

FROM CRISIS TO CUSTOMISATION: TRANSFORMING NEURODEGENERATIVE CARE BY 2040

Reimagining a Person-Centred Care
System
July 2025



Executive Summary

The Issue

With age being the primary risk factor for most neurodegenerative diseases, as the aging population increases in the UK, these diseases will become increasingly prevalent. Current care systems are not equipped to handle their growing need for complex long terms care which people living with these conditions require. The system is largely dependent on unpaid carers, poorly tailored to individual needs and without meaningful reform, people living with neurodegenerative diseases will be increasing under supported due to the system of care being under unsustainable pressure.

Approach

This brief draws on secondary research, systems mapping, and futures thinking tools including scenario building, signals and driver mapping. Primary research was conducted with unpaid carers to co-develop visions of preferable care futures. Expert input from charity organisations such as the MSA Trust and Alzheimer's Society was gathered through a expert interviews to inform practical, steps towards it.

Key Findings

- Existing care environments contribute to negative health outcomes and lack personalisation.
- Models like dementia villages risk segregation rather than inclusion.
- Quality of life is strongly linked to better outcomes and should be central to care planning.
- Innovations such as intergenerational housing and robotics offer promising, scalable alternatives.
- NHS assessments focus more on eligibility than on long-term, evolving care needs.

Conclusion

A preferable future for neurodegenerative care in 2040 includes:

- Cultural shift towards value placed on personalised care and quality of life.
- Technological support easing workforce strain.
- Customisable care system with adaptable and holistic care models.
- Care as a public good, not a private burden.
- Seamless support throughout the progression of a diagnosis.

Policy Recommendations

1. Redesign NHS care assessments to prioritise personalisation and adaptability.
2. Invest in diverse care models, such as multigenerational and nature-integrated housing.
3. Support unpaid carers through mental health services, respite care, and time banking.
4. Scale assistive technologies to improve access and reduce workforce pressure.
5. Reframe care as a public good through national campaigns and policy reform.
6. Establish a national strategy aligning healthcare, housing, and social care for neurodegenerative conditions.

Why It Matters

With the NHS 10-Year Plan (2025-2035) in consideration, this brief offers proactive and relevant steps for long-term neurodegenerative care that complements existing NHS ambitions while addressing emerging demographic and systemic challenges.

Implementing these actions would create a more resilient, person-centred care infrastructure able to support people to live well with neurodegenerative conditions.

Policy Brief

Introduction

Age is the primary risk factor for Neurodegenerative diseases; one in ten people above the age of 65 have Alzheimer's disease (Hou et al. 2019). The number of people of 65 years and over is expected to increase to 14.7 million by 2040 (Robinson, 2002). Neurodegenerative conditions require long-term, complex, and often multidisciplinary care, which they become more dependent on as their disease progresses eventually leading them to require round the clock care. The current system in the UK is heavily reliant upon unpaid carers (friends, family, relatives) who are forced into unpaid labour as required care support is inaccessible to the majority. In the future, the majority of elderly people will be living alone (Anttonen and Karsio, 2014), making it harder to access the unpaid care they do today. Results also show that the demand for long term care will reach a peak somewhere after 2040 (Pickard et al., 2007). Without action, the number of people with neurodegenerative diseases who require personalised and adaptive care, but do not receive it, will continue to rise. This will lead to poorer health outcomes and increased pressure on families, unpaid carers, and on

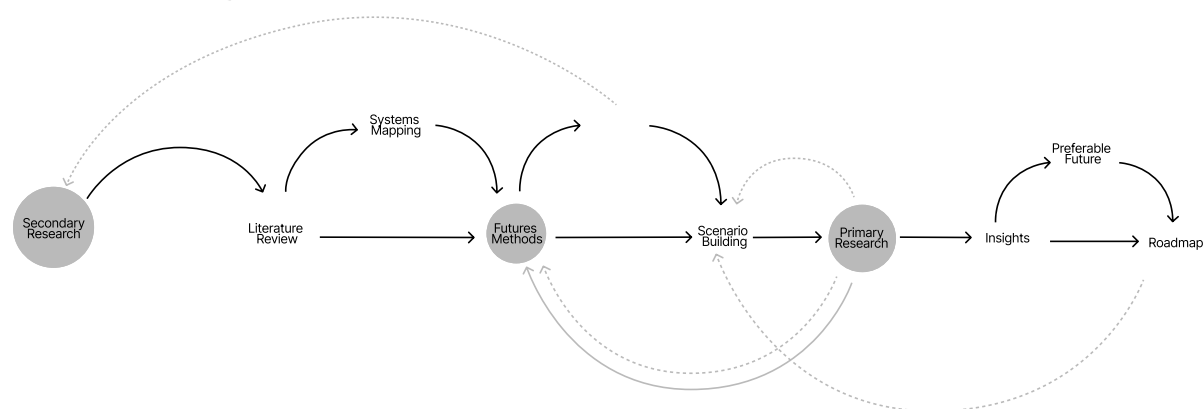
the NHS. This brief will explore the key challenges facing this population, assess the future risk landscape, and propose actionable recommendations for sustainable care delivery in the UK.

Methodology

This brief draws on a combination of secondary research, futures methods, and primary stakeholder engagement. Research began with secondary research to understand the overall scope of the issue, gather quantitative data, and identify key stakeholders within the UK care system. To support this, systems mapping was used to explore the roles and interactions between different actors, and to identify existing gaps in the UK care system.

To gain a broader perspective, archival research was conducted on innovative global care models, including Dementia Villages in Denmark and France, the Admiralty model in Singapore, and the Green House Project in the USA to explore alternative approaches to long-term care. Building on this, futures methods were applied, such as signals mapping, driver mapping, scenario planning, and scenario building, to explore how the future of neurodegenerative care in the UK might unfold by 2040.

Figure 1. Process Diagram



For primary research, activity packs were distributed to unpaid carers, inviting them to reflect on future care scenarios and share what a more desirable future would look like from their perspective. Their feedback informed a second round of scenario development, incorporating lived experience into a more refined vision of a preferable future.

Finally, a version of the Delphi method was used to gather expert insights, consulting professionals including Andy Barrick (Chief Executive, MSA Trust) and Ashton Fitzell (Policy Manager, Alzheimer's Society), whose perspectives helped refine a policy roadmap grounded in both professional and lived experience.

Research Results and Conclusions

Current models of care in the UK, particularly traditional nursing homes, often contribute to confusion, social isolation, and faster disease progression for individuals with neurodegenerative conditions. These environments typically lack personalised care and fail to accommodate the changing needs of individuals as their conditions evolve, leading to worsening outcomes.

While innovative approaches like dementia villages offer more tailored settings, they risk reinforcing segregation by separating those with dementia from the broader community, creating a "simulated normality" rather than true societal integration.

Evidence suggests that quality of life strongly correlates with better long-term outcomes for individuals with neurodegenerative diseases. Personalised, person-centred approaