n; 7:n.</td>
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