

# Dementia Management and Coordination for People with Dementia and Their Carers in Community Via a Key Professional Contact: What Can Australia Learn from Other Countries?

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## Abstract

Receiving post-diagnostic support after a diagnosis of dementia is imperative for people with dementia and their carers. One of the most desirable aspects of post-diagnostic support is the role of a case manager who supports both individuals with dementia and their carers, focusing on both medical and social aspects of care. Australian studies have highlighted the need for this role and the importance of harmonizing its description and implementation. To achieve this, health professionals, researchers, people with dementia, carers and policymakers must co-design the role and work collaboratively on its implementation. Collaboration with the Australian Government is crucial for the successful implementation of this role across Australia.

## Opinion

Dementia is a syndrome caused by one or more neurodegenerative diseases, which is progressive and may show decline in cognitive, functional, physical, behavioural and psychological domain of a person [1]. This condition is a challenge for individuals, families, communities and health care system worldwide. Life after a dementia diagnosis brings many questions and requires structured support given the fear of losing independence, changing family relationships and altering life habits [2-4]. Key questions associated with this condition and diagnosis include: How can one live with an incurable terminal condition? Where can medical and psychological help be found? How can one access recently approved medications? Are there social services that provide support? What are the rights and responsibilities of diagnosed individuals and their families, particularly regarding work, driving and participation in social and political life? These concerns can be addressed through various models of post-diagnostic support. A recent review identified five models, with two models being the “key support worker models” (short-term support worker and ongoing support worker) [5].

Australian studies showed that people with dementia and carers want to be guided and supported by a person who will be their key professional contact [6-9]. An experts' opinion paper suggests that Australians need a dementia care specialist who will build the partnership with primary practice and GPs of people diagnosed with dementia as well as the partnership with specialist services to support people through the process of diagnosis and then disease management and life with dementia [10]. Of course, in dementia care, it is imperative that support extends to the entire family or to any other supporters depending on living arrangements and life situation of a person with dementia. Therefore, the role of a key professional support person in managing and coordinating dementia care in the community is considered integrative. This role involves working between primary and secondary health care sectors and third sectors (e.g., non-government organizations) and linking people with

community social care, health services, aged care and disability organizations.

The main organisation in Australia that specializes in dementia support is Dementia Australia, which is the national peak body for Alzheimer's disease and other dementias, offering a variety of services for people living with dementia, carers, and health professionals [11]. Dementia Australia used to provide some form of a case management through dementia advisors [12] and key Younger Onset Dementia (YOD) workers [13,14]. However, the provision of post-diagnostic support through dementia advisors was fragmented. The service was available across New South Wales but not in other states. While YOD key workers were nationally spread, remote areas of Australia and some regional areas were not covered. The service of YOD key workers was terminated as the role was moved from Dementia Australia to disability organizations funded by the National Disability Insurance Scheme [13]. Currently, a new post-diagnostic program, composed of six sessions within the first 12 months from the dementia diagnosis, is led by a key person in post-diagnostic support [11]. However, this program is limited to the first year following the diagnosis and does not meet one of the essential needs of people with dementia and their carers: the need for continuous and ongoing support.

Internationally, there are numerous similar roles under various titles including "admiral nurse", "link worker", "key dementia worker", "case manager" "dementia advisor", "dementia care navigator", "dementia care coordinator", "dementia key support worker", etc. [12,15-17]. Literature, largely from the UK and the Netherlands, documents how this key point of contact role, regardless of title, has been developed, standardized and evaluated as effective case management [18-25]. A Cochrane review aimed to evaluate the effectiveness of case management approaches to home support for people with dementia included 13 RCTs involving 9615 participants with dementia [26]. In this review "case management is defined as any intervention delivered in the community (not in hospital or residential care settings) predominantly focused on the planning and co-ordination of care required to meet the identified needs of the person with dementia" [26]. Given this, there is no clear difference between case management and care coordination in dementia care. Both of these roles involved planning, coordination, guiding and focus on the needs of people with dementia, which includes family and other supporters too. Similar definition is suggested by Iliffe et al. [21] established by Case Management Society of the UK asserts that case management is "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"(pp. 953). Hence, the terms "case management" and "case manager" will be used for the purposes of this paper. In addition, the review by Reilly et al. [26] showed that case management, through a key person responsible for planning and coordination, was effective in reducing behavioral disturbances, carer burden, and depression, as well as improving carers' well-being and social support. This review also found

that case management improved the use of community services and decreased the need for people with dementia to move into residential care.

