

# Supporting carers of people with dementia: what is effective?

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Carer stress is well documented, especially in those caring for individuals with dementia. A recommendation of all national dementia strategies is to provide excellent support and information to informal carers of people with dementia. NICE guidance suggests that a range of tailored interventions, including psychological input, psychoeducation and training courses, should be offered to reduce caregiver burden and stress, although good-quality outcome-based evidence is lacking. On the basis of a narrative review of the literature, we describe individual and multi-component carer support packages and discuss their evidence base, reflecting on outcomes for carers. Multicomponent interventions have the best evidence for effectiveness.

## LEARNING OBJECTIVES

- Consider the risks of both physical and psychological harm experienced by carers of people with dementia (often referred to as carer burden or caregiver burden)
- Be aware of the interventions available for the support of carers of people with dementia
- Consider the evidence for the effectiveness of these interventions and be aware of the limitations of the evidence

## DECLARATION OF INTEREST

None

Caring for a relative or friend with dementia is often described as burdensome (Acton 2001) and it can have an impact on carers' physical health (Pinquart 2003; Zhu 2015) and anxiety levels (Cooper 2007). In addition to providing care for people with dementia, health and social care services offer support for their carers, to improve outcomes for both and to reduce carer burden. Interventions to aid this group of carers include general carer support, education, formal approaches to care and respite, as well as multicomponent interventions (a combination of different types of intervention). But availability of these interventions varies nationally, and evidence of their efficacy is at best mixed, with considerable heterogeneity in results.

Reviewing the effectiveness of interventions for carers of people with dementia is not easy – mixed results from heterogeneous studies challenge the generalisability of findings and make it difficult to make evidence-based decisions regarding appropriate and timely support for carers. Furthermore, studies of such interventions are fraught with methodological difficulties, including poor quality (Acton 2001), lack of conceptual clarity of outcome measures (e.g. 'burden', which has subjective and objective measures), overlap between intervention types, poor definition of interventions, and small samples that often do not include men or ethnic minorities.

The purpose of this article is to provide an updated overview of the evidence base for interventions that are principally aimed at carers of patients with dementia. It is important to recognise, as pointed out by Gitlin and colleagues (2015), that most studies are carried out separately from the care system and may not be reflected in real-world practice.

## Method

Our review method is shown in online Fig. DS1. In essence, we searched MEDLINE, CINAHL, PsycINFO, the Cochrane Database, Social Care Online and Applied Social Sciences Index and Abstracts (ASSIA) for completed studies of all interventions principally aimed at carers of people with dementia. We excluded meta-analyses and reviews, and studies that scored <3 on a five-criteria quality assessment: this left us with 56 studies, the findings of which we discuss here. In keeping with similar reviews (e.g. Acton 2001; Cooper 2012), we categorised interventions into eight discrete groups: counselling and support; education; psychology; occupational therapy; formal approaches to care; telecare; multicomponent; and other.

## Results

### *Counselling and support*

Counselling and support groups are informal, mutually supportive and often run by the third sector (the voluntary sector).

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Carers anecdotally report strong benefits from peer support of others ‘in the same boat’ as them. Often, counselling is provided in settings outside of health and social care services, which may increase accessibility.

Counselling and support groups have been shown to benefit carers in a number of ways, including reducing burden (Chien 2008; Wang 2011), ameliorating depressive symptoms (Ulstein 2007; Mittleman 2008) and improving quality of life. There is also evidence to suggest improvements in carers’ self-rated health and greater overall satisfaction with the caregiving role (Mittlemann 2007). Comparative studies between existing support groups in different settings (i.e. day hospital and third-sector groups) show no statistically demonstrated benefits of one over the other (Bartfay 2013). More structured counselling interventions delivered over a fixed period of time (Joling 2012) anecdotally reduce carer burden, but have not significantly demonstrated benefit. Perhaps this suggests that a more flexible, less prescriptive approach is better.

