



**THE EFFECTIVE INGREDIENTS OF SOCIAL CARE SUPPORT
AT HOME FOR PEOPLE WITH DEMENTIA: A LITERATURE
REVIEW**

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Introduction

Due to demographic trends towards an ageing population, dementia care is one of the fastest growing areas of need in the UK with predictions that there will be more than 1.7 million people in the UK with dementia by 2051 (Alzheimer's Society, 2013). These trends have been coupled with a longstanding policy commitment to the community care of vulnerable groups, the development of a system of welfare pluralism and a corresponding purchaser-provider split (Alakeson, 2007), with service users being reframed as active consumers rather than as the passive recipients of welfare (Department of Health, 1990). Arising from these developments has been a progressive increase in the amount of intensive home care provided to older people and the targeting of these services on high-risk and high-dependency groups (UK Home Care Association, 2016). Accompanying these service transformations, have been demands for improvements in the delivery of these services (Department of Health, 2009; 2013, 2015), with the widespread advocacy of person-centred and personalised care (Glasby and Littlechild, 2009) and the adoption of integrated approaches in the provision of this care. In recognition of the service fragmentation arising as a result of welfare pluralism, this policy commitment to integrated approaches was reiterated in the Prime Minister's Dementia Challenge (Department of Health, 2015). This encourages more collaborative working and coordination between different care sectors thus promoting continuity and responsiveness in the care provided. Other components of this joined up approach include better trained staff, the creation of dementia friendly communities, the guarantee of a personalised plan of care and the involvement of people with dementia and their carers in the management and control of this care (Woolrych and Sixsmith, 2013). A similar focus on integration has been apparent in the home care guidelines recently published by the National Institute for Health and Care Excellence (2016). These guidelines include recommendations on the length of home care visits and the need for a planned, integrated and person centred approach in care delivery. It also suggests the need for the better provision of information about support options to clients, measures aimed at ensuring the safety of these clients and the more effective recruitment, training and support of home care workers.

In spite of these policies, there are still huge variations in the quality of home support provision and that older people still do not receive integrated, personalised, effective and responsive care. For example, focusing on the front line workforce issues, the All Party Parliamentary Group on Dementia (2014) observed that while the majority of people with dementia live at home, home care workers still lack relevant skills and knowledge in dementia care and tend to be task-orientated in their approach to their role. The report goes on to identify a number of reasons for these deficiencies such as high levels of staff turnover, lack of regulation over required levels of dementia training as well as inadequacies in leadership and resourcing. Moreover, with regard to the broader service context, joint working is often inconsistent or short term and

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3 multiagency coordination and cooperation is poor with older people still falling
4 through the gaps in services (Care Quality Commission, 2016) and in subsequent
5 need of crisis intervention rather than lower level and preventative support (UK
6 Home Care Association, 2016). As recently observed, these gaps are increasing
7 due to the chronic underfunding of social care services (Humphries *et al.*, 2016) and
8 of home care provision (UK Home Care Association, 2016). These issues are
9 further exacerbated by an apparent lack of clarity amongst service providers on the
10 meaning of person centred and integrated care and how it should be implemented,
11 suggesting the need to establish a shared understanding of this issue if services are
12 to be improved (Care Quality Commission, 2016). Similar issues of conceptual
13 clarity are apparent in the meaning of home care which is poorly understood and
14 little-researched (Godfrey *et al.*, 2000). Thus, at the outset of the review presented
15 here, the following quotation held true: *“The necessary conditions for delivering
16 improved home care services for older people with dementia are not fully understood,
17 particularly in comparison with standard service provision”* (Rothera *et al.*, 2008: 71).
18 In the light of the above discussion, this review set out to find empirical evidence
19 concerning aspects of home care that might be relevant to setting standards or
20 monitoring criteria for home care for people with dementia. It was undertaken to
21 inform a research programme investigating the ingredients of good home care for
22 people with dementia. [REDACTED]
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31 **Methods**

