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Concept Paper

Admiral Nursing in Primary Care: Peri and Post-Diagnostic Support for Families Affected by Dementia within the UK Primary Care Network Model

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Abstract

The population of the United Kingdom is ageing. In 2017 approximately 18% of the UK population were aged 65 years or over and projected to grow to almost 21% by 2027 according to the Office of National Statistics. Increased age is the greatest risk factor for developing dementia. It is estimated that there are 850,000 people living with dementia in the UK and if current figures relating to incidence and prevalence are realised, this will increase to 1 million people by 2025 and 2 million by 2051.

The National Health Service (NHS) England Long Term Plan aims to move services closer to home and improve 'out of hospital' care. The overall aim being to reduce the pressure on acute hospital resources, give people more control over their own health, and more personalised care closer to home when they need it. Given the increasing number of people with dementia and their families there is a growing need to ensure primary and community services are developed to meet their often complex needs. Admiral Nurses are specialist dementia nurses that could support the delivery of the NHS Long Term Plan and improve the provision of specialist support offered to families affected by dementia within new models

of care. This article aims to articulate some of the current gaps in peri and post-diagnostic support for families affected by dementia, and how the inclusion of Admiral Nurses within Primary Care Networks could be a solution to redressing some of these gaps.

Keywords
Dementia; Primary Care Networks; Admiral Nursing; integrated care systems; peri and post-diagnostic support

1. Background

Dementia services within the United Kingdom (UK) are fragmented and often offer a reactive approach to care and support, usually at a point of crisis as opposed to a proactive, preventative model of care. There is a growing propensity to try and meet the often-complex needs of people with dementia and their families in primary and community care. However, there is a lack of specialist resources within primary and community care services to facilitate this. The current reconfiguration of primary and community services in the UK offers an opportunity to redress this within the new models of care with the inclusion of specialist support services inclusive of Admiral Nurses.

The UK population is ageing. In 2017 approximately 18% of the UK population were aged 65 years or over and projected to grow to almost 21% by 2027 according to the Office of National Statistics (ONS) [1]. Projections suggest that in 50 years' time there will be an expected additional 8.6 million people over 65 years old [2]. Similarly, it is predicted that the number of people over 85 will increase to 3.5 million by 2043, equating to 5% of the total UK population, placing further pressure on already struggling resources [3]. There is growing evidence that older people often have complex health and social care needs with most over 65's having at least one long term condition, increasing to two by the age of 75 [4]. This increases further with age, with 80% of 85-year olds having at least 3 comorbid conditions and 40% living with in excess of four comorbid conditions [5].

In the next 20 years, England will see increases in the number of people with complex care needs, due mainly to more individuals living beyond 85, when they are likely to have higher levels of dependency, dementia, and comorbidity [6].

2. Dementia

Increased age is the greatest risk factor for developing dementia [7]. Dementia is an umbrella term used to describe a broad range of symptoms including memory loss, confusion, personality and behavioural changes and difficulty carrying out everyday tasks. It is a progressive, life-limiting, debilitating condition caused by underlying diseases and brain disorders such as Alzheimer's disease and Vascular Disease [8]. ONS data from 2016 recorded that Dementia and Alzheimer's disease was the leading cause of death in England and Wales, accounting for 12.0% of all deaths registered in 2016, up from 11.6% in 2015 [1].

It is estimated that there are 850,000 people living with dementia in the UK and if current figures relating to incidence and prevalence are realised, this will increase to 1 million people by 2025 and 2 million by 2051 [9]. Currently two thirds of people with dementia live in the community [9] supported by 700,000 family carers [10] with the remaining third living in residential care. Dementia currently costs society £26.3 billion per annum with costs expected to increase to £55 billion per annum by 2040 [9].

In 2012 the Prime Ministers Challenge on dementia [11] was published aiming to ensure that every person with a diagnosis of dementia gets the treatment and support which meets their need. The main aims of the challenge were to improve dementia diagnosis, provide better support for carers, develop dementia friendly communities and improve dementia research. This was superseded in 2015 by the Dementia 2020 report [12] with the continued aim to improve diagnosis rates of dementia to 66.7%. Although nationally this target has been achieved, data from NHS Digital demonstrates that there are significant variations in diagnosis rates at Clinical Commissioning Group (CCG) localities in July 2019 ranging from 40.6% to 92.6% [13].

