

Review

## **Admiral Nurse Case Management: A Model of Caregiver Support for Families Affected by Dementia**

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### **Abstract**

There has been a strong thrust to identify the needs of people with dementia against a background of person-centred care, however, people with dementia do not exist in isolation; they live within relational contexts with family members. Case management is a model of care that has its origins in supporting patients with a long term disease, however, a very practical approach to case management that can support the care needs of both the person with dementia and the family carers is emerging in the UK. Admiral Nursing is the only defined model of case management that integrates health and social care for all members of the family unit affected by dementia in the UK. Admiral Nursing is learning from best practice across several countries and developing an approach that is congruent with meeting the complex health and social care needs that affect families living with dementia. This paper discusses the evidence base for case management and the functioning of the Admiral Nurse approach to relationship centred care.

### **Keywords**

Dementia; case management; caregiver support; relationship centred care; Admiral Nurses



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## 1. Introduction

Dementia is a growing global challenge. It is estimated that there are approximately 44.4 million people worldwide with dementia, and (if mortality, prevention and treatment remain the same) this number will increase to an estimated 75.6 million in 2030, and 135.5 million in 2050 [1]. In the UK this figure equates to 1.3% of the entire UK population. While the statistics on the prevalence of dementia have been challenged [2, 3], increasing age appears to be the strongest risk factor for developing dementia [4] and the number of people with the condition is forecast to rise.

Dementia is a term used to describe a syndrome; a collection of symptoms, including a decline in memory, reasoning and communication skills, and a gradual loss of skills needed to carry out daily living activities. These symptoms are caused by structural and chemical changes within the brain as a result of neurodegenerative changes and as such dementia is the end stage manifestation of numerous brain disorders [5].

## 2. Carers of People with Dementia

There are an estimated 670,000 family members and friends in the UK acting as primary carers to people with dementia [6]. In 2014, the Alzheimer's Society's [7] found that dementia was costing the UK £26 billion a year, which is higher than costs associated with cancer, heart disease and stroke [7], and that family carers of those with dementia were saving the UK economy an estimated £17.5 billion of this amount in a year [8].

Carer distress is a common factor in caring for someone with dementia, whether the carer lives with the person with dementia, or is trying to maintain that person's independence while they are living alone [9]. Education, advice and support for the carer regarding dementia and the effects that it can have on relationships, communication, behaviour and social functioning, as well as financial and legal issues, should be central to any carer intervention [6]. There is evidence that education, advice, support and future planning can all help to reduce some of the anxieties around care [10].

Although there are a variety of community and care services available for community-dwelling people with dementia and their family carers, they are often inconsistent with significant regional variations across the UK and people often lack information regarding what is available to address their care needs [6, 11, 12]. Many experience a fragmentation of service provision, insufficient support, management and continuity of care during the disease course of dementia [13].

The majority of family carers of people with dementia are at risk of becoming distressed and overburdened through their caring responsibilities [14, 15] and are at high risk of developing depressive and/or anxiety disorders as a result [16, 17]. Moreover, the worsening psychological and physical health in family carers can also have a negative impact on the person with dementia due to the increased likelihood of admission to a care home or acute hospital [18, 19], which is associated with decreased psychological and physical health and increased mortality in the person with dementia [20].

### **3. Family Centred Approaches in Dementia**

Family-centred approaches tailored to individual families' requirements have been identified as being beneficial in the support of families affected by dementia [21]. For many families, concern first arises when it is detected that 'something is not right', often before a diagnosis is established. Once a diagnosis has been made, interventions structured around a family-centred approach, such as case management, can help to untangle and clarify issues, and provide a structure to help unite families, whilst still recognising the individual values of the person with dementia and of the family carer [22].

### **4. Case Management**

Case management was developed to provide specialist services or to support narrowly defined population groups with severe and/or intractable illnesses, aiming to improve outcomes through coordination of care, reducing fragmentation of service delivery and supporting the receipt of the right level of care at the right time for an individual. Case management has been developed over a long period of time with an approach that has differed in the population it serves and also in its application. Though in existence as far back as the late 19th century, case management re-emerged in the 1970's in the United States when the Department of Health, Education and Welfare introduced funding to test integration of care for people with long term mental health conditions through the role of a 'systems agent' (case manager) [22].

Case management has been proposed as an intervention to delay institutionalisation of the person with dementia and improve the mental health of family carers [23]. This type of collective approach can help to reduce conflict and improve relationships in the family in the context of caring [24, 25]. Case management is defined as a "collaborative process of assessment, planning, facilitation, care coordination, evaluation, and advocacy for options and services to meet an individual's and family's comprehensive health needs through communication and available resources to promote quality and cost-effective outcomes" (The components of case management in relation to the Admiral Nursing model will be discussed later in the paper) [26]. The majority of the early literature on case management and its effectiveness is from the USA and focuses on the fields of mental health and long-term conditions [23], however, there is a growing body of interest in the effectiveness of case management in supporting families affected by dementia in the UK [27-30]. In their Cochrane review Reilly et al. [31], in the meta-analysis of the 13 studies, found there were clear benefits to adopting a case management approach in dementia; such as, reducing admission to residential or nursing homes; reducing length of stay in hospital and reduction in behaviour disturbances.

### **5. Models of Case Management in Dementia Care**

Research into case management models and practice in dementia care is growing. Van Mierlo [32] described two types of case management; the linkage model and the intensive model, though descriptions vary across countries, similarities are to be found. The linkage model is comprised of independent care agencies where case managers provide the family with informative, practical and emotional support though may or may not be based within a professional dementia care

network. In the linkage model the case manager will often have dual roles, for example, where approximately 50% of their time spent as a district nurse and the other 50% a case manager.

The second case management model, and of greater international interest, is whereby the case manager is employed full time in the role and works within a multidisciplinary team [32]. They may be a case manager within an identified professional dementia network [33, 34], such as in the Aging Brain Care (ABC) programme in the United States [35], successfully replicated in Germany [36], or as in dementia care management team (DCM). Such models are demonstrating positive outcomes through better recognition and assessment of dementia, increased prescribing and use of anti-cholinesterase inhibitors, improved recognition and treatment of depression, and reductions in the carers' symptoms of distress [35]. This form of networked and or collaborative case management for families affected by dementia seems to be thriving and proving to be a successful model in many countries and adaptable to varied commissioning and funding arrangements [33-36]. This approach offers support to the family unit from the point of diagnosis and continues throughout the period of time the person with dementia resides in their own home; indeed its emphasis is on supporting the person to live in their own home for as long as possible. Discharge from the case management caseload only comes about upon the death of the person with dementia or upon admission to a care home [32, 35-37].

However, case management for families affected by dementia in the UK is a relatively new concept within the field with early research proving inconclusive as to its potential [38, 39]. In a pilot study Iliffe et al. [39] adopted the 'linkage' model of case management across four sites where a practice nurse or a social worker or district nurses each took on additional case management responsibilities. There were several factors that hindered the success of the pilot; a lack of clarity and consistency in the function of the case managers as the demands of their other roles conflicted with their case management responsibilities making ring-fenced time for case management difficult. Iliffe et al. reported that contextually the case manager also struggled against poor integration with existing services resulting in a lack of their embeddedness within primary care. Only one of the sites achieved a level of case management activity that might have influenced patient and carer outcomes.

Similarly, care pathways and care home provision in countries where case management is more successful and very different to that in the UK [40]. Care home units are often part of a continuous pathway supported by a dedicated multi-disciplinary team led by a physician. Thus a case manager would provide community support in that pathway and hand over care to this skilled and professional workforce. Care homes in the UK are categorised as either nursing; where there is 24-hour nursing provision on site alongside care to support Activities of Daily Living (ADLs), or residential where there is 24-hour care to support ADLs but no provision of nursing care [40]. There is no specific connection or continuity between community or domiciliary care and care home for families affected by dementia; with often a service divide in the transition from one to another [40].

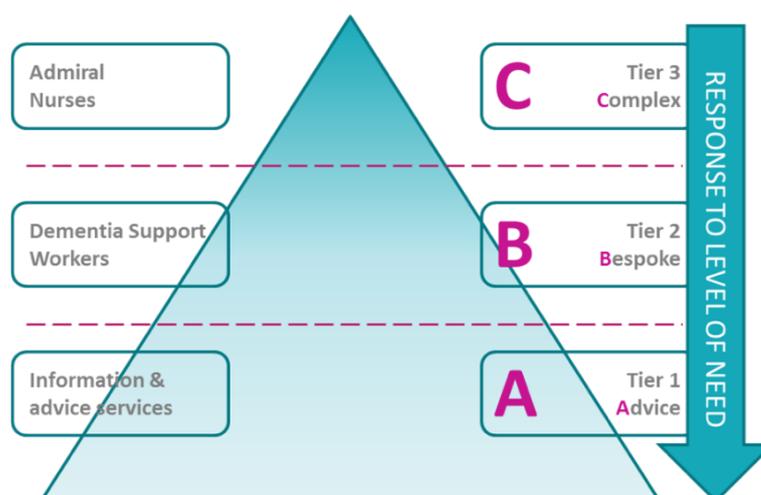
Case managers can be of any profession but noted success is where the case manager is of the nursing discipline as they are seen as the most appropriately trained and skilled member of the multi-disciplinary team to do so; they also provide cost effectiveness to the approach [32, 33, 37, 40, 41]. Coordinated care for families affected by dementia in the UK is patchy with few consistent approaches. However, Backhouse et al. [42], in a subgroup analysis of a meta-analysis of community based coordinating interventions in dementia, found using a case manager with

nursing background showed a greater positive effect on quality of life than those that used case managers from other professions. This finding is also supported in other studies [34, 37]. Admiral Nursing is a model of case management in the UK that is growing in both strength and numbers and is currently the only defined case management approach in support of families affected by dementia [23, 43].

## 6. Admiral Nursing

Admiral Nursing [44] has evolved from delivering an intervention that was specifically aimed at supporting family carers into delivering an intervention that supports the entire family unit through a case management approach (see Figure 1) [43].

### The Dementia UK ABC Tiered model of case management



**Figure 1** The Dementia UK ABC model of case management.

## 7. The Components of Case Management

There are a suggested set of core components to effective case management [43, 45, 46], which are; case finding, assessment, care planning, care co-ordination and case closure which are well demonstrated in Admiral Nursing [23, 42].

### 7.1 Case Finding

Case finding is the element of case management that identifies the target population to whom the care is to be delivered. This is an approach that is proactive rather than one that waits for a crisis to develop and that identifies a case which is subsequently triaged (a system of assigning priorities of treatment or attention based on urgency [47]) to ensure that the intervention offered is appropriate for the level of need and/or complexity. As we know the complexity of a case may be determined through a variety of concomitant factors, for example; multiple morbidity of person with dementia and/or carer, issues of safeguarding or risk, difficult interpersonal family dynamics, behavioural issues, etc.

## 7.2 Assessment

When the process of case finding confirms a level of need sufficient to warrant a case manager then a comprehensive assessment ensues. The assessment will cover a wide and varied range of issues for both the family carer and the person with dementia; not just health needs and may involve the use of a variety of measures and tools, such as; quality of life, depression and anxiety, satisfaction with care, frailty index, etc. The Admiral Nurse Assessment Framework (ANAF) is set within a bespoke electronic record keeping system which facilitates and records a comprehensive assessment of not only the needs of the person with dementia but also those of the family carer; this may in fact include several family carers that support the person with dementia as needs often vary across family members. An often unconsidered population are young children, either of the person diagnosed with dementia, as in young onset, or as grandchildren of an older person in the family with dementia [48] (see Box 1).

### Box 1 the Admiral Nurse Assessment Framework (ANAF) domains.

1. Physical health and wellbeing of the person with dementia
2. Mental health and wellbeing of the person with dementia
3. Physical health and wellbeing of the carer(s)
4. Mental health and wellbeing of the carer(s)
5. Managing medication
6. Knowledge and understanding of dementia
7. Skills in coping with behaviour/symptoms
8. Communication and understanding with professionals
9. Environment
10. Financial and legal issues
11. Practical and assistive aids
12. Practical support
13. Informal supports and networks
14. Adjustment and loss
15. Balancing needs (carer)
16. Time for self (carer)
17. Looking to the future (carer)
18. Risk