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33 Systematic reviews are gaining increasing popularity as a reproducible,
34 comprehensive and unbiased means of evaluating and summarising research
35 through the adoption of predetermined stages and criteria and through the meta-
36 analysis of quantitative data. However, there are many challenges in systematically
37 reviewing literature in this area (Pawson *et al.* 2003) due, for example, to the fact
38 that, unlike health care literature, relevant sources for literature on social care
39 interventions are not clear cut and relevant studies are hugely diverse in their design
40 and contexts. Therefore, for pragmatic reasons, the mode of working adopted in this
41 review combined a systematic literature search and selection process with other
42 methods of research synthesis (Petticrew and Roberts, 2008). These included
43 elements of a scoping review in order to identify the range of home care ingredients
44 and a qualitative, narrative review to examine the nature of these elements.
45 Searched databases included MEDLINE (PubMed), EMBASE (www.embase.com)
46 and PsycINFO [REDACTED]
47 [REDACTED]
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51 [REDACTED]
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53 [REDACTED] In order to identify all potentially relevant studies, key words for ‘home care’ and
54 ‘dementia’ were the relevant terms used in each database which were each
55 searched from January 1991 to July 2011. These dates also incorporated the twenty
56 years timespan since the launch of the NHS and Community Care Act (Department
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of Health, 1990) which led to the sustained transformation of domiciliary support services. Potentially relevant articles were reviewed against predetermined inclusion and exclusion criteria which included all types of dementia and study type and excluded issues of unpaid care, studies with a solely health care or economic focus and those not written in the English language. The final screening process involved checking the remaining references against this criteria. Where there was a difference of opinion regarding the inclusion of literature, these were referred to the team for resolution.

Results

The initial search process yielded 7867 references and after removing duplicates, 5135 articles were selected for further screening which was performed independently by two reviewers. Following a screening of records, a further 3561 were excluded leaving a total of 1574. From these 1574 another 1310 were excluded after abstract screening. During the final screening process of the remaining 264 potentially relevant references, 252 references were excluded as they were duplicates (5), there was no full text availability (76) or the text available was unclear (41). Many references were excluded because they had an inadequate focus on social support at home for people with dementia (130). A further two studies (Brooker *et al.*, 2011; Riordan and Bennett, 1998) were identified and added by the team. This was because they were considered to be relevant to the review. The large number of exclusions and the fact that two key studies were not identified by the initial search highlights the challenges of conducting a systematic review of literature into social care issues (Pawson *et al.*, 2003). Of the 14 included studies, four were randomised controlled trials, 3 were cohort studies, two were quasi experimental studies, 3 were qualitative studies and two were case reports. In addition, 8 were conducted in the UK and 6 outside the UK.

Quantitative studies

Table 1: *Quantitative studies included in the review*

Within this category, a randomised controlled trial by Brooker *et al.* (2011) and two quasi-experimental studies (Riordan & Bennett, 1998; Challis *et al.*, 2002), possibly, provided the strongest levels of evidence from the UK for this review. It is notable that all three of these studies involve augmentation significantly beyond what is generally provided by English social care support at home and the extent to which their results may be applicable to less intensive home care remains open to question. However, they do provide indications of what might, or might not, better enable such care to work at its best when unaugmented. For example, effective leadership and relevant staff training (Brooker *et al.*, 2011), a systematic approach