The National Institute for Health and Care Excellence (NICE) guideline on dementia (NG97) [14] acknowledges the progressive and complex nature of dementia and makes recommendations for high quality assessment, management and ongoing support for people with dementia and their families. But of course, without a diagnosis, many will be unable to access such support to meet their health and social care needs. This is further challenged by evidence that services offered to families affected by dementia are fragmented and not person-centred, and there is limited knowledge and skills within the workforce, poor communication across services and ineffective healthcare policies [15].

Currently the majority of dementia assessment and diagnosis in England is carried out within secondary mental health services, although some people may be diagnosed in other settings such as Neurology, Learning Disabilities services or Older Persons Medicine. Following receipt of a diagnosis, care is more often handed back to an individual's General Practitioner (GP). In many locations the person with dementia may never have their condition reviewed by specialist services unless there is considered to be a complex need, usually involving distressed behaviours or when seen to be within a state of crisis.

Historically, dementia has been managed predominantly within mental health services and indeed diagnostic classification sits within the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) [16] and also the mental and behaviour disorders chapter of ICD-10: international statistical classification of diseases and related health problems [17].Therefore, the perception of dementia differs from other neurological disorders [18]. This is problematic in a primary and community care setting as there is limited specialist support to assess and manage the ongoing, often complex, health and social care needs of families affected by dementia post diagnosis [19]. It is recognised that there still remains a skills and resources gap in Primary Care services in relation to dementia [19, 20].

3. Comorbidity

It is estimated that 90% of people with dementia are likely to have at least one comorbid condition [21] with some studies indicating that that 61% of people with dementia have an average of at least three comorbid conditions [22, 23]. There is also growing evidence regarding

the relationship between frailty and dementia. Frailty describes a condition in which multiple systems gradually lose their in-built reserves and resilience. It is often present in people who have a diagnosis of dementia or cognitive impairment particularly in those over 76 years old [24]. Due to the increased vulnerabilities and complexities of this group, delays in identifying changes in health status and subsequent provision of healthcare and support can lead to an increased risk of inappropriate hospital admissions, morbidity and mortality [25-27].

There is likely to be a melange of comorbid conditions and social care needs impacting upon both the person with dementia and their family, which, when assessed in isolation of each other, may not be seen as problematic. However, when considered in totality and in the context of the relationship, they present a picture of complexity which requires specialist support to reduce the risk of crises by implementing a preventative and proactive approach as opposed to reactive approach to care needs. Such needs require regular review over many years and so benefit from care coordination [28, 29]. However, currently services are fragmented and are often commissioned to provide health *or* social care for the person with dementia *or* their carer [30] within a singular disease management process. This makes care coordination difficult to implement, despite the NICE guidelines and quality standards acknowledging the need to do so [14, 30].

People with dementia and their families find navigating health and social care systems difficult and confusing which can lead to increased use of emergency services especially at end of life [15, 31]. Poorly constructed dementia pathways can lead to inappropriate responses increasing the risk of unnecessary medical interventions, extended lengths of stay in acute care settings, poor experiences of care and premature admission to residential care [15].

4. Care Homes

Care homes in the UK are categorised as either *Nursing homes,* where there is 24-hour nursing provision on site alongside care to support Activities of Daily Living (ADLS), or *Residential care homes* where there is 24-hour provision of care to support ADLs but no provision of nursing care on site [32]. There are currently in excess of 400,000 people living in care homes in the UK which in bed numbers alone equates to approximately three times that of hospital beds [4]. Studies indicate that 69% of residents in residential and nursing care homes are likely to either have dementia on admission or develop dementia post admission, many of whom do not receive a diagnosis [9, 20]. Of the 400,0000 residents it is estimated that 311,730 have dementia with 180,500 living in residential care homes and 131,230 living in nursing homes [9]. Half of care homes residents are over 85 years old with complex health and social care needs [33].

Dementia diagnosis rates in care homes are particularly poor [20]. Failure to diagnose dementia in care home residents can prevent timely access to appropriate support for the person with dementia and their family. A diagnosis can support advance and anticipatory care planning discussions that inform care plans in the event of a resident deteriorating, preventing inappropriate hospital admissions [34]. People with advanced dementia are likely to have significant care needs and therefore a diagnosis can enable staff to predict and plan care for these needs more effectively, and can inform staff provision and training [29, 34].