#### *Educational interventions*

Educational interventions primarily aim to impart knowledge or skills to help carers in their caregiving role. Dementia education is a priority in the UK and most post-diagnostic follow-up includes a component of psychoeducation. However, evidence is mixed (Table 1) and larger studies (Kurz 2010; de Rotrou 2011) failed to demonstrate any benefit in their measured outcomes.

Although psychoeducation may not reduce depressive symptoms in carers, other benefits have been demonstrated in smaller studies, including increased confidence in caring (Ducharme 2011), reduced burden (Chien 2008), increased competence (Hepburn 2007) and an improvement in mental health (Dias 2008).

The current ‘one size fits all’ approach to education groups needs to change – they should be culturally sensitive, and may need to be gender specific. Many published trials have failed to reflect this. Male carers may benefit from an approach based more on problem-solving, for example.

#### *Psychology*

The National Institute for Health and Care Excellence (2006) recommends that carers who experience psychological distress as a result of caring for someone with dementia should be offered psychological therapy by a specialist practitioner. Group-based cognitive-behavioural therapy (CBT) has demonstrated positive results (Losada 2011) in modifying carers’ dysfunctional thoughts and a small but significant benefit in reducing depression. Time is of the essence for many carers – although longer, intensive interventions work, many carers simply cannot commit the time to them. Shorter CBT sessions (Márquez-González 2007) and 2-week intensive CBT (Gitlin 2010) have also demonstrated benefit on anxiety and depressive symptoms, as has a manual-based coping strategy (Livingston 2013, 2014).

#### *Formal approaches to care*

This includes appropriate care management, care programming and use of specialist nurses to deliver care. Formal care management involves one clearly identified member of health or social care staff who coordinates care throughout the patient’s and carer’s journey. Early assessment and identification of problems can trigger appropriate care pathways, often guided by a protocol followed by the care manager in collaboration with the carer. The proposed benefits include improved communication between health and social care services, screening of carers for mental health problems and early access to

**TABLE 1** Evidence base for psychoeducation of carers of people with dementia

Study	n, intervention/control	Intervention	Outcome measured	Results
Kurz <i>et al</i> , 2010	156/136	7 fortnightly group sessions	Depression, QoL, time spent caregiving	No significant differences
de Rotrou <i>et al</i> , 2011	79/78	12 weekly group sessions	Depression	No significant difference
Ducharme <i>et al</i> , 2011	62/49	7 weekly group sessions	Confidence, self-efficacy, coping ability	Greater confidence, self-efficacy and coping ability
Chien & Lee, 2008	44/44	Workshop, 12 sessions over 6 months	QoL, burden, level of social support	Reduced burden and increased QoL
Dias <i>et al</i> , 2008	41/40	1 visit per fortnight for 6 months minimum	Overall mental health, burden, distress due to problem behaviours	General mental health improved, no change in burden
Hepburn <i>et al</i> , 2007	30/22	12 hours of training (6 fortnightly sessions), group based	Competence, mastery	Both increased compared with waiting-list control

QoL, quality of life.

treatment, well-coordinated planned support, timely identification of potential crises, and more organised collaborative care (Lam 2010). Continuity of staff is key, but in reality very difficult to achieve (Spijker 2011). Additionally, this approach may be too prescriptive for most carers – consequently, most studies do not show statistically demonstrable benefits.

To encourage more collaborative care between caregivers and health professionals, Simpson *et al* (2006) developed caregiver-held care records, with sections for completion by carers, families and health professionals. Use of the record was associated with reduced carer strain, but did not improve carer knowledge of dementia overall, nor did it improve health outcomes for carers. However, this study was completed before the introduction of widespread cholinesterase inhibitors for dementia in the UK, and at a time when patients with dementia were often referred late in their diagnosis, so the carers may have been under significant strain for a prolonged period. The authors postulate that caregiver-held records may be of greater benefit to patients and carers in the earlier stages of diagnosis.

An exploratory analysis of data (Connor 2008) examined the significance of a number of variables in a nurse-led care management programme. While use of a care manager to explore care options in general was not associated with an improvement in caregiver mastery, specific approaches, such as assessment of the home environment, were.