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3 and individualised packages of care (Challis *et al.*, 2002) and support for the
4 principal carer (Riordan and Bennett, 1998), are all key enablers identified in the
5 above studies.
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8 In contrast to the preceding UK-based studies, which tended to focus on the
9 evaluation of specialist models of care and their impact on the wellbeing of
10 participants, relevant included studies from outside the UK largely focused on issues
11 of care transitions and case management. In addressing these issues, the non-UK
12 evidence also considered the impact of home care interventions on carer support,
13 commissioning and flexible and responsive services. Research designs included
14 three randomised controlled trials (RCTs) which were conducted in Finland and the
15 US (Eloniemi-Sulkava *et al.*, 2001; 2009; Miller *et al.*, 1999) and three cohort studies
16 all carried out in the US (Gaugler *et al.*, 2005; Pot *et al.*, 2005; Temple *et al.*, 2010).
17 Of these, Eloniemi-Sulkava *et al.* (2001; 2009) actually apply 'health' interventions to
18 augment social care and, thus, seem not to illuminate what could make current
19 straightforward English social care support work better. However, they do indicate
20 the possibilities that arise from integrated approaches involving cooperation and
21 coordination between health and social care services and targeted within an
22 individualised plan of care.
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28 In the United States, Gaugler *et al.* (2005) followed a cohort of caregivers over three
29 years, with the aim of determining whether being in receipt of community-based
30 services early in the dementia caregiving career delayed time to nursing home
31 placement. Miller *et al.* (1999) conducted a randomised controlled trial in order to
32 determine whether an intervention aimed at improving caregiver outcomes through
33 case management and subsidised community services affected the nursing home
34 entry rate of clients with dementia. Temple, Andel and Dobbs (2010) aimed to
35 examine risk of nursing home placement among older adults with dementia
36 according to whether they received community-based home care input or assisted
37 living support. While most studies in this section have focused on aspects of case
38 management and on the transition from home to institutional care, in their cohort
39 study Pot *et al.* (2005) focused on transitions in paid home care and its impact on the
40 wellbeing of the principal care givers of relatives with dementia. They also
41 recognised that, due to such things as long gaps between first and second follow-
42 ups and the fact that the cohort of carers were self-selecting, their study had a
43 number of limitations.
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50 *Qualitative studies and case reports*

51 **Table 2: Qualitative studies and case reports included in the review**

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56 Three UK based qualitative studies evaluated specialist home care services which
57 were community based (Gladman *et al.*, 2007) multi-agency (Rothera *et al.*, 2008) or
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3 provided on a respite basis for the carers of younger people with dementia (Parahoo
4 *et al.*, 2002). They reported that carers valued home care services that specialised
5 in working with people with dementia. Five desirable characteristics of such services
6 emerged from these qualitative evaluations which taken together offer tentative
7 criteria for evaluating home care provision. These include integrated and
8 multidisciplinary input, care worker autonomy, continuity of personnel, continuous
9 client reassessment and a respect for 'personhood'. Two case reports on a
10 domiciliary respite service (Ryan *et al.*, 2008) and a specialist home care service
11 (Russell *et al.*, 2002) reported similarly positive impressions on the part of staff,
12 family carers and people with dementia in the UK.
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16 17 **Discussion**

