



Collaborating for Change: Shaping the Future of Dementia Care

CHAMPIONING CHANGE, REIMAGINING DEMENTIA CARE TOGETHER



IN ASSOCIATION WITH



THE SUPREME COURT LONDON 10TH APRIL 2025



Foreword

Dementia is one of the most urgent health and social challenges we face today. As the number of individuals affected by dementia grows, it is critical that we rethink how we understand and care for those living with the condition. Often, dementia is reduced to memory loss, failing to capture the broader range of behavioural, emotional, and sensory changes. This limited view can lead to stigma and delays in care.

This report aims to transform how dementia is perceived and addressed, advocating for a more holistic, compassionate approach. We call for a shift in public and clinical understanding, the implementation of better diagnostic and post-diagnosis support, and the integration of technology to enhance, not replace, human care.

The recommendations outlined here focus on improving outcomes for individuals living with dementia and their families. We urge policymakers, healthcare professionals, and communities to adopt these actions and actively champion a future where dementia care is person-centered, supportive, and dignified for all.

Chair:

Professor Martin Green – Chief Executive, Care England

The Panellists:

Beth Britton – Beth Britton

Samantha Crawley – Chief Executive, Bracebridge Care Group

Amrit Dhaliwal – Chief Executive, Walfinch

Julian Hallett – Services Development Manager, Down's Syndrome Association

Phil Harper – Senior Lecturer in Health and Social Care, Newman University

Louise Keane – Co-chair London Social Care Nursing Advisory Council (SCNAC)

Frances Lawrence – Chief Executive, Dementia Carers Count

Ian McCreath – Director, Think Local Act Personal (TLAP)

Suzanne Mumford – Head of Dementia and Lifestyles, Care UK

Nicola Payne – Family Engagement Manager, MacIntyre

Claire Peart – National Lead Dementia Nurse Specialist, Barchester

Kerry Southern Reason – Managing Director, Care Home Interiors

Deborah Sturdy – Chief Nurse Adult Social Care, Department of Health and Social Care

Jane Townson – Chief Executive, Home Care Association

Lee Walsh – Operations Director, Bluebird Care

Helen Wildbore – Director, Carers Rights UK

Executive Summary

This report provides a comprehensive framework for improving dementia care, emphasising the need for a holistic, compassionate, and inclusive approach. It identifies the challenges and opportunities within dementia care, focusing on the public and clinical understanding, diagnosis, post-diagnosis support, and systemic gaps in care provision. The report outlines key areas for transformation and offers actionable recommendations to enhance the quality of life for individuals living with dementia and those who care for them.

Key Findings:

Reframing Dementia in the Public and Clinical Imagination

Dementia is often oversimplified, with a primary focus on memory loss. This reduces understanding and engagement with the broader spectrum of dementia symptoms, including behavioural, emotional, and sensory changes. A shift toward more inclusive, human-first terminology is essential for improving public and clinical perceptions.

Diagnosis and Post-Diagnosis Support

Early diagnosis is critical, but barriers such as time constraints and limited diagnostic tools contribute to delays and misdiagnoses. Many families also report inadequate post-diagnosis support. A fragmented system leaves individuals and families without the necessary resources to manage dementia care effectively. A national care pathway that includes comprehensive post-diagnosis support is urgently needed.

Stigma, Language, and Cultural Sensitivity

The language surrounding dementia can stigmatise and alienate individuals. Shifting to more inclusive, culturally sensitive language can reduce stigma, promote engagement, and encourage earlier help-seeking behaviours.

Innovations in Care: Technology and Data

While technology offers innovative solutions, it cannot replace the relational aspects of care. The development of assistive technologies should prioritise enhancing human care and ensuring ethical use and integration into dementia care.

Systemic Misalignment and Outcome-Based Metrics

Current policy focuses heavily on diagnostic targets, but this does not necessarily equate to improved care. Transitioning to outcome-based metrics that reflect the quality of care and the lived experiences of those affected by dementia is crucial.

Workforce Recognition and Lived-Experience Leadership

Frontline carers, both paid and unpaid, are often undervalued and unsupported. Recognising emotional labour and providing adequate training, support, and compensation are key to enhancing dementia care. Additionally, empowering individuals with dementia to lead and educate is vital for creating meaningful change.

Cross-Sector Collaboration and Policy Shifts

Cross-disciplinary collaboration between health, social care, and community sectors is critical for delivering comprehensive care. Learning from advanced models of care in Scotland and Wales can inform improvements in collaboration and regulation.

Hope, Prevention, and a New Narrative

The traditional narrative surrounding dementia is often negative, focusing on decline and inevitability. A shift toward promoting hope, living well with dementia, and emphasising strengths and agency can help individuals and families better navigate the condition and contribute to society.

Recommendations:

The report outlines several key actions for building a compassionate and inclusive dementia care pathway:

- **Develop a national public education strategy with culturally relevant, accessible messaging.**
- **Mandate post-diagnosis care pathways as part of standard care.**
- **Invest in lived-experience leadership and peer education roles.**
- **Scale community-based resources and move beyond hospital-focused solutions.**
- **Measure outcomes that reflect real lives, including caregiver well-being and access to ongoing support.**
- **Regulate technology and AI use with ethical, human-first guidelines.**
- **Foster cross-sector collaboration through co-produced solutions and integrated care.**

By adopting these recommendations, we can ensure that dementia care evolves to better meet the needs of individuals and families affected by dementia, supporting dignity, quality of life, and respect. This report advocates for a shift in how dementia is understood and approached, promoting a future where dementia care is comprehensive, compassionate, and person centered.