Managing the complex medical needs of care home residents requires a systematic approach and an opportunity for Primary Care staff to properly assess their needs and draw upon the

expertise of others as, historically, many of these patients would have been in receipt of care from a geriatrician prior to their transfer to a care home setting [35]. However, this can prove difficult given the current contract variations, resource constraints and lack of specialist resources, such as geriatricians accessible in Primary Care to support care home residents [36]. This huge gap in provision means that older residents living in care homes are 40-50% more likely to attend Accident and Emergency departments (A&E) or; be admitted to an acute hospital bed and; are less likely to have planned admissions or attend Out-Patient Appointments (OPAs) compared to community-based patients of the same age [35].

5. Hospital Admissions

Data collated by the Care Quality Commission suggests that over half of older residents in care homes do not have appropriate access to the NHS services they need and consequently many are admitted inappropriately to hospital [35]. Older residents living in care homes are 40-50% more likely to attend A&E or be admitted to an acute hospital bed, and are less likely to have planned admissions or attend OPAs compared to community-based patients of the same age [35]. Around 43% of unplanned hospital admissions for people with dementia are due to pneumonia and urinary tract infections [37], which are often noted as conditions that could have been treated within a Primary Care setting. The admission is rarely attributed to dementia as a causative factor and therefore this may not be the primary focus of the staff [23]. Equally the person with dementia may not yet have a diagnosis. Due to people with dementia often having multiple comorbidities, alongside reduced cognitive and functional reserves, they are left particularly vulnerable to poor outcomes and adverse events in the acute hospital setting, such as undetected delirium, falls, immobility, incontinence and further functional decline [38, 39].

Admission to an acute hospital can be distressing and disorientating not only for a person with dementia, but also their families. Older people with dementia who are admitted to hospital following an acute event have a higher risk of mortality, longer length of stay in hospital and reduced quality of life compared to those without dementia or cognitive impairment [38]. The potential for decline and adverse incidents in hospital can lead to increased carer strain and dissatisfaction for families [38]. Similarly, care home residents with advanced dementia who are admitted to an acute hospital have a significantly higher risk of death during admission than those admitted from their own homes or sheltered accommodation [37].

6. Service Provision

It must be acknowledged that Primary Care is under pressure; the number of consultations per patient per year in English Primary Care increased by approximately by 10% between 2007–08 and 2013–14 [40]. GP contacts with those over 85 years old has increased by 28% [41] at a time when funding and sustaining the workforce has been challenging. During the period 2010-2014 the number of whole-time equivalent GPs had increased faster than the 3% growth in the whole population, but during the same period the population of over 85s had increased by 19%. This has impacted negatively upon the ratio of whole-time GPs in relation to the population over 85 years old, falling from 0.0303 to 0.0289 [41]. This is of significance given the increasingly ageing population and the complex needs of this group, both in the community and in residential settings, this vulnerable group has reduced contact time with GPs which limits the opportunity for the

proactive approach required to manage the long-term health and social care needs of families affected by dementia.

Primary Care is not alone in experiencing increasing demand; this is evident across the entire health and social care system. Such issues are leading to significant changes being implemented throughout the NHS England Long Term Plan [42] which aims to move services closer to home and improve 'out of hospital' care. The overall aims are to reduce the pressure on acute hospital resources, and give people more control over their own health, and more personalised care closer to home when they need it. The integration of services and budgets are a key component of this shift, which it is considered will not only offer efficiencies but enable care interventions that deliver person-centered, coordinated, population-based care via Primary Care Networks (PCNs).

7. Primary Care Networks

In 2015 the Primary Care Home model was introduced via the New Models of Care [43], Developed by the National Association of Primary Care, the model brings together a range of health and social care professionals to provide enhanced personalised and preventative care for their local community. Staff and resources come together as a complete care system, drawing upon existing roles from within GP surgeries, community, mental health and acute trusts, social care and the voluntary sector to focus on local population needs and provide care closer to persons' homes. The Primary Care Home model is further evolving and being adopted in the context of PCN's.

