

T. Koch, S. Iliffe, J. Manthorpe, B. Stephens, C. Fox, L. Robinson, G. Livingston, S. Coulton, [M. Knapp](#), C. Chew-Graham, and C. Katona

The potential of case management for people with dementia: a commentary

Article (Accepted version)
(Refereed)

Original citation:

Koch, T., Iliffe, S., Manthorpe, J., Stephens, B., Fox, C., Robinson, L., Livingston, G., Coulton, S., Knapp, M., Chew-Graham, C. and Katona, C. (2012) The potential of case management for people with dementia: a commentary. [International journal of geriatric psychiatry](#), 27 (12). pp. 1305-1314. ISSN 0885-6230

DOI: [10.1002/gps.3783](https://doi.org/10.1002/gps.3783)

© 2012 [John Wiley & Sons Ltd](#)

This version available at: <http://eprints.lse.ac.uk/49497/>

Available in LSE Research Online: April 2013

LSE has developed LSE Research Online so that users may access research output of the School. Copyright © and Moral Rights for the papers on this site are retained by the individual authors and/or other copyright owners. Users may download and/or print one copy of any article(s) in LSE Research Online to facilitate their private study or for non-commercial research. You may not engage in further distribution of the material or use it for any profit-making activities or any commercial gain. You may freely distribute the URL (<http://eprints.lse.ac.uk>) of the LSE Research Online website.

This document is the author's final accepted version of the journal article. There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

The potential of case management for people with dementia: a commentary

Dementia Case Management

Koch T (1), Iliffe S (1), Manthorpe J (2), Stephens B (3), Fox C (4), Robinson L (5), Livingston G (6), Coulton S (7), Knapp M (8), Chew-Graham C (9), Katona C (6) for the CARE-DEM research team

Author's affiliations

- 1) Department of Primary Care & Population Health, University College London
- 2) Social Care Workforce Research Unit, King's College London,
- 3) Dementia UK
- 4) Dementia Research Unit, University of East Anglia
- 5) University of Newcastle
- 6) Department of Mental health Sciences, University College London
- 7) Centre for Health Service Studies, University of Kent
- 8) Personal Social Services Research Unit, London School of Economics and Political Science; and Centre for the Economics of Mental and Physical Health, Institute of Psychiatry at King's College London
- 9) School of Community Based Medicine, Primary Care Research Group, University of Manchester

Corresponding author

Professor Steve Iliffe, Department of Primary Care & Population Health, University College London, Royal Free Campus, Rowland Hill St., London NW3 2PF, UK email: s.iliffe@ucl.ac.uk

Word count (excluding abstract): 3,609 words in version 14

The potential of case management for people with dementia: a commentary

Abstract

Aim: To propose a research agenda on case management for people with dementia.

Background: A recent review of studies of case management in dementia argues that lack of evidence of cost-effectiveness should discourage the use of this approach to care. We argue that that this is too conservative a stance, given the urgent need throughout the world to improve the quality of care for people with dementia and their caregivers.

Method: Critical comparison of studies identified in two systematic reviews of trials of case management for dementia, with selective inclusion of non-trial studies and economic evaluations.

Findings: Our interpretation of the literature leads us to four provisional conclusions. First, studies with long follow-up periods tend to show delayed relocation of people with dementia to care homes. Second, the quality of life of people with dementia and their caregivers may also influence the likelihood of relocation. Third, different understandings of what constitutes case management make interpretation of studies difficult. Fourth, we agree that the population most likely to benefit from case management needs to be characterised. Earlier intervention may be more beneficial than intervening when the condition has progressed and the individual's situation is highly complex. However, this runs counter to some definitions of case management as an administrative, professional and systemic focus on people with high needs and where expensive support is accessed or in prospect.

Conclusions: More work needs to be carried out in a more focused way, in order to establish the value of case management for people with dementia. Since care home residence is such a sizeable contributor to the costs of dementia care, studies need to be long enough to capture possible postponed relocation. However, case management studies with shorter follow-up periods can still contribute to our understanding since they

may demonstrate improved quality of life. Future research should be built around a common, agreed definition of types of case management.

Key words: dementia •case management • care co-ordination

4 key points:

Providing timely, responsive, and appropriate care for people with dementia has proved difficult, worldwide.

Case management appears to be an approach that could be beneficial, in co-ordinating care.

However, the number of trials of case management is small, and their conclusions tentative; case management for people with dementia needs further evaluation.

Future research should be built around a common, agreed definition of types of case management, should use quality of life of people with dementia and carers as proxy outcome measures, and should include trials with long-term follow up.