Fortinsky *et al* (2009) looked at the effect on patient outcomes and carers of a dementia care consultation intervention for family caregivers that included a targeted, carer-held care plan,

counselling and collaboration with the carers' general practitioner. The rate of admission to hospital or a care home was twice as high among controls than among actively managed patients: the difference was small but approached significance. Carers who were more satisfied with the intervention showed the greatest improvement in self-efficacy, but there were no significant differences specifically on burden or depression, perhaps as the small sample meant that the study was insufficiently powered to identify small but significant change.

### Telecare

Distance-based interventions, using telephones and other technology, have become increasingly used in recent years. Use of technology to provide carer support may be more convenient for the carers, save money for both carers and providers, and eliminate travel and the need for extra support for the patient while the carer is away. A summary of the evidence is given in Table 2.

### Telephone interventions

The most studied distance-based interventions are those delivered by telephone, probably because telephones are readily available, cheap and carers do not require training to use them. Results on the benefits of telephone interventions are promising, although some studies are of suboptimal quality and involve small numbers. Tremont *et al* (2008) showed that a telephone-based intervention providing psychoeducation, emotional support and direction of carers to appropriate services was significantly beneficial in reducing caregiver burden and reactions to problem behaviours of

**TABLE 2** Evidence base for distance-based support for carers of people with dementia

Study	n, intervention/control	Intervention	Outcome measured	Results
Winter & Gitlin, 2007	58/45	6-months: telephone support group	Burden, depression, personal gains	No significant difference
van Mierlo <i>et al</i> , 2012	46/8	20 weeks: telephone coaching	Competence, mental health	Increased competence, improved mental health
Gallagher-Thompson <i>et al</i> , 2010	40/36	12 weeks: skills-training DVD	Positive affect, depression, stress	Positive affect significantly increased, stress decreased
Tremont <i>et al</i> , 2008	32/28	12 months: telephone	Depression, burden, reaction to problem behaviours of dementia	Lower perceived burden, less severe reaction to problem behaviours
Finkel <i>et al</i> , 2007	23/23	6 months: computer based	Depression, burden, health behaviours, social support	No significant effects
Gant <i>et al</i> , 2007	17/15	12 weeks: video/workbook/telephone	Self-efficacy, positive and negative emotions of caring, upset relating to target complaints	Both interventions improved measured outcomes but video condition not superior
Tremont <i>et al</i> , 2015	133/107	6 months: family intervention telephone support compared with simple telephone support	Depression, burden, reaction to problem behaviours of dementia	Improvement in depression ratings and in reactions to problem behaviours

dementia, identified as a main contributor to caregiver stress. Furthermore, fewer depressive symptoms were reported in those randomised to the telephone intervention compared with controls, although this did not reach statistical significance (this may in part have reflected that those recruited to the study had lower baseline depression scores than in comparative studies). A more recent study by the same group demonstrated that a more refined family-based telephone intervention reduced depression and reactions to behaviour problems compared with more conventional telephone support (Tremont 2015). In contrast, a telephone coaching intervention (van Meirlo 2012) was shown to have a significant large effect (0.96) on carers' mental health complaints (measured using the General Health Questionnaire) and effects were greater when combined with day care compared with day care alone.

With regard to specifically targeting depressive symptoms, a randomised controlled trial (RCT) (Glueckauf 2012) showed superiority of telephone CBT over face-to-face treatment, although the sample was particularly small ( $n = 7$ ) and involved African American caregivers only. Group-based telephone support may also be effective (Winter 2007). Using conference calling technology, small groups 'met' weekly to share coping strategies, including cognitive reframing and practical approaches to organising care routines, and to provide each other with social support. Although there was no difference in overall depression scores at 6 months, older carers appeared to benefit more from the intervention, perhaps, as the study's authors suggest, because of greater baseline levels of social isolation (there was no significant difference in baseline depression scores). However, older carers also participated in significantly fewer sessions than younger ones, and as with any 'high tech' intervention that requires an initial period of learning, there are concerns that lack of participation may be attributed to difficulties in using the technology by the older group.