From July 2019 the majority of GP practices in England have joined together to form around 1300 geographical PCNs covering between 30- 50,000 people [41]. PCNs will bring general practices together to work at scale rather than in isolation. They will also be the footprint around which Integrated Care Systems (ICS) will develop community-based teams, with the expectation that community and mental health services will configure their services to align with PCN boundaries.

There will also be opportunities to receive funding to employ additional staff under an Additional Roles Reimbursement Scheme. There will be five reimbursable roles introduced between 2019 and 2021 to support delivery of the PCN service specifications (see Box 1); clinical pharmacists and social prescribing link workers are the first roles to be introduced with physician associates, first contact physiotherapists and first contact community paramedics to follow over the next two years.

Box 1 PCN Service specifications.

Start by April 2020:	**Start by 2021**
• Structured medication reviews • Enhanced health in care homes • Anticipatory care (with community services) • Personalised care • Supporting early cancer diagnosis	• Cardiovascular disease case-finding • Locally agreed action to tackle inequalities

These teams will provide services to people with more complex needs, providing proactive and anticipatory care [41].

PCNs will eventually be required to deliver a set of seven national service specifications (see Box 1).

Given the increasing numbers of people with dementia, and the current gaps in skills, knowledge and service provision that exist within primary and community-based services, there is a need to develop roles that can support the delivery of the PCN service specifications. Services that can deliver enhanced personalised and preventative care to people with dementia and their families in line with the NHS Long Term Plan [42] are required. As noted earlier, a lack of skills and knowledge exists in relation to meeting the complex needs of people with dementia and their families, which will not be addressed through the reconfiguration of roles within the current workforce. The inclusion of Admiral Nursing offers an approach that can reduce the existing fragmentation and gaps for families that exist in current skills, knowledge and service provision for families affected by dementia within PCN, ICS and multi-disciplinary team (MDT) models of care.

8. Admiral Nursing within Primary Care Networks

Admiral Nurses are specialist nurses who work across health and social care systems to deliver specialist clinical support to families affected by dementia who have complex needs. The support lasts from peri diagnosis (during the diagnostic process), throughout the course of the condition, through to post bereavement. Although Admiral Nurse services vary, for example in their composition, funding, remit and where they are sited, their core principles and values remain the same [44, 45] (see Box 2). Over recent years the model of Admiral Nursing has evolved rapidly, offering specialist support across health and social care systems inclusive of primary, community, acute and social care. It has evolved from delivering an intervention that was originally aimed at supporting family carers into delivering an intervention that supports the entire family unit through a case management approach. Following triage of referrals, and acceptance onto caseload, Admiral Nurses weight each case to one of three levels of intervention; Intensive, Maintaining or Holding. This is determined by complexity of need and level of response required to deliver case management; the case may be reallocated to a different level of support as needs increase or decrease [45] (See Figure 1).

Alongside direct clinical interventions offered to families, another key role of the Admiral Nurses is to improve dementia care across the wider integrated system. Admiral Nurses provide support, education and consultancy to health and social care professionals to promote best practice in dementia care, helping to build staff confidence and competence by improving their skills and knowledge in the provision of person-centred dementia care.

Case management was developed to provide specialist services to and/or support narrowly defined population groups with severe or long-term conditions to improve healthcare outcomes by coordinating care, reducing the fragmentation of service delivery and supporting individuals to receive the right level of care at the right time [46]. Admiral Nurses work across traditional service boundaries to offer case management to families affected by dementia, underpinned by a holistic specialist clinical assessment guided by the Admiral Nurse Assessment Framework, providing the opportunity to consider the biopsychosocial needs of the person with dementia and their family carer [47] (Table 1).

Box 2 Admiral Nurse case management [45].

- Admiral Nurses focus on the needs of the whole family affected by dementia, including psychological support to help the person with dementia and family carers to understand and deal with their thoughts, feelings and behaviour, and to adapt to the changing situation. Caregiving involves a change in ongoing patterns of exchange between the caregiver and care recipient. Both the caregiver and recipient have to adjust to the transformation of their relationship into a caregiving relationship; this includes a change in the balance of roles, as the caregiver takes more responsibility for the welfare of the recipient.
- Admiral Nurses use a range of specialist interventions that help people live well with the condition and develop skills to improve communication and maintain relationships.
- Admiral Nurses work with families at particular points of difficulty in the dementia journey, including diagnosis, when the condition progresses, or when tough decisions need to be made, such as moving a family member into residential care. Anticipated problems are misdiagnosis, delayed diagnosis, and lack of information and services for people with dementia and their families, which give rise to the risk for inappropriate management, crises, poor psychological adjustment to the diagnosis, reduced coping capacity and ability to forward plan.
- Admiral Nurses help families cope with feelings of loss and bereavement as the condition progresses. There is an acknowledgement that family care does not end once "hands-on" caregiving ceases.
- Admiral Nurses care coordinate and manage referrals to other appropriate services and liaise with other health professionals on behalf of the family.

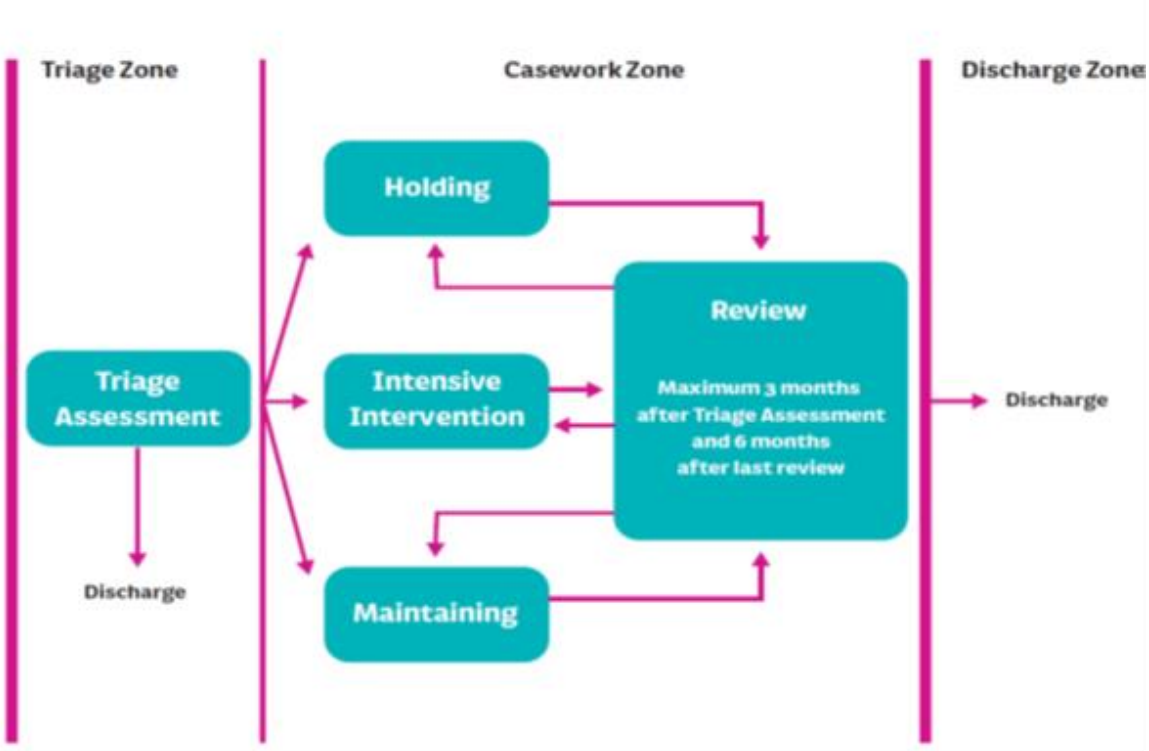

Figure 1 Admiral Nurse Casework Model [45].

Table 1 The domains of the Admiral Nurse Assessment Framework [47].

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

The breadth of specialist skills and knowledge that Admiral Nurses possess in relation to dementia care could be implemented to improve the outcomes for people with dementia and their families and also meet service specifications of the PCN. Similarly, Admiral Nurses can offer a skilled and holistic approach to Enhanced Health in Care Homes which would reduce inappropriate admission to hospital and avoid other adverse events. Offering direct Admiral Nurse case management for the most complex cases and supporting colleagues to manage less complex cases where dementia is a factor, addresses the current gap in specialist resource. It also improves confidence and competence in the skills of other health and social care professionals. Admiral Nurses would support people with dementia and their families in advance and anticipatory care planning throughout the dementia trajectory. The current fragmentation in services creates unnecessary barriers to advance care planning. However, where Admiral Nurse services exist within Primary Care services they support families to consider their future needs and wishes in a timely manner.