## 7.3 Care Planning

Care planning is central to case management and following the assessment of needs, care plans are developed to address the identified needs of each family member. It may not always be appropriate that the case manager is the professional to deliver an intervention to resolve a need, they may identify and refer on to a suitable other to do so; for example; if the person has an unmet need for chiropody, speech and language therapist (SALT), dentistry, etc. The case manager may not have the skills to undertake this themselves but will ensure a referral is made and the need addressed by a person qualified to do so. However, Admiral Nurses are skilled nurses that can deliver many physical, psychological and social interventions themselves to support

family carers, such as, cognitive behavioural therapy, brief solution focused interventions, anxiety management, etc., (see figure) but can also source and plan care from another discipline or service. This part of case management is made particularly seamless by Admiral Nurses as they are able to work collaboratively across health, social care and voluntary services to ensure family's needs are met.

#### **7.4 Care Co-Ordination**

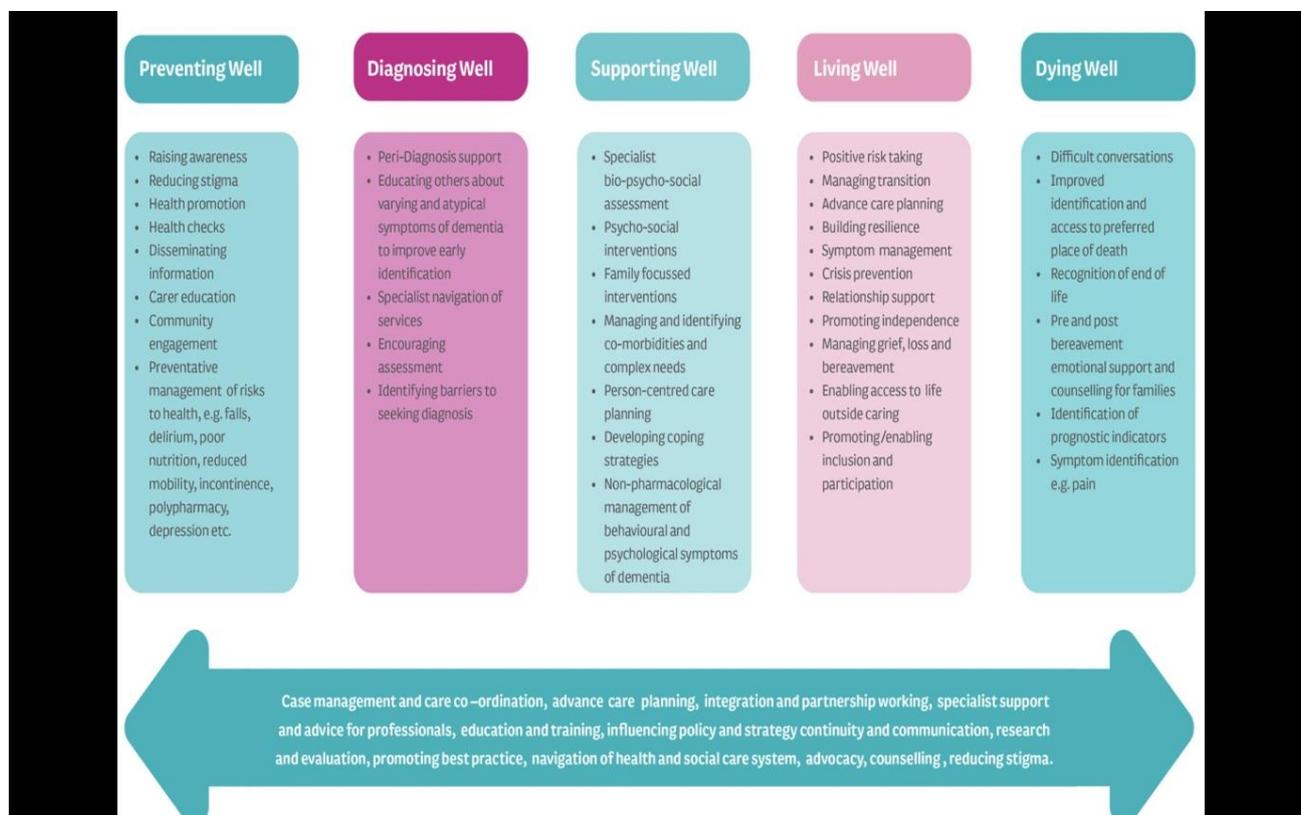
Probably the most significant element of case management is in the coordination of care, especially where there are several services and providers involved and/or where care is required for a number of co-morbidities. Ross et al. [49] describe the co-ordination of care as the very essence of case management and fundamental to the role, especially in enabling working across organisations, care settings and individuals to deliver care. Sargent et al. [50] state that care co-ordination can reduce duplications of health care, avoid gaps in service and care for individuals and reduce health and social care service costs as well as having positive outcomes for the person with dementia and family carers, such as, improved access to services, avoidance of unnecessary investigations and procedures, improved disease management, faster discharge from hospital, preventative interventions and promotion of well-being in family carers.

