



DementiaUK

Helping families face dementia

Research Strategy 2023-26



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Foreword

To ensure the work of Dementia UK in supporting some of the most vulnerable people affected by dementia is backed by evidence and best practice, this paper sets out Dementia UK's Research Strategy. It reflects a commitment to work with dementia care researchers to ensure that our nurses are supported in their practice and impact.

Our research priorities have been developed collaboratively with the support of over 100 people. This included active engagement with people with dementia and their family carers, dementia specialist Admiral Nurses, Dementia UK staff, health and social care professionals, health and care service commissioners, academics, and researchers. Collectively, we identified three research priorities that form our plan for the next three years.

This plan demonstrates our commitment to supporting dementia care research that can directly inform the work and future of Admiral Nursing. Dementia UK does not fund research, but actively contributes to its growth through national and international collaboration and co-authorship, working alongside world-leading researchers to improve the lives of people with dementia and their families.

At the time of writing there are 437 Admiral Nurses working across many care settings: hospitals, GP surgeries, hospices, social care and care homes, along with Dementia UK's Helpline and virtual clinics. As specialists in dementia care, Admiral Nurses are recognised as experts, supporting people living with dementia and their families. They demonstrate what is possible and use research evidence to implement change and encourage innovation. This strategy reflects Dementia UK's commitment to developing a positive research culture to support Admiral Nurses to develop their research skills and confidence.

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Executive summary

Our priorities

Following extensive consultation, three research priority areas have been agreed. These priorities are areas where Dementia UK will seek collaboration and funding to support the implementation of best evidence.



People with dementia who live alone and families providing support from a distance



People with young onset dementia and rarer dementias



People living with multiple health conditions alongside dementia, including people who have additional mental health problems

To identify research questions within the three topic priorities we will:



actively engage with Admiral Nurses and the people they support to focus on the issues they want addressed



invest in building research capacity of Admiral Nurses



embed a questioning culture across Dementia UK that values a critical approach to how care is provided and evidence of effectiveness

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Research priorities



“The true measure of any society can be found in how it treats its most vulnerable members.” Mahatma Gandhi

Introduction

A diagnosis of dementia can be a barrier to accessing support from health and social care services, but there are some people with dementia and their families who face additional unfair and avoidable inequalities to accessing the support they need.

Over the last decade, health and social care inequalities have widened. We want to ensure that the support of Admiral Nurses reaches the most vulnerable and excluded people living with dementia and their families in our society.

Through our consultation we have agreed three priorities that focus on individuals with dementia who continuously face barriers to accessing post-diagnostic support. These priorities are not isolated from each other; some of the most vulnerable people may well fit within all three of these areas. We also recognise that within these priority groups there will be diversity and individual differences.

The specific disadvantages and the degree to which people face inequalities in accessing support will vary from one place to another. We will work with partners and communities across the UK to ensure that Admiral Nurses can respond effectively to their local landscape.

How we selected our priorities

Our three priorities were identified in our consultation with people with dementia, family carers, Admiral Nurses, Dementia UK staff, healthcare professionals, commissioners and researchers. These will inform the focus of our research over the next three years.

A series of online and in-person focus group meetings over a period of six months (January to July 2023) enabled people to share their views and rank priorities in order of importance. A steering committee representing people with dementia, carers, health and social care professionals and researchers oversaw the project and came together for a full-day workshop to agree through consensus the final priorities. The priorities were then shared with all those who took part for feedback in an iterative process. The headline is these top three priorities, but underneath these are a number of questions to address.

Our priorities



In addressing the complexity and risk associated with dementia, while also tackling the widening health and social care inequalities, it is essential to ensure that Admiral Nurses can effectively reach the most vulnerable and excluded individuals living with dementia and their families. The following priorities reflect areas of challenge and complexity that we want to learn more about to ensure we provide support in the best way we can.

Understanding the needs, issues, rights and risks facing individuals living with dementia and their families across these three priority areas will allow us to tailor the engagement and support provided by Admiral Nurses.



1. People with dementia who are living alone and families providing support from a distance

In the UK about 120,000 people with dementia live alone – a number predicted to double by 2039¹. People with dementia who live alone report more loneliness and less satisfaction with life². People living alone with dementia face unique challenges in accessing assistance and care, particularly if their families are trying to provide support from a distance.