#### DVD support

Multimedia (DVD) training programmes have also received some interest. In one study (Gallagher-Thompson 2010), a DVD intervention using role-play and narration to illustrate managing problem behaviours of dementia and provide education and strategies for preparing for placement was compared with a control 'information only' DVD. While both groups showed a decrease in depressive symptoms on the Centre for Epidemiologic Depression Scale (CES-D), the difference between them was not statistically significant, although

those in the intervention group did score significantly higher on the positive affect subscale than controls. Stress related to problem behaviours was also significantly reduced in those using the intervention DVD. Such benefits were not seen in a study (Liddle 2012) that used a brief DVD-based training programme focusing on memory and communication strategies between caregivers and the person with dementia. Although a greater proportion of carers who received the intervention reported improved perceptions related to their caregiving role (46% v. 13% of controls), the difference did not reach significance. Nor was there a significant impact on burden.

A preliminary RCT (Gant 2007) comparing telephone-based psychoeducation with combined telephone and video support in male caregivers ( $n = 15$  and  $17$  respectively) showed benefit in both groups in terms of increased positive affect, decreased negative affect and improved general health (measured by total number of subjective complaints reported), although no superiority of the combined intervention was demonstrated.

#### Internet and web-based interventions

Given that many homes now have internet access via computers and mobile phones, the use of the internet to deliver carer support seems promising. Finkel *et al* (2007) developed a support intervention using screen phones with computer access to a website to deliver individual education sessions and group-based support for 6 months. Similar to other technology-based interventions, they did not observe a significant benefit when compared with an information-only control group, although in stratifying the results it did appear that those who were most depressed significantly benefitted the most, suggesting that timely delivery of this type of intervention should be considered. However, a systematic review (Boots 2014) concluded that internet interventions were not supported by high-quality research evidence, and called for further research.

#### Multicomponent interventions

Multicomponent interventions consist of two or more different types of intervention. They might include components of support, counselling, education, respite care and psychology. There is a moderate positive evidence base for multicomponent interventions (Table 3), although there is still debate regarding which components and in which combination are most effective. Trials in this area are often larger, perhaps because recruitment is easier as the intervention is more representative of day-to-day practice.