Often families affected by dementia articulate the desire for a navigator through their journey with dementia. A key function of the Admiral Nurse is in identifying a network of services and resources and developing links to ensure families in their care access the right care and support at the right time. Aldridge et al. [43] identified a tiered approach (see Figure 1) of local resources and dementia services; following triage by an Admiral Nurse the appropriate tier of intervention was identified based upon a skilled assessment. Coordination of care was central to the allocation of the appropriate tier of intervention. Further iterations of this service model have been implemented and enabled a case management approach across services that enabled coordination of care across team and organisational boundaries [51]. The coordination of care is thought to be the cornerstone of the Admiral Nurse case management model in supporting both the person with dementia and their family members [52-54].

### **8. Case Management in Dementia - The Well Pathway**

The UK government set out its ambition for NHS and Social Care in England to truly transform dementia care and support for families by 2020 and defined actions that were necessary in order to deliver their vision [55]. NHS England developed a transformation framework that set out a pathway for dementia which was based on NICE guidelines [14], the OECD framework for Dementia [56] and the Dementia i-statements. A significant part of this ambition was to outline a 'well pathway' (<https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf>) for families affected by dementia that encompassed defining what was required of services to; prevent well, diagnose well, support well, live well and to die well. An expert reference group was established to identify Admiral Nurse interventions and activities that fall within each of the strands of the NHS dementia pathway, that adhere to standards, best-evidence and deliverables charged of practitioners by the PM's Challenge 2020 [55].

Dementia UK developed a response to the Prime Minister’s call [55] for interventions and supports to ensure a ‘well pathway’ for people with dementia and their family carers to detail the Admiral Nurse case management approach in a pathway format where the health and well-being of all members of the family unit are of equal weight and significance in recognition of the relational elements of dementia care rather than taking a patient specific stance (see Figure 2).



**Figure 2** The Admiral Nurse 'Well-Being Pathway'.

## 9. Relationship Centred Care

Successful case management for a family affected by dementia involves a relationship centred approach that is inclusive of all family members and enables an approach that reflects respect and value the interests of all involved. However, it can be challenging to support this, sometimes, delicate balance of interests and requires a skilled case manager that enables the sharing of knowledge, experience and wishes and preferences for care across all stakeholders: the person with dementia, the family carers(s) and professionals [57, 58]. In practice, this might mean an imbalance between considering the perspectives and wishes of the person with dementia and those of the carer. Whilst we strive to make the wishes and preferences of the person with dementia influence delivery of care they may conflict with what is in the best interests of the carer.

## 10. Conclusions

People with dementia do not exist in isolation and whilst there has been a strong thrust to identify the needs of people with dementia against a background of person centred care, they live within relational contexts, whether that be with family members or with professional carers but

often, both. Therefore, approaches that seek to redress this current imbalance are imperative particularly as there will be a growing reliance on family carers in the future to enable the sustainability of health and social cares ever diminishing resources against a background of increasing demand. Case management has a long history in supporting people with long term conditions and mental illness, however, research into case management in the UK remains limited. Admiral Nursing offers a flexible and practical approach that is showing distinct promise in supporting families affected by dementia in the UK. Admiral Nursing is a case management approach to that ensures the needs of all family members affected by dementia, including the person diagnosed, benefit from a coordinated approach to care which is essential as a diagnosis of dementia impacts on the whole family.

### **Author Contributions**

KHD conceived of the article content and structure; KHD & ZA co-authored the paper.

### **Competing Interests**

The authors have declared that no competing interests exist.

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