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19 This review has provided evidence of a number of effective ingredients of paid social
20 support at home for people with dementia. At an individual level, expert opinion and
21 policy recommendations (NICE, 2016) supported by the findings presented in this
22 review suggests the importance of care worker autonomy, continuity of the
23 relationship between individuals and their care workers and frequent reassessment.
24 Diagnosis should also be prompt in order that appropriate services can be
25 introduced at an optimal stage in the dementia trajectory and the intensity of the
26 service needs to be 'person-centred' and responsive to users needs and aspirations
27 (Care Quality Commission, 2016). In order for this responsiveness to be achieved,
28 commissioning practices need to be similarly flexible and adequately resourced
29 (Humphries *et al.*, 2016). For while policy recommendations have consistently
30 supported the need for early diagnosis (All Party Parliamentary Group, 2014), the
31 lack of availability of appropriate post diagnosis support is likely to undermine the
32 goal of prompt intervention that such measures aim to promote. The review has also
33 pointed to the likely benefits that arise from an integrated and multidisciplinary
34 approach involving health and social care providers in the delivery and co-ordination
35 of services (Brooker *et al.*, 2011; Department of Health, 2015), thus reflecting the
36 efficacy of an integrated approach to home care recently recommended by NICE
37 (2016). If some or all of the above criteria are fulfilled in services provided to people
38 with dementia living at home, evidence from this review suggests that their
39 admission to residential or nursing home care might be delayed (Riordan & Bennett,
40 1998; Challis *et al.*, 2002; Eloniemi-Sulkava *et al.*, 2001, 2009; Gaugler *et al.*, 2005;
41 Temple, Andel and Dobbs, 2010).
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50 Nevertheless, further questions still remain, including the optimal amount of home
51 care input for specific needs, as well as the optimal stage in the dementia trajectory
52 to introduce this input, with included studies yielding opposing evidence on this latter
53 point. Thus, Gaugler *et al.* (2005) suggest that, if interventions are delivered early in
54 the trajectory, they are more likely to defer institutionalisation. Conversely, Eloniemi-
55 Sulkava *et al.* (2001) recommend that services should be targeted at those in later
56 stages of the dementia trajectory if this deferral is to be optimally achieved. The
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3 conflicting findings of included studies may well be due to the differing characteristics
4 of the interventions adopted and corresponding ambiguities in the interpretation of
5 central concepts such as home care and integrated care and the policy and social
6 contexts in which the interventions were located. For example, as Woolrych, and
7 Sixsmith (2013) observe, not only are there many approaches to flexible and
8 integrated care but the context in which this care takes place is likely to influence the
9 impact that it has. Furthermore, many of the included studies used 'ideal type'
10 interventions, including intensive service provision involving a range of professionals
11 (all the UK studies), while the two Finnish studies applied health interventions to
12 augment standard social care for people with dementia. In spite of their benefits,
13 these types of intervention may be more costly to provide (Brooker *et al.*, 2011) and
14 financially unsustainable in the long term (Challis *et al.*, 2002; Gladman *et al.*, 2007).
15 Such issues of cost are also relevant to the type of research design adopted and the
16 different criteria used in determining the success of the intervention being evaluated.
17 Thus, UK studies often included process measures of home care and its
18 acceptability to participants. However, this may neglect its impact on such things as
19 acute hospital admissions as well as the cost of the service being provided
20 (Gladman *et al.*, 2007). In contrast, non-UK studies mainly reported the impact of
21 home care intervention. However, this focus not only overlooks the acceptability of
22 the service to clients and their carers, it may also overlook the impact of intervening
23 variables which are likely to influence care transition, such as the availability of wider
24 supportive services.
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32 These problems of generalisability when attempting to compare the findings of
33 research in this area demonstrate the need for consistency so that relevant
34 comparisons can be made both with regard to measuring the quality of interventions
35 as well as in evaluating their impact. Similar recommendations for consistency have
36 been made by the Care Quality Commission (2016) both with regard to defining the
37 meaning of integrated care and in the methods used to identify those in need of this
38 care. In doing so, they also highlight the importance of care recipients identifying
39 their own care needs and outcomes thus indicating a move away from the
40 professionally-led needs assessments (Alakeson, 2007; Glasby and Littlechild, 2009;
41 NICE, 2016). The advocacy of a user-led approach rather than one which is
42 professionally defined is compatible with the recommendation by Pawson *et al.*
43 (2003) for the adoption of a wide and inclusive range of knowledge when
44 researching social care issues. Such an inclusive approach has also been adopted
45 in this review, in order to maximise coverage of the limited range of relevant
46 literature while also highlighting the significant problems of gathering evidence in this
47 area. These challenges arise from the increasingly blurred distinction between health
48 and social care provision (Glasby and Littlechild, 2009) the different criteria used to
49 judge the quality and relevance of knowledge domains in these two areas (Pawson
50 *et al.*, 2003) and ambiguities in the meaning of central concepts such as home care.
51 Related to these issues is the methodological heterogeneity of the included studies,
52 due for example to their varying choice of research design and subject groups,
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3 meaning that a meta-analysis of the data was not seen as appropriate or feasible.
4 Moreover, as with other literature reviews, the material incorporated was inevitably
5 constrained by the dates adopted in the initial literature search, although it is likely
6 that the themes emerging will be reflected in more recent studies not included in this
7 review. Consequently, while this review does not yield definitive or clearly
8 generalisable answers, it does indicate areas in need of further investigation which
9 are outlined below.
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13 No criteria were included in this review regarding the stages of dementia covered.
14 Therefore, defining the critical period within which home care can help is one
15 challenge for future enquiry. Similarly, the optimal amount of home care needed in
16 order to meet specific needs merits exploration. Due to current ambiguities in their
17 respective meanings, another question is the definition of the nature and extent of
18 care inputs which might be deemed 'social' and 'integrated' and the potential barriers
19 and facilitators to their implementation within diverse policy and social contexts. A
20 further question is whether demonstrable adherence to best practice in home care
21 can be linked to cost-effectiveness, with most of the included studies focusing on the
22 impact of short term 'ideal type' interventions and not on their long term effectiveness
23 or feasibility. With regard to future research, secondary analysis of existing datasets
24 could be a relatively inexpensive way to increase our understanding of the impact of
25 home care. The data kept by local authority commissioners and providers of home
26 care concerning their interventions with clients over time provide a valuable resource
27 for resolving many questions. These include whether home care is more cost-
28 effective in delaying institutional admissions if introduced early, rather than late, and
29 what is the ideal combination between home care and informal care provision.
30 Within the increasingly diverse home care market (Alakeson, 2007), there may also
31 be opportunities to conduct large, well-controlled studies of the active ingredients
32 and benefits of different types of home care. These should take account of the
33 social context in which the services operate, the characteristics of the people for
34 whom they care, the impact of those services on these individuals and their
35 subsequent role in deferring transition to long term care.
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44 **Conclusion**