**TABLE 3** Evidence base for multicomponent interventions for carers of people with dementia<sup>a</sup>

Study	n, intervention/control or by intervention arm	Intervention	Outcomes measured	Results
Dröes <i>et al</i> (2006)	94/34	6 months: education meetings, discussion groups, social activities	Subjective carer burden, carer competence	Small effect size on subjective burden
Belle <i>et al</i> (2006)	Hispanic: 106/106 White: 113/106 Black: 104/107	7 months: didactic instruction, role-play, problem-solving, skills training, stress management techniques, telephone support groups (to provide education, develop skills to manage troublesome behaviours of dementia, social support, cognitive reframing, and strategies for enhancing healthy behaviours and managing stress)	Carer burden, depression, social support, self-care	Three ethnic groups were studied: Hispanics/Latinos showed less burden, reduced rates of depression, greater social support and self-care; White/Caucasian participants benefited in terms of increased support. All groups showed lower prevalence of clinical depression and increased quality of life
Onor <i>et al</i> (2007)	8/8	4 months: reality orientation or reminiscence for patients with dementia, psychoeducation	Anxiety, depression, carer burden	Reduced anxiety and depression; no effect on burden
Holland <i>et al</i> (2009)	224 (multisite variable interventions: 14/13, 10/9, 13/11, 12/11, 10/6, 11/6, 28/12, 11/12, 34/30)	18-month follow-up: REACH programme	Symptoms of normal and complicated grief	Lower in carers who had received intervention
Lewis <i>et al</i> (2009)	209 (before and after study)	9 weeks: Stress-Busting Program, psychoeducation, support	Perceived stress, depression, subjective carer burden, anxiety	Decreased perceived stress; decreased depression; reduced subjective burden; reduced anxiety; reduced anger; reduced hostility
Eloniemi-Sulkava <i>et al</i> (2009)	63/62	24 months: specialist nurse provided individually tailored interventions; geriatrician assessment and treatment; support group	Self-rated health, sleep quality, physical health, emotional health	Improvement in all domains
Gitlin <i>et al</i> (2010)	137/135	24 weeks: combined nursing and occupational therapy focusing on patient's problem behaviours	Carer upset, reducing negative communication, carer well-being	Improvement in all domains
Gallagher-Thompson <i>et al</i> (2008)	Non-Hispanic White: 50/45 Hispanic/Latino: 47/42	4 months: Coping with Caregiving Programme: CBT, psychoeducation, telecare	Depression, general stress, stress at problem behaviours of dementia	Improvement in all domains. Comparison of Hispanic/Latino and non-Hispanic White carer groups demonstrated no significant difference between groups
Villareal-Reyna <i>et al</i> (2012)	CBT mood management: 10 CBT + humour: 12 Humour: 11 Control: 13	8 weeks: 4 arms: CBT-based mood management; CBT + use of humour; use of humour; control	Anxiety	Reduction in anxiety, greater effect if laughter intervention used
Tremont <i>et al</i> (2008)	16/17	12 months: emotional support; directing carers to resources; encouragement to attend to own needs; problem-solving strategies	Perceived burden, stress related to BPSD, depression	Perceived burden and stress significantly reduced; no change in depressive symptoms
Chien & Lee (2011)	46/46	18 months: keyworker allocation; psychoeducation; personalised support	Burden, quality of life	Improvement in both
Meeuwse <i>et al</i> (2012)	87/88	12 months: post-diagnostic support by memory clinic v. that by GP	Perceived burden	No improvement
Nichols <i>et al</i> (2011)	Pre-/post-intervention evaluation: 129 carers	6 months: home support; telephone support; group telephone support	Burden, depression, impact of depression on daily lives, caregiving frustration	Improvement in all domains
Waldorff <i>et al</i> (2012)	167/163	12 months: counselling; psychosocial support; education	Depression, quality of life	No significant difference
Tanner <i>et al</i> (2015)	183/106	18 months: individualised care planning; linkage to dementia services; caregiver education and skill building	Carer burden, depression, quality of life, number of unmet needs	No significant difference

a. A more detailed version of this table appears in the online supplement as Table DS1.

BPSD, behavioural and psychological symptoms of dementia; CBT, cognitive-behavioural therapy; GP, general practitioner; REACH, Resources for Enhancing Alzheimer's Caregiver Health.



Most of the trials that we identified demonstrated favourable outcomes for carers, which can extend beyond the period of support delivered. For example, a post-study analysis of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) trial (Holland 2009) demonstrated that those supported with a multifaceted intervention while their loved one was alive showed lower symptoms of complicated grief at long-term follow-up following bereavement.

Larger multicomponent trials have also allowed comparisons across ethnic groups. Belle *et al* (2006) compared outcomes of a combined education, psychological support and telephone-based intervention across three groups of caregivers in the USA (White/Caucasian; Black/African American; and Hispanic/Latino). There were some intergroup differences: the Hispanic/Latino participants showed significant benefit in all measured domains, and the White/Caucasian group gained greater social support. All of the intervention groups showed significant improvement in quality of life, with a lower prevalence of clinical depression.

### Other interventions

Other support interventions that we identified include befriending, exercise and poetry writing.

#### Befriending

Third-sector organisations can provide befrienders, who help carers by signposting services and providing emotional support through companionship, conversation and being a 'listening ear'. These services have face validity in improving carers' well-being, health-related quality of life, loneliness and perceived social support, but an RCT involving 236 carers (Charlesworth 2008) failed to demonstrate benefit of befriender services when compared with 'usual care'.