An example of an integrated Primary Care-based model of care of peri and post diagnostic support for families affected by dementia inclusive of Admiral Nurses was developed during a pilot in Norfolk which commenced in 2013. The pilot was sited across seven GP practices, five of which were operating within a MDT model, enabling an open referral system accepting referrals from health and social care professionals, third sector organisations, and families themselves.

There was significant demand for the Admiral Nurse Service and due to the high volume a telephone triage system was established, whereby all those referred were contacted and initially

assessed by the Admiral Nurse Clinical Lead. This ensured that those with the greatest need were prioritised and offered the most appropriate and timely support to meet those needs. It soon became apparent that there were three distinct groups of families being referred to the service with varying levels of need [48];

- **High-level: complex needs** – Often at / near crisis point with multiple areas of need requiring intensive clinical case management;
- **Mid-level: moderate needs** – Families needing specialist dementia advice, education and support, without which their situation would deteriorate and escalate into high level, complex needs;
- **Low-level: non-complex** - Families needing general information and advice that required minimal intervention.

As a result, the ABC tiered model of support (Figure 2) was developed which reflected a service response to the varying levels of need and identified the roles and resources that might be able to meet those needs within each tier. The model implemented a pathway approach to ensure an efficient use of resources and increase capacity, facilitating a step-up approach whereby the level of support needed to be increased within a higher tier service, or step-down to a lower tier service when the level of need had decreased. It acknowledged that not every family affected by dementia requires specialist clinical intervention, but also identified that no existing service could meet the complex needs of the person with dementia and their family in totality.

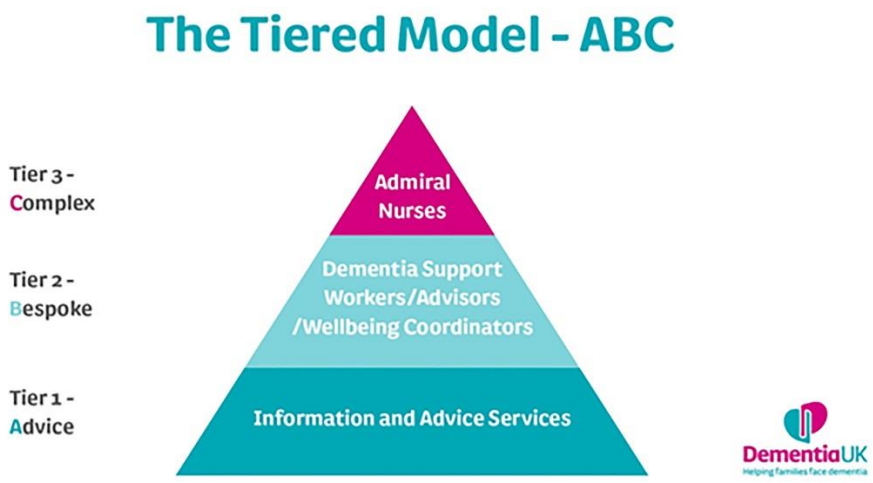

Figure 2 The ABC Tiered Model [46].

There was also a demand for the consultancy element of the Admiral Nurse role across the wider MDT, including GP's, nurses, physiotherapists, occupational therapists, social workers, community mental health nurses and third sector staff who reported a lack of confidence and competence in relation to all aspects of dementia care. The Admiral Nurses were able to offer training and education, but also act as a point of contact to advise, support and work alongside other health and social care professionals within the MDT in relation to all aspects of dementia care. This reflects the evidence base that highlights the need to offer learning and development across health and social care to ensure a skilled workforce and improve staff confidence in relation to cognitive impairment, mental capacity and care management of people with dementia across services and throughout the dementia trajectory [15].

The service was evaluated using a mixed methods design to collate data which included questionnaires for professionals, interviews with family carers and case reviews with several positive outcomes being identified [49];

- Improved physical, emotional and mental wellbeing for people with dementia and their families;
- Improved identification and diagnosis of dementia;
- Improved anticipation of deterioration and care coordination at end of life;
- Reduced and delayed transitions into residential and nursing care;
- Reduced inappropriate hospital admissions (both acute and mental health);
- Improved communication between services.