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46 Due to demographic trends and policy developments, recent years have seen the
47 rapid growth of social support at home for people with dementia. However,
48 community based home care services are not always designed to meet the specific
49 needs of people with dementia and their carers. It has, therefore, been the purpose
50 of this review to explore the ingredients of social support at home for this client group,
51 in order to inform research and practice. Clearly, this exploration has faced many
52 challenges due to the relative paucity of literature on this topic and the heterogeneity
53 of relevant studies both in terms of their design and focus. This has led to conflicting
54 findings and a lack of generalisability of these findings. These challenges have been
55 exacerbated by issues of definition, with the blurred divide between health and social
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3 care, and the different criteria for judging knowledge in these two areas forming a
4 barrier to the performance of a systematic review on this issue. Nevertheless, while
5 the evidence from this literature review does not indicate complete answers or
6 definitive solutions, its findings do suggest the effectiveness of a flexible, responsive
7 and person-centred approach towards home care for people with dementia. It also
8 highlights the role of inflexible commissioning practices and inadequately resourced
9 or poorly integrated service provision in impeding the development and subsequent
10 impact of these types of interventions.
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Table 1: Quantitative studies included in the review

Author (date), country	Study purpose	Study design	Summary findings
Brooker, <i>et al.</i> (2011), UK	To evaluate the impact of a multi-level intervention for people with dementia.	Randomised controlled trial with 300 people with dementia living in 10 extra care housing schemes.	Residents in experimental group who participated rated their quality of life more positively over time than the active control group.
Challis <i>et al.</i> (2002), UK	To evaluate a model of intensive case management based in a community-based mental health service.	Quasi-experimental design with 43 matched pairs of people with dementia and their primary carers who were followed for a two year period.	At the end of year two, 51% of the experimental group remained at home compared with 33% of the comparison group. They also had significant improvements in social contacts.
Eloniemi-Sulkava <i>et al.</i> (2001), Finland	To determine whether community care of demented patients can be prolonged by means of a 2-year support programme based on nurse case management.	Randomised controlled trial with 100 people with dementia living at home with informal caregivers.	Rate of institutionalisation was initially lower in the intervention group than the control group but the relative benefit decreased with time..
Eloniemi-Sulkava <i>et al.</i> (2009), Finland	To determine whether community residence can be prolonged by a 2-year multi-component intervention programme.	Randomised controlled trial with 125 couples one of whom had dementia who were allocated to the control or intervention group.	At 1.6 years, a larger proportion in the control group than in the intervention group was in long-term institutional care. The intervention led to a reduction in use of community services but when the intervention costs were included, there was no difference between the two groups.
Gaugler <i>et al.</i> (2005), USA	To determine whether community-based long-term-care services early in caregiving delayed time to care home placement.	Cohort study following 4,761 dementia caregivers over a 3-year period	Caregivers who used home help services earlier in their dementia caregiving careers were more likely to delay institutionalisation. This suggests the cost effectiveness of early community based service use.