- How do people who live alone with dementia access the support of an Admiral Nurse, and what needs to be in place to reduce inequities of provision?
- How can Admiral Nurses enable people who live alone to remain independent for as long as possible?
- What strategies used by Admiral Nurses support families caring from a distance?

1. Alzheimer's Society, 2019. A lonely future: 120,000 people with dementia living alone, set to double in the next 20 years ([alzheimers.org.uk](https://www.alzheimers.org.uk)).

2. Clare L, Martyr A, Henderson C, Gamble L, Matthews FE, Quinn C, Nelis SM, Rusted J, Thom J, Knapp M, Hart N. Living alone with mild-to-moderate dementia: Findings from the IDEAL cohort. *Journal of Alzheimer's Disease*. 2020 Jan 1;78(3):1207-16.



2. People with young onset and rare dementia

Ageing is the major risk factor for dementia. However, approximately 7.5% or 70,800 of the estimated 944,000 people living with dementia in the UK are living with young onset dementia, where symptoms develop before the age of 65³.

Dementias that affect younger people can be rare and difficult to recognise. This population of people living with dementia and their families faces significant challenges in accessing appropriate health and social care support, and for some, a diagnosis will involve navigating child or parental responsibilities and managing employment.

- How can Admiral Nurses better support people living with young onset and rarer forms of dementia to promote their independence, maintain their identity, and enhance their overall wellbeing?
- How can Admiral Nurses best support families caring for a relative with young onset or rarer dementia, ensuring they maintain their own identity and wellbeing throughout their caregiving journey?



3. People living with multiple health conditions alongside dementia, including people who have additional mental health problems

Dementia rarely travels alone. Many people living with dementia will have multiple other physical and mental health conditions that impact on and are impacted by their dementia. People living with long-term conditions and mental health problems disproportionately live in deprived areas and have access to fewer resources of all kinds. Family carers supporting someone living with multiple health conditions alongside their dementia often have extra responsibilities and worries.

- In identifying the needs of people managing multiple conditions alongside their dementia, how do Admiral Nurses work with other health and social care professionals?
- What outcomes matter to people living with multiple health conditions alongside dementia and their families? What barriers do they face, and how can Admiral Nurses make a difference to their lives?
- How does the presence of other health conditions impact the care and support people with dementia and their families receive from their Admiral Nurse?

³. Dementia UK, About young onset dementia , dementiauk.org/young-onset-dementia

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Our commitment

Ensuring that our research brings benefits to people with dementia, their families and Admiral Nurses depends on investment and joint working across the teams within Dementia UK.

In order to support us to generate high-quality research in line with our priorities, we have identified a number of objectives and actions that will ensure we can make progress in these areas.



Objective

To actively engage with people with dementia, their families and Admiral Nurses to ensure our research focuses on issues they want addressed.



To invest in building the research capacity of Admiral Nurses. We will continue to enhance the research-focused learning resources available to Admiral Nurses.



To embed a questioning culture across Dementia UK that values a critical approach to how care is provided and evidence of effectiveness.

Actions

We will co-create bespoke research training for members of our Dementia UK Lived Experience Advisory Panel (LEAP) who wish to become involved in research.

We will only support research that involves people with dementia and carers as experts by experience.

We will expand the ways we share research findings with Admiral Nurses creating new engaging ways to keep nurses up to date – including a new dementia webinar series.

We will make it easier for Admiral Nurses to get support from the Research and Publications Team at Dementia UK.

We will propose a set of core outcomes to demonstrate the impact of Admiral Nursing services and their related cost-benefits.

We will communicate more with the public and beneficiaries about our research activity through updating and improving the research section of our website; and creating bitesize summaries of research findings.

We will make it easier for our colleagues across Dementia UK to find out about research we are involved in.

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Review of Research Strategy



Our research priorities will be reviewed fully in a three-year cycle, but in the event of any significant policy, guidance or research contextual factors an earlier review may be considered. Any proposed changes to the research priorities will be agreed by the Board of Trustees and incorporated into an updated version of the document.



We would like to thank everyone who contributed to our nominal groups, interviews, and our steering committee, particularly the Lived Experience Advisory Panel (LEAP) at Dementia UK; the Hull Dementia Advisory Board; the Chinese, Caribbean, South Asian and African Working Group on Dementia; Martin Robertson, our Patient and Public Involvement Steering Committee Lead; and Professor Claire Goodman, University of Hertfordshire.



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