The UK is a leading model in implementation of dementia case management through various role models and titles (e.g. specialist dementia nurse-admiral nurse, key worker, dementia advisor, link worker) [18,20,25,27]. Research from the UK shows robust evidence relating to the admiral nurse service. Briefly, admiral nurses have a key role in providing emotional and psychosocial support to the carers of people with dementia; source of information about dementia, diagnosis, changes in behavior; assisting to access services [18,28,29]. The service was established to link different parts of health and social care system, to help carers to develop coping strategies and support people with dementia to stay at home [30]. However, this model depends on health-care model that provide service. Therefore, different sub-models of admiral nurses appear in primary, secondary and third sector organizations. The case management model in the Netherlands is embedded into two different systems: the link model and intensive case management. The link model involves independent agencies that connect clients to various services, while intensive case management is part of multidisciplinary teams (e.g., memory clinics) that provide services within their organizations and follow clients until the end of their lives [21,23,31,32]. In recent years, primary care case management has gained global prominence and has a long tradition in Canada. In Canada, the role of a case manager is integrated within collaborative primary memory clinics. The aim is to link individuals with cognitive problems to specialists and community services throughout the diagnostic process and during post-diagnostic support and provide ongoing disease management [33,34]. This role is placed into the hands of the family physician (general practitioner GP). Conversely, the role under the title of "care navigator" recognized in the US does not require professional qualification [35,36]. However, the training and the integration of the role into multidisciplinary team is necessary. The role description and duration of the service vary, but the mutual characteristics of the role are general dementia education and support in accessing dementia and social care services.

Experiences in dementia case management from Europe, Canada, and the US provide valuable insights that may serve as starting points for discussions on co-designing a new role tailored to Australia's health care, disability, and aged care systems. This is an urgent need, as currently approximately 421,000 people in Australia live with dementia, and two in three people live in the community [37]. However, even though extensive data on the dementia case manager role shows good efficiency where implemented, barriers to translating this role into practice still exist in the Australian context. For instance, if the case manager role is implemented in memory clinics, it would require hiring a new person or allocating additional time for an existing staff member, necessitating additional funding [8]. Even if the implementation occurs in Dementia Australia or other aged care or health organizations, additional funding would still be required. Given this, the health care system itself appears to be the main barrier. For any services implemented in memory

clinics, the health system is identified as a barrier [8]. Even in the UK, system is recognised as a barrier, manifesting as a lack of funding, insufficient shared information systems, and inadequate links between primary, secondary, and third-sector organizations [25,38]. Since the need for a case manager role in post-diagnostic support is clear and strongly advocated by both lived experience experts (people with dementia and their caregivers) and health professionals, consultation and collaboration with the Australian Government is the only solution to overcome the system's barriers [7]. However, before this can happen, recommendations for the role description need to be made. Thus, data from literature describing this role in the UK, the Netherlands, Canada, and the US, along with its effectiveness, should be synthesized and summarized to form the initial points for discussion. Moreover, the opinions of lived experience experts, health care professionals, researchers, and policy advocates and makers need to be included in the discussion regarding the optimal characteristics of the case manager role, including role description, responsibilities, competencies, qualifications, personal attributes, training, setting, and funding sources.

In conclusion, future studies on the role of case managers in the Australian context of dementia care should aim to address the existing knowledge gap regarding role descriptions. Additionally, translating this knowledge into practice should enhance the continuity and efficiency of dementia post-diagnostic support.

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