Miller <i>et al.</i> (1999), USA	Did the Medicare Alzheimer's Disease Demonstration, with its goal of improving caregiver outcomes through case management and subsidised community services, affect the nursing home entry rate of people with dementia?	Randomised controlled trial with 8095 people with dementia and their caregivers.	The intervention had no effect on care home entry rates between the intervention and control groups.
Pot <i>et al.</i> (2005), USA	To examine the association between family caregivers' decisions to initiate or stop home care provision and their stress and psychological well-being.	Naturalistic, observational study in which a cohort of 264 caregivers completed up to 3 interviews during 1 year	Taking up home care was associated with increases in carer worry and strain and ending it was strongly associated with a decrease in depressive symptoms. Sustained use of paid home care was related to reduced overload.
Riordan and Bennett (1998), UK	To evaluate an augmented home care service for people with dementia.	Quasi-experimental study with 38 client-carer matched pairs. 19 pairs received the intervention.	Clients in the intervention group were able to continue living at home for longer than the control group.
Temple, Andel and Dobbs (2010), USA	To examine risk of care home placement among older adults receiving publicly funded home and community-based services or assisted living and to explore whether these settings of care modify the relationship between dementia and risk of care home placement.	Cohort study over 5 years of Medicare and Medicaid beneficiaries (not exclusively with dementia) who received home and community based services or resided in assisted living.	The setting of care modified the relationship between dementia and care home placement: dementia was associated with a 50% increased risk of care home placement from home-based settings but not associated with placement from assisted living settings.

Table 2: Qualitative studies and case reports included in the review

Author (date), country	Study purpose	Study design	Summary findings
Gladman <i>et al.</i> (2007), UK	To evaluate a specialist community-based dementia service in order to establish whether high quality services were being delivered.	Qualitative study including non-participant observation. Emergent themes were identified and pursued over an 18 month period.	The care provided was appreciated by carers, and the service was approved by staff and stakeholders. Clients were usually referred with the object of preventing unwanted admission to institutional care but moving into an institution gradually ceased to be a uniformly undesirable outcome.
Parahoo, Campbell and Scoltock (2002), UK	To evaluate a domiciliary respite service for carers of younger people with dementia.	Qualitative study of using semi-structured interviews with 8 carers of people with dementia and their families	Carers reported satisfaction with the service. Most gained respite in the form of help with bathing and dressing the person with dementia. Carers reported that they used the respite time to catch up with things.
Rothera <i>et al.</i> (2008), UK	To evaluate a specialist multiagency home care service for people with dementia, to establish if it delivered better quality care than standard services, and how any improvements were achieved.	Qualitative study conducting semi-structured interviews, focus groups and small group interviews.	The specialist service demonstrated greater flexibility and responsiveness to the particular needs and circumstances of clients and carers. Encouraging carers involvement in decision making and activities helped to reduce carer stress and prevent crisis.
Russell, Hovey and Fairlie (2005), UK	To report on a specialist home care service for people with dementia which placed an emphasis on staff continuity, flexibility and training	Case report drawing on the views of people with dementia, their paid and unpaid carers and relevant professionals.	The transition to long term care of people with dementia was reduced. Care staff were able to develop skills and strong links developed between front line and senior staff. The flexibility of the service provided was potentially threatened by commissioning practices.

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Ryan <i>et al.</i> (2008), UK	To report on a domiciliary respite service for people with dementia using the senses framework and relationship centred care	Case report drawing on the views of clients, carers and staff	The service was successful in meeting the needs of people with dementia and their carers. It provided high levels of job satisfaction for staff. These mutual benefits were described as providing a sense of continuity, security and belonging.
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