The service achieved these results by working in a manner congruent with the NHS Long Term Plan, delivering integrated case management by working across traditional health and social care service boundaries. The Admiral Nurses facilitated opportunities for people with dementia to develop advance and anticipatory care plans, reducing crisis situations that often lead to inappropriate hospital admissions or premature transitions into long term care.

Further iterations of this service model have been developed within primary & community-based care (Figure 3) and, due to the flexibility of the Admiral Nursing model, have been adapted to meet the needs of the population served by identifying and filling the gaps that exist within current service provision which closely aligns with the ethos of the new PCN models. The services aim to improve the quality and experience of care for people with dementia and their families by delivering person-centred, proactive, preventative and seamless peri and post-diagnostic support to families affected by dementia with complex needs. Alongside this, it supports and improves the practice of other health and social care professionals who support families throughout the dementia trajectory, from improving identification of dementia through to end of life and post bereavement.

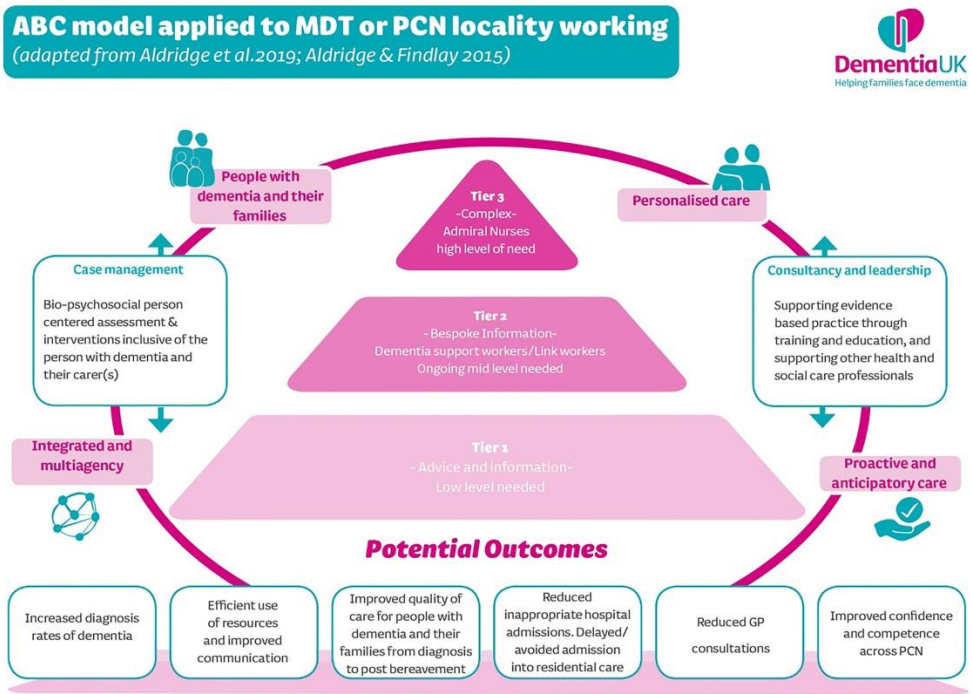

Figure 3 The ABC model applied to MDT or PCN locality working [46, 48].

9. Conclusions

The ongoing development of the PCN and ICS models will require Primary Care to have the appropriate skill mix to meet the needs of the population they serve. Reconfiguration of existing services will not eliminate the fact that there is a lack of specialist skills and knowledge in Primary Care in relation to holistic dementia care currently. People with dementia and their families, whether within the community or within a care setting, are clearly a group that needs significant consideration in the planning and development of services and systems. This is of significant importance in relation to meeting PCN obligations on delivering enhanced care in care homes, anticipatory care and personalised care. Given the current lack of skills, knowledge and resources within Primary Care the inclusion of Admiral Nursing within PCN and ICS models could offer an opportunity to incorporate the specialist clinical skills and knowledge required to affect change and offer services closer to home. This will improve outcomes for those families affected, and the wider health and social care system in line with the NHS Long Term Plan (2019).

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Author Contributions

ZA conceived the article content and structure. The paper was co-authored by ZA and KHD

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Competing Interests

The Authors have declared that no completing interests exist.

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