Introduction

Dementia is one of the leading causes of disability among older people, and its prevalence is likely almost to double by 2030 (Alzheimer's Disease International, 2010). Because dementia affects global functioning, the needs of the person with dementia are often long-term, cumulative, and require support from a complex matrix of social networks and services as well as from family caregivers. The interactions of doctor, patient, family and systems barriers to recognising and responding to this syndrome may explain why providing timely, responsive, and appropriate clinical care have been difficult (Koch & Iliffe 2010). One recent systematic review of empirical trials designed to improve detection or management of dementia in primary care concluded that case managers (as functioning in parts of the United States (US) healthcare system) could enhance diagnostic skills and some aspects of clinical management (Koch & Iliffe 2011).

However, the number of trials of case management is small, and their conclusions tentative; case management for people with dementia needs further evaluation.

The Case Management Society of America defines case management as “*a collaborative process of assessment, planning, facilitation and advocacy, for options and services to meet an individual’s health needs through communication and the available resources to promote quality, cost-effective outcomes*” (2010). This definition is broad, but it focuses solely on the medical aspect of case management. The Case Management Society of the United Kingdom (UK) defines case management as “*a collaborative process which: assesses, plans, implements, co-ordinates, monitors and evaluates the options and services required to meet an individual’s health, social care, educational and employment needs, using communication and available resources to promote quality cost effective outcomes*” (2010). This definition is much wider and incorporates many other aspects of need and services. However, the studies evaluating case management have tended to focus on health more than social care outcomes.

Case management offers multi-component interventions, and has been shown to be effective for some people with multiple or single long-term care needs, for example people requiring home care (whether palliative care patients, house-bound people, or people newly-discharged from hospital), or for people with long-term conditions such as depression, diabetes, cardiovascular or respiratory disease (when case management has taken the form of Community Matron care) (Chew-Graham et al 2007, Christensen 2008, Morales-Asencio et al 2008). Intuitively, case management does appear to offer an approach which could suit the complex needs of some people with dementia, and of their caregivers. However, Pimouguet and colleagues (Pimouguet et al 2010) recently published a systematic review of randomized controlled trials of case management for people with dementia and their caregivers, measuring mainly time-to-institutionalisation and cost. They concluded that the evidence for the efficacy of case management with reference to cost and resource usage remains equivocal, and that further studies ought to consider who might benefit more from case management. This cautious assessment coincides with a critical review of nurse-led case management as a technique for supporting patients with complex needs in Britain’s NHS (Goodman et al 2010).

Such caution may or may not be justified scientifically but does not assist the policy process. Service providers and those purchasing services need to make decisions about investing in interventions like case management which have face validity and which are supported by some evidence. As Black has pointed out, in these matters timing is everything. Windows of opportunity for change when policy-makers' values correspond with those of researchers only occur rarely and fleetingly. The "offside rule" from football applies; acting too early is penalised and advance is halted; but moving too late impedes progress (Black 2001).

This paper examines the potential role of case management for people with dementia, from the perspective of service providers and commissioners wanting to make investment decisions. It questions whether it is possible to identify cohorts who might benefit most from case management, what skill-set would be best-suited to the role, and what outcomes and measurements may demonstrate efficacy. We argue that a more efficacious form of case management which suits individuals, caregivers and social and healthcare systems may be identified for testing if the remit of case management in dementia care were better defined, if the recipients were more carefully selected, if thought was given to the wider and longer-term costs of doing so, and if the outcome measures were broader than those selected by Pimouguet et al (2010).

Method

Our search strategy replicated that carried out by Pimouguet et al (2010), using Medline, Embase & PsycInfo databases, and Scopus, but we additionally included studies that were not randomised controlled trials (RCTs). This was done to learn from non-experimental studies that had high external validity, as well as from trials that have lower external validity. The same search terms and keywords were used, but the search was extended from the date theirs ended (September 2009) to October 2010. Like them we accessed English language publications only. Papers describing case management for patients with dementia, or evaluating the costs and benefits of case management for this patient group, were identified by two authors (TK & SI). Using a quality assessment method (PEDro) designed for trials where blinding for the intervention is not possible, we identified the highest quality trials (see Koch and Iliffe 2011 for further details). These

trials, plus other studies deemed relevant for this discussion paper by the authors, were summarised by three research team members (TK, SI & MK).

Data Extraction:

Summaries of selected papers were then reviewed by all authors to answer these questions:

- What are case managers and how do they relate to dementia care?
- Can dementia care be improved by case management?
- What do people with dementia and their carers want from a case manager? Can this be provided?
- Can we measure cost and cost-effectiveness of case management for dementia?
- What direction does research into case management need to take?

What are case managers and how do they relate to dementia care?

Understanding of what case management is and what the case manager does varies considerably (Challis et al 2010). Many definitions are context-specific with a lack of consensus about their core components. This has led to difficulty in establishing its impact, deciding who is the most appropriate practitioner (if any) to undertake the role, which populations might benefit most, and what services and support ought to be offered within a case management programme. In England, Goodman et al (2010) scrutinized several case management studies (generally not in the area of dementia care) in order to identify which factors might influence the success of nurse-led case management. They concluded that a case manager needed four attributes: 1) a broad clinical skill-set, 2) designated and protected time for case management, 3) close involvement in multi-disciplinary teamwork involving a medical clinician, and 4) possess the mandate to undertake case management activities recognized by providers or commissioners or funders of services, especially if continuity of care and stability of services were to be assured. These conclusions suggest that the role does not necessarily need to be 'dementia'-specific but may be suited to older people (and indeed others) with unmet complex and continuing social and health care needs.

Several studies have attempted to analyse the characteristics of case management specifically needed for people with dementia, to identify components which determine success, lack of impact, or failure, and clarify the effects of the health and social care system in which case management operates. Minkman et al (2009) used a qualitative, case study methodology to explore case management in dementia care within the Dutch healthcare system. Success factors included the case manager having a wide knowledge base, working in a strong, local provider network which accepted case management, having effective multi-disciplinary teams with medical input, and a low threshold for accessing support services. Conversely, the factors associated with failure included a lack of investment, distrust by local providers and competition for delivering services, an absence of involvement of primary care practitioners, and ill-defined inclusion criteria for patients.

Verkade et al (2010) used a consensus-building Delphi-technique by collecting the views of Dutch experts in case management in dementia. They found that 44 components were regarded as essential, and concluded that case management programmes ought to be based on individual needs, empower patients and caregivers, prevent problems and initiate early intervention, integrate management into the care chain, offer a systematic, active care approach, and provide information, support, coordination and monitoring roles. Other research has employed a more conceptual analysis. Using secondary data from Vickrey et al's (2006) trial, which improved adherence to guidelines and usage of medication and community referrals in California, Connor et al (2009) constructed a theoretical framework to analyse case management approaches in order to understand its component activities. The activities most frequently undertaken by nurse and social worker case managers included providing clinical therapy information and linking caregivers with volunteer respite care. Altogether 45 constructed variables were identified, which were spread over four main case management domains. These included 'behaviour management', 'clinical strategies & caregiver support', 'community agency' and 'safety' (see Table 1). They postulated that the nature of *ad hoc* but regular contact and the individualistic approach inherent in case management were responsible for the wide variety of activities. They also proposed that this analytical construct could be useful in planning and training for future case management programmes.

Table 1 near here

A framework for the sorts of roles a case manager could perform, and the conditions that a health and social care system environment would need to provide, are beginning to emerge. This assumes that the lived experience of dementia is a condition where case management may have beneficial outcomes.

Can dementia care be improved by case management?

Several empirical studies have tested the use of an additional staff member who has been defined, by those carrying out the studies, as a case manager for people with dementia. The variability of each of these studies illustrates the wide range of roles that a case manager might undertake. The diversity of approaches includes case managers carrying out tasks ranging from assessment, care-planning, and education, to problem-solving, liaising, monitoring, and counseling (Vickrey et al 2006, Callahan et al 2006, Clark et al 2004, Mittelman et al 2006, Fortinsky et al 2006). Some studies showed some positive results, although few recorded a large effect. Vickrey et al (2006) recorded that case management care was more adherent to guidelines, and people received more prescribed medications and referrals to community services. Clark et al's (2004) intervention group in Cleveland, US, experienced fewer hospital and emergency department admissions, and reported less embarrassment, isolation, and relationship strain. Mittelman et al (2006) showed that counseling caregivers could delay moves by their relative with dementia to a care home. Conversely, the caregivers in Callahan et al's (2006) trial were less stressed, but rates of hospital and nursing home admissions were unaffected, while Fortinsky et al (2006) demonstrated no positive effects at all. Time-to-care home move was not often measured in these studies, but, in a meta-analysis of caregiver interventions, Pinquart et al (2006) concluded that case management can lead to a reduced *risk* of care home relocation, if not a demonstrable delay, Table 2 shows the higher quality trials included in the review.

Table 2 near here

The divergence in roles, measurements, outcomes, and findings makes comparisons difficult, and conclusions even harder to reach. The benefits ascribed to case management are highly variable and context-specific; with differences between

outcomes for people with dementia and for caregivers that may be distinct but sometimes entwined. While there may be potential for case management to enable people with dementia or caregivers to improve their coping abilities, and subsequently to increase caregivers' confidence in maintaining care at home, those who have close caregivers do not represent the whole population of people affected by dementia.

Duration of effect of intervention

There is conflicting evidence about the duration of any effects produced by a case management intervention. Sprecht et al (2009), whose case manager offered service coordination and delivery, noted a significant improvement in activities of daily living (ADL) as early as 9 months after the intervention began, and Spijker et al (2008), in their meta-analyses, showed that a caregiver support programme can delay nursing home entry by an average of 4.9 months. In addition, Eloniemi-Sulkava et al (2001) found that time-to-institutionalisation was delayed in the first few months of their 2-year case management intervention, but by the end of 2 years there was no difference between intervention and control groups. Conversely, Mittelman et al (2006) showed that a care manager, whose main role was providing caregiver counseling, produced a median delay in nursing home entry of 585 days, and, highly unusually, they followed up their participants for up to 17 years.

Which professionals are best-suited to the role of case management?

The role of being a case manager for people with dementia and caregivers in these trials was undertaken by a variety of professionals, including specialist nurses, counselors, primary care nurses, mental health nurses and social workers. Newcomer et al (1999) compared a social worker case management intervention with a specialist nurse case management intervention, and found little difference between the two, as well as little effect overall (and there was no collaboration between case management and primary care services). Whilst some of the other case management studies appear to have justified their choice of professional and suitability to the case management role, there is a dearth of literature comparing professions and levels of experience or skills. There is, of course, no internationally agreed definition of skills in health and social care and we lack information on what competencies are taught to different practitioners in different

contexts. It is difficult to know whether the success or otherwise of a case management intervention could be altered were another professional with a different skill-set chosen to perform the role.

Which population would benefit most from case management?

Once again, the heterogeneity of the participants' levels of dementia both within and certainly between trials, as well as the absence of sub-group analysis in most cases, makes it nigh impossible to identify a specific target group of people with or without caregivers likely to benefit most from case management. The variety of sampling has ranged from people with memory loss, to caregiver-patient dyads (some spouse and co-resident), people with any dementia, or specifically with Alzheimer's Disease. Recently, Jansen et al (2011) carried out a trial comparing case management with 'normal care' for people with cognitive decline and their caregivers, in the Netherlands. Their intervention comprised case management delivered by a district (community) nurse over 12 months, and the measurements they used included the caregiver's sense of competence, depression, burden, and the caregiver's and patient's quality of life. They were unable to detect a significant difference between the groups on any of their measures. This suggests that either the cohort they tested was not yet in need of case management, that the difficulties that they and their caregivers faced could not be addressed or solved by case management, or that they had already been addressed and solved by usual care. Some participants did not have a diagnosis of dementia or were in the very early stages of the disease. Few had symptoms of behavioural and psychological symptoms of dementia (BPSD) and their caregivers had low levels of distress at baseline. Mittelman et al (2006) attempted sub-group analysis and found that greater severity of dementia, worse physical health of the patient or caregiver, worse BPSD symptoms, or more caregiver burden, were not surprisingly all significant predictors of faster transition to nursing home care.

It is not yet clear whether it would be best to develop a resource-rich case management programme for those most severely affected by dementia, or a more modest programme aimed at supporting the person with dementia and caregiver in advance of a deterioration of symptoms and function.

What do people want from a case manager? Can this be provided?

There is some evidence to suggest that people with dementia and their caregivers consider their needs revolve mainly around social networks, daytime activities, company, and psychological distress (Miranda-Castillo et al 2010, van der Roest et al 2009), with BPSD symptoms and lack of social networks impacting indirectly on the person's perceived quality of life (Miranda-Castillo et al 2010). These findings match the potential of aspects of various case management programmes well. As Mittelman et al (2006) suggested, perhaps there is a direct association between quality of life and other measures such as time-to-institutionalisation, so that quality of life functions as an intermediate, early-changing, surrogate measurement for consequences which may take longer to appear. All this depends, of course, on regarding life in a care or nursing home as an undesirable outcome which leads to diminished quality of life.

However, Pimouguet et al (2010) argued that, from clinical effectiveness and economic perspectives, there is little reason to promote case management programmes based on the current available evidence. Nevertheless, one could postulate that because Mittelman et al (2006) - having followed participants for so long - reported such convincing results, most of the trials described have failed to follow up participants for adequate periods of time to be able to demonstrate any outcome improvements or cost-effectiveness gains.

We suggest that the main limitations in these studies were the choices of outcome measures. Aiming to delay nursing/care home relocation may be an unrealistic or inappropriate goal, certainly in the short term, and the ambitions for case management ought therefore to be re-visited. Most of the studies with positive findings report improvements in measures such as reduced caregiver burden or stress (Callahan et al 2006, Sprecht et al 2009, Challis et al 2002), improved caregiver confidence (Vickrey et al 2006), fewer negative feelings about the patient (Clark et al 2004), improvement in function (Sprecht et al 2009), or increased uptake of community services (Newcomer et al 1999, Lam et al 2009). Moreover, in Mittelman's study (2006), spouse caregivers' reactions to memory loss and BPSD, and satisfaction with social support, accounted for at least 30 percent of the effect of the intervention on nursing home relocation. Reducing caregivers' negative reactions to memory and BPSD accounted for 48.7% of the

intervention's impact, while depressive symptoms and frequency of BPSD were weaker (but still significant) mediators of the intervention effects. This sub-analysis is pertinent, as it seems to suggest that the intervention is more effective when it positively influences caregivers' perceptions and reactions to the problems presented by dementia, rather than effecting any practical changes in their ability to manage the problems themselves. These findings corroborate the proposition that case management may affect the quality of life of both people with dementia and their caregivers.

Can we measure cost and cost-effectiveness?

The case management trials reviewed showed substantial heterogeneity in many domains: the number of activities or services offered, the length of the programme, the intensity of contact with the person with dementia or caregiver, and the personal and clinical characteristics of those individuals. Each of these could significantly affect the cost or cost-effectiveness of case management. Employing a case manager in primary care is likely to increase use of other health and social care resources in the short term, which would need to be included in any economic evaluation. In many of the studies which attempted economic evaluations and which concluded that using case management was too costly, the unfunded opportunity costs of caregivers' and others' inputs – be they lost work time, lost leisure time, or diminished caregiver health and wellbeing - were not considered. Case management should be costed from a societal perspective not just from the perspective of health and social care services if we are to understand its full impact and potential.

Case management does not need to reduce service costs to be cost effective. It needs to demonstrate that any improvement to outcomes is worth any additional expenditure incurred. For example, Duru et al (2009) found that using internet-based care management software, developing a care plan, and referring on to primary care and community agencies for specific treatment and care services was not cost-saving compared to standard care, but was cost-effective because of improvements in patient and carer outcomes, and because dementia care quality was also significantly better.

In their review, Pimouguet et al. (2010) found only three randomized trials that included an explicit economic analysis, and concluded on that basis that no conclusion can be

drawn about the economic impacts of care management. Nevertheless, some well-conducted, long-term studies with other designs have demonstrated how case management can delay admission to long-term care, with potentially important economic pay-offs (Mittelman et al 2006, Chien and Lee 2008).

Future Research

From the studies considered it is possible to design an exploratory case management trial with detailed specification of the sorts of activities to be included in case management, how case managers might tailor their support, and the requirements for health and social care systems in order for the intervention to be evaluated. The type of system environment suited to ensure an effective programme requires active engagement on the part of all stakeholders, strong networks between tiers of services and agencies, and easy access to a range of different skills and disciplines – all of which may be characteristics that provide supportive dementia services in any event.

It remains to be established which specific skills are most-appropriate to the case management role and where these should be located, which cohort of patients with dementia would benefit most from the case management intervention, the type and intensity of contact, and the length of follow-up required to reveal the full spectrum of impact. Rigorous economic analysis is needed, and should include measures of quality-adjusted life years (QALYs) (NICE 2010) and take into account the costs of system support, role substitution, and carer support. Once these methodological problems have been explored more thoroughly we may better understand the extent to which case management could help people with dementia and their caregivers best manage their problems and enhance their quality of life.

Funding source: A pragmatic randomised controlled trial to evaluate the effectiveness and cost effectiveness of Collaborative cARE for people with DEMentia in primary care (CARE-DEM trial). (HTA 08/58/14)

The authors declare they have no conflicts of interest with the contents of this manuscript

Table 1. Connor et al (2009) Care Management Domains identified and examples of activities categorized in each domain

Care Management Domains	Examples of case management activities which might be undertaken
Behaviour Management	Behaviour management strategies, assessing lack of knowledge or support, medication management, liaising with medical care
Clinical Strategies and Caregiver Support	Education and counseling, clinical therapy information, linking with respite care and support groups
Community Agency	Linking to community options, education and materials, linking to legal assistance
Safety	Safety support, 'safe return programme', information and tools

Table 2. A Descriptive Comparison of Controlled Trials of Case Management for People with Dementia

Authors, date & country	Size	Recruitment	Intervention	Method	Outcomes	Results
Downs et al 2006 Central Scotland & London	35 practices	Local group meetings, postal and phone invitations, practice visits	Three arms 1. Tutorial on CD Rom 2. Decision support software 3. Practice-based workshops	Unblinded, cluster randomized before and after controlled trial	<ul style="list-style-type: none"> Detection rates Concordance with guidelines 	Significant increase in the detection of dementia in arms 2 & 3 No improvement in adherence to guidelines
Callahan, et al 2006 US	153 patients with AD	Primary care centres	Collaborative care management	Randomized controlled trial	<ul style="list-style-type: none"> Neuro-Psychological Index Cognitive function Carer stress, Service use 	Intervention group had lower NPI scores but no difference in depression, cognitive status, or functional scores. Carers showed less stress. Intervention group had higher number of contact with physician/nurse visits, but no difference in hospital or nursing home admissions.
Vickrey et al 2006 US	408 patient and caregiver dyads from 18 clinics	Patients identified from organizational database	Dementia Care Manager with web-based support software for care planning and coordination. interactive educational seminars for practitioners in intervention group	Cluster RCT	<p>Primary:</p> <ul style="list-style-type: none"> Adherence to guidelines <p>Secondary:</p> <ul style="list-style-type: none"> Use of cholinesterase inhibitors Person QoL Caregivers' knowledge QoL Social support Confidence 	intervention group care more adherent to guidelines & got more community services, were prescribed more cholinesterase inhibitors Care-givers were more confident in Intervention group
Fortinsky et al 2009 US	84 care-givers	Family care-givers of patients with dementia were recruited from the Alzheimer's Association, and primary care.	Intervention group received educational materials which were discussed with a dementia care consultant.	Cluster randomized trial	<p>Primary outcome:</p> <ul style="list-style-type: none"> Admission to a Nursing Home in the study period. <p>Secondary outcomes:</p> <ul style="list-style-type: none"> Caregiver self-efficacy Caregiver burden Depression Health Satisfaction with the service. 	Intervention group were 40% less likely to end up in Nursing Home than control, but this did not achieve statistical significance. No difference was found between groups for secondary outcomes.
Clark et al 2004	89 participants with a symptom of memory	Patients registered with Kaiser with diagnosis of	Intervention group received care-consultation	RCT	<ul style="list-style-type: none"> Hospital admissions A&E visits 	Intervention group reported more memory symptoms, but were less

Authors, date & country	Size	Recruitment	Intervention	Method	Outcomes	Results
US	loss or diagnosis of dementia, but no mention of how many in control and how many in intervention groups.	dementia on medical records or symptoms indicative of cognitive impairment.	- telephone interaction between Alzheimer's Association staff and patient/care-giver.		<ul style="list-style-type: none"> • Number of physician contacts • Satisfaction with service • Depression • Strain in person with dementia 	likely to have hospital admissions or A&E visits, & had fewer physician contacts. Also experienced less embarrassment isolation & relationship strain.
Mittelman et al 2006 US	406 caregivers of community-dwelling people with dementia	Spouses of persons attending the New York University Alzheimer's Disease Centre, or recruitment via the Alzheimer's Association or other community organisations	2 individual and 4 family counseling sessions tailored to the needs of the caregiver over a 4 month period. Attendance of a support group, Provision of resource information, referrals to additional agencies, financial planning, and assistance with the management of behavioural problems	RCT	<ul style="list-style-type: none"> • Person with dementia function • Caregiver reported memory and behaviour problems of person • Psychological status of caregiver • Burden scale for caregiver • Caregiver satisfaction (eg with social support, family support) • Caregiver and person with dementia physical health • Admission to care home • Death • Place of residence • Generally measures of quality of care and quality of life including: • Depression and dependency • Person with dementia satisfaction • Caregiver burden and strain • Indicators of need/perceived need 	Persons with dementia whose caregiver received the intervention experienced a 28% reduction in care home admission compared to controls. Improved satisfaction with social support, symptoms of depression, and response to behavioural problems, accounted for more than 60% of the intervention's positive impact.
Challis et al 2002 UK	45 persons with dementia in one community mental health team for the elderly and 50 persons with dementia from another team as intervention and control groups	New cases were identified by staff on the team (staff were encouraged to refer those most suitable)	Assessments at baseline, 6 and 12 months. Case managers maintained structured care plans and tracked costs and service use.	Quasi-experimental design	<ul style="list-style-type: none"> • Place of residence • Generally measures of quality of care and quality of life including: • Depression and dependency • Person with dementia satisfaction • Caregiver burden and strain • Indicators of need/perceived need 	Significant increase in social contacts, and improvements on ratings of overall need reduction, aspects of daily living and level of risk. Significant decrease in caregiver stress and input to the care of the person with dementia.

Authors, date & country	Size	Recruitment	Intervention	Method	Outcomes	Results
Sprecht et al 2009 US	Client and caregiver dyads	Persons with memory impairment who lived in any of 8 counties in Iowa, US. Referrals could be made by self or family, physician or social care or public health services, or from other community agencies	Nurse Care Manager: Assessed person with memory impairment and caregiver. Identified needs and methods to meet those needs. Care and resources to sustain community living. Facilitated collaboration and communication between services. Weekly visits initially tailing off accordingly. Resource mobilization, anticipatory guidance. Grant-funding, referrals to services. Control group received 'traditional' case management services (with the client not caregiver, focuses on coordination not delivery of services	Cluster-controlled trial	<ul style="list-style-type: none"> Assessment of risk Measurements taken at baseline, then 3-6 months after enrollment, then 9-15 months after enrollment 'Client' Measures of: <ul style="list-style-type: none"> Cognition Activities of daily living Behaviour Caregiver measures of: <ul style="list-style-type: none"> Health status Well-being Stress Endurance potential Clients who were admitted to care homes or who died were excluded from analysis	Significant improvement in client activities of daily living. At 3-9 month follow-up the comparison group were more likely to have more stress and worse well-being than intervention group.

1
2 **References**
3
4

5 Alzheimer's Disease International. The Dementia Research Group. The World Alzheimer Report
6 2010 Available from: URL: <http://www.alz.co.uk/research/world-report>

7 Black N. Evidence-based policy: proceed with care. *BMJ* 2001 323:275-279

8 Callahan C, Boustani M, Unverzagt F, et al. Effectiveness of collaborative care for older adults
9 with Alzheimer Disease in primary care: a randomized controlled trial. *JAMA* 2006;295(18):2148-
10 57.

11 Case Management Society of America. Standards of practice for case management. Arizona:
12 Little Rock; 2010.

13 Case Management Society UK. 2010 [cited 2010 Feb 8th]. Available from URL:
14 <http://www.cmsuk.org/>

15 Challis D, von Abendorff R, Brown P, Chesterman J, Hughes J. Care management, dementia
16 care and specialist mental health services: an evaluation. *International Journal of Geriatric*
17 *Psychiatry* 2002;17:315-25.

18 Challis D., Hughes, J., Berzins, K., Reilly, S., Abell, J. and Stewart, K. (2010) *Self care and Case*
19 *Management in Long-term Conditions: The Effective Management of Critical Interfaces*,
20 Southampton, NIHR SDO (08/1715/201)
21

22 Chew-Graham C, Lovell K, Roberts C, Baldwin B, Morley M, Burns A. Achieving target
23 recruitment in a primary care trial: lessons from PRIDE. *Primary Health Care Research &*
24 *Development* 2007;8:264-278.

25 Chien, W.T., & Lee, Y.M. A disease management program for families of persons in Hong Kong
26 with dementia. *Psychiatr Serv* 2008;59(4):433-436

27 Christensen H, Griffiths K, Gulliver A, Clack D, Kljacovic M, Wells, L.. Models in the delivery of
28 depression care: A systematic review of randomised and controlled intervention trial. *BMC Family*
29 *Practice* 2008; 9(25)

30 Clark P, Bass D, Looman W, McCarthy C, Eckert S. Outcomes for patients with dementia from
31 the Cleveland Alzheimer's managed care demonstration. *Aging & Mental Health* 2004;8(1):245-
32 51.

33 Connor K, McNeese-Smith D, van Servellen G, Chang B, Lee M, Cheng E, et al. Insight into
34 dementia care management using social-behaviour theory and mixed methods. *Nursing*
35 *Research* 2009;58(5):348-58.

36 Duru K., Ettner, S., Vassar, S., Chodosh, J., & Vickrey, B. Cost evaluation of a coordinated care
37 management intervention for dementia. *The American Journal of Managed Care*, 2009;15(8):521-
38 528

39 Eloniemi-Sulkava U, Notkola I, Hentinen M, Kivela S, Sivenius J, Sulkava R. Effects of supporting
40 community-living demented patients and their caregivers: a randomized trial. *JAGS*
41 2001;49:1282-7.

- 42 Fortinsky R, Kulldorff M, Kleppinger A, Kenyon-Pesce L. Dementia care consultation for family
43 caregivers: collaborative model linking an Alzheimer's association chapter with primary care
44 physicians. *Aging & Mental Health* 2009;13(2):162-70.
- 45 Goodman C, Drennan V, Davies S, Massey H, Gage H, Scott C, et al. Nurses as case managers
46 in primary care: the contribution to chronic disease management, 2010. Southampton, NIHR SDO
47 Report No.: 08/1605/122.
- 48 Jansen, A., van Hout, H., Nijpels, G., Rijmen, F., Droes, R-M., Pot, A-M., Schellevis, F., Stalman,
49 W., & van Marwijk, H. Effectiveness of case management among older adults with early
50 symptoms of dementia and their primary informal caregivers: A randomized clinical trial.
51 *International Journal of Nursing Studies*, 2011, In Press.
- 52 Koch T, Iliffe S. Changing practice in the diagnosis and management of dementia: narrative
53 review. *British Journal of General Practice* 2010 pending
- 54 Koch T, Iliffe S. Rapid appraisal of barriers to the diagnosis and management of dementia in
55 primary care: a systematic review. *BMC Family Practice* 2010 [cited 2010 Nov 30];11(52)
56 Available from: URL: <http://www.biomedcentral.com/1471-2296/11/52>
- 57 Lam L, Lee J, Chung J, Lau A, Woo J, Kwok T. A randomized controlled trial to examine the
58 effectiveness of case management model for community dwelling older persons with mild
59 dementia in Hong Kong. *International Journal of Geriatric Psychiatry* 2009; 25:395-402.
- 60 Minkman M, Ligthard S, Huijman R. Integrated dementia care in The Netherlands: a multiple case
61 study of case management programmes. *Health and Social Care in the Community*
62 2009;17(5):485-94.
- 63 Miranda-Castillo C, Woods B, Galboda K, Ooman S, Olojugba C, Orrell M. Unmet needs, quality
64 of life and support networks of people with dementia living at home. *Health Quality Life Outcomes*
65 2010;8(1):132.
- 66 Mittelman M, Haley W, Clay O, Roth D. Improving caregiver well-being delays nursing home
67 placement of patients with Alzheimer Disease. *Neurology* 2006;67:1592-9.
- 68 Morales-Asencio J, Gonzalo-Jimenez EM-SFM-HJC-MMCAG-AJ&T-L, I. Effectiveness of a
69 nurse-led case management home care model in Primary Health Care. A quasi-experimental,
70 controlled, multi-centre study. *BMC Health Services Research* 2008;8(193).
- 71 National Institute for Health and Clinical Excellence. Measuring effectiveness and cost
72 effectiveness: the QALY. National Institute for Health and Clinical Excellence 2008 [cited 2010 Nov
73 30]; Available from: URL:
74 <http://www.nice.org.uk/newsroom/features/measuringeffectivenessandcosteffectivenessstheqaly.js>
75 [p](#)
- 76 Newcomer R, Spitalny M, Fox P, Yordi C. The Medicare Alzheimer's Disease Demonstration
77 Program: Effects of the Medicare Alzheimer's Disease demonstration on the use of community-
78 based services. *Health Services Research* 1999;34(3):645-67.
- 79 Pimouguet C, Lavaud T, Dartigues J, Helmer C. Dementia case management effectiveness on
80 health care costs and resource utilization: a systematic review of randomized controlled trials.
81 *The Journal of Nutrition, Health & Aging* 2010;14(8):669-76.
- 82 Pinquart M, Sorensen S. Helping caregivers of persons with dementia: which interventions work
83 and how large are their effects? *International Journal of Psychogeriatrics* 2006;18(4):577-95.

- 84 Spijker A, Vernooij-Dassen M, Vasse E, Adang E, Wollersheim H, Grol R, et al. Effectiveness of
85 nonpharmacological interventions in delaying the institutionalization of patients with dementia: a
86 meta-analysis. *Journal of American Geriatrics Society* 2008;56(6):1116-28.
- 87 Sprecht J, Bossen A, Hall G, Zimmerman B, Russell J. The effects of a dementia nurse care
88 manager on improving caregiver outcomes. *American Journal of Alzheimer's Disease & Other
89 Dementias* 2009;24(3):193-207.
- 90 van der Roest H, Meiland F, Comijs H, Derksen E, Jansen A, van Hout H, et al. What do
91 community-dwelling people with dementia need? A survey of those who are known to care and
92 welfare services. *Int Psychogeriatr* 2009;21(5):949-65.
- 93 Verkade P-J, van Meijel B, Brink C, van Os-Medendorp H, Koekkeok B, Francke A. Delphi-
94 research exploring essential components and preconditions for case management in people with
95 dementia. *BMC Geriatrics* 2010;10(54).
- 96 Vickrey B, Mittman B, Connor K, Pearson M, Della Penna R, Ganiats T, et al. The effect of a
97 disease management intervention on quality and outcomes of dementia care. *Annals of Internal
98 Medicine* 2006;145:713-26.
- 99 World Health Organization. Global Burden of Dementia in the year 2000. World Health
100 Organization 2003 [cited 2010 Nov 12]; Available from: URL:
101 www.who.int/entity/healthinfo/statistics/bod_dementia.pdf