#### Exercise

Studies have shown that the benefits of exercise include improved mental and physical health and better sleep. It seems reasonable to assume that these benefits could extend to carers and a few studies have investigated this. In one small RCT (intervention group  $n=16$ ), Stella *et al* (2011) showed that a 6-month exercise programme for both patients with dementia and their carers decreased neuropsychiatric symptoms and depression in the patients and significantly reduced burden in caregivers. The programme consisted of aerobic and balance exercises for 60 minutes three times a week. The authors attributed the reduction in caregiving burden to an improvement

in neuropsychiatric symptoms in the patients. A major strength of the intervention was that it targeted both patients and carers simultaneously, although larger studies with greater power would be required to confirm the results. A similar study (Hirano 2011) showed that moderate exercise three times a week could reduce caregiver burden and improve sleep, although again numbers in the intervention group ( $n=17$ ) were small. In contrast, a larger RCT ( $n=157$ ) by Connell & Janevic (2009) did not demonstrate a significant benefit of exercise for carers in terms of reducing burden, depressive symptoms or perceived stress. At baseline, however, those randomised to the intervention spent significantly greater time exercising than the controls, which may have skewed results. Furthermore, individuals in the intervention group chose their own exercise goals and these varied considerably, which may account for the absence of a significant difference between those exercising and those not. Carbonneau *et al* (2011) looked at adapting a leisure programme for patients with dementia, with the specific aim of maintaining leisure pursuits in daily life, but failed to quantitatively demonstrate an improvement in caregiver well-being. Although caregivers in the intervention group initially showed an improvement in self-efficacy, this was not sustained.

#### Poetry

Kidd *et al* (2011) reasoned that a simple poetry writing intervention may benefit caregivers by providing a means of expressing some of the challenges they face. Carers were given open-ended instructions to write poetry over a 4-week period. Most chose to write about their caregiving situation and expressed an increased sense of acceptance with their caregiving role as a result. However, the results are not generalisable because of the small and homogeneous sample.

### Conclusions

There is a rapidly expanding evidence base for psychosocial interventions to support carers of patients with dementia, but the significant heterogeneity in both the interventions studied and the outcomes measured make drawing generalised conclusions difficult.

Support interventions are more likely to be effective if:

- multiple supports are offered (i.e. a multi-component approach is taken)
- educational interventions provide opportunity for active learning (e.g. role-play scenarios rather than 'information only')

## MCQ answers

1 e 2 b 3 a 4 b 5 a

- they are simple: the more complicated an intervention is, the less likely a carer is to adhere to it.

Distance interventions can be effective and should be considered, especially for older carers and those in isolated rural locations.

Simply allocating a specific keyworker, supplying written only information or referring on to peer support groups are not likely to be effective.

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## MCQs

Select the single best option for each question stem

### 1 Regarding the evidence base for supports for carers of people with dementia:

- a drawing generalised conclusions regarding their effectiveness is easy
- b longer, complex interventions are more effective than short, simple interventions
- c there is no evidence that distance-based interventions are effective
- d referring carers to Alzheimer's UK groups is the only thing you can do
- e a combination of different interventions at different times is most effective.

### 2 Education groups for carers:

- a should provide support over several months
- b should promote active learning
- c that have culturally sensitive adaptations are no more effective than standard groups
- d are less effective for male carers
- e have been shown to reduce rates of depression in carers.

### 3 As regards formal approaches to care:

- a they include care management, care programming and specialist nurses to deliver care
- b formal care management has consistent evidence of effectiveness
- c use of a protocol to trigger appropriate care pathways for carers can reduce carer anxiety
- d caregiver-held records can reduce carer anxiety
- e regular care meetings have been shown to reduce depression in carers.

### 4 As regards use of telecare for carers of people with dementia:

- a use of technology to support older carers does not work
- b providing telephone support to carers can be effective in reducing carer stress
- c telecare is not effective in providing support to male carers
- d there is strong evidence that computer-based supports decrease perceived burden in carers
- e there is no evidence that skills-training DVDs are helpful.

### 5 As regards multicomponent interventions for carers:

- a they may include combinations of support, education, counselling and psychology
- b trials are too small to generalise results
- c interventions are too complicated and expensive to work
- d the evidence suggests that the most effective combination includes psychoeducation and CBT
- e they do not reduce burden of caring in Latino caregivers.