Changes and Opportunities in Dementia Care

Funding Pressures and Workforce Shortages

Despite policy attention to acute care systems, long-term and community-based dementia services remain underfunded. Funding is often directed towards politically visible areas such as hospital discharge, while community services and post-diagnostic support are left fragmented and inconsistent. This imbalance leads to burnout among professional careers and overwhelming stress on unpaid carers who lack adequate recognition or support.

Expanding Community-Based Support

Community-led programs, such as Good Life with Dementia, showcase how individuals with dementia can lead education efforts and challenge stigma. However, with the closure of centralised bodies like the Dementia Action Alliance, families now rely on grassroots efforts for support and information. These gaps can be bridged through virtual resources, peer networks, and public education rooted in cultural relevance and accessibility.

Post-diagnostic care remains inconsistent across the UK. Despite the existence of digital tools and support networks, access is limited, and families frequently report feeling abandoned after diagnosis. A coordinated national approach is urgently needed to ensure all individuals receive consistent support throughout their care journey.

Addressing the Impact of Abolishing Diagnosis Targets

The removal of national diagnosis targets risks reducing accountability for early intervention. Misdiagnosis is also a major concern, especially where symptoms of grief, sensory decline, or depression are mistaken for dementia. GPs often lack time and tools to conduct thorough assessments, resulting in delayed or inaccurate diagnoses.



Outcomes-based metrics are proposed to replace crude diagnosis rates, focusing instead on the quality and timeliness of support received by individuals and families.

Strengthening Health and Social Integration

Collaboration Between GPs, Memory Clinics, and Social Care

Disjointed care pathways lead to fragmented experiences for individuals living with dementia. Limited coordination between GPs, memory clinics, and social care services results in delays, missed opportunities for early support, and duplications in care planning.

Better integration is needed, drawing on lessons from Scotland and Wales where coordinated models have improved patient outcomes through shared resources and consistent policies.

Enhancing Hospital Discharge and Preventing Readmissions

Poor hospital discharge planning remains a weak point in dementia care. Individuals are often discharged without clear follow-up, leading to increased likelihood of readmission. Technology such as fall detection and remote monitoring can aid in the transition home, but only when paired with human support systems and local follow-up services.

Strengthening Support for Unpaid Carers and Families

Unpaid carers are an essential part of the dementia care infrastructure. However, they often face emotional strain, lack of financial support, and limited access to respite. Recognition programs, mentorship networks, and immersive policymaker experiences are needed to build empathy and policy alignment with caregiver realities.



Care workers are our early-warning system – let's equip them with the respect, tools, and voice they deserve.

Amrit Dhaliwal –
Chief Executive, Walfinch



Innovations and Workforce Development

Leveraging Digital Tools to Enhance Care and Track Outcomes

AI-supported tools, remote monitoring systems, and multilingual communication platforms offer significant promise in dementia care. However, their implementation is hindered by limited training, ethical concerns, false positives, and privacy risks. The involvement of carers and people with dementia in tech design is vital to ensure usability and relevance.

While diagnosis rates have traditionally been the main performance metric, new tools provide opportunities to measure care quality through caregiver wellbeing, access to services, and lived experience.

Retaining and Upskilling the Workforce

Care workers face high emotional labour, low pay, and limited advancement opportunities. Establishing national standards for pay, training, and emotional support can improve retention and service quality. Recognition of dementia care as a skilled profession is critical.

Lived-experience leadership, in which people with dementia and carers become educators and advocates, is gaining traction and offers a powerful model for change.

Implementing Person-Centred and Community-Based Models

Empowering individuals to make choices about their care and caregivers leads to better outcomes and greater dignity. Integrated, community-based care that bridges health and social systems has proven effective in other regions and should be scaled nationally.

Inclusive communication plays a key role in reducing stigma and improving service uptake. Terms like “dementia patient” and “memory clinic” can alienate people and delay help-seeking. Framing services as support hubs and using culturally resonant language enhances accessibility and respect.



Support shouldn't stand still – our care must grow and adapt alongside the person, not around them.

Beth Britton – Beth Britton



Key Takeaways

Challenges and Opportunities in Dementia Care

- Reallocate funding to under-resourced areas including long-term care and post-diagnostic support.
- Expand community-led programs like Good Life with Dementia across the UK.
- Develop user-friendly national resources accessible to families regardless of region.
- Introduce outcome-based performance metrics focused on post-diagnostic support and caregiver wellbeing.
- Address misdiagnosis by increasing GP training and access to diagnostic tools.

Strengthening Health and Social Care Integration

- Promote cross-disciplinary collaboration between GPs, social care, and memory services.
- Improve hospital discharge planning and follow-up to reduce readmissions.
- Create national caregiver recognition programs, financial support, and respite options.
- Learn from devolved models in Scotland and Wales to support seamless care delivery.

Innovations and Workforce Development

- Standardise training for carers and promote emotional support structures.
- Ensure AI and digital tools are co-designed with end users, including carers and people with dementia.
- Establish ethical guidelines for data use and robust governance mechanisms.
- Encourage lived-experience leadership and create educator roles for those with dementia.
- Reframe prevention to include living well with dementia, reducing stigma and promoting inclusion.



You can't separate culture from care – if you don't speak my language, how can you understand my fear?

Phil Harper -

Senior Lecturer in Health and Social Care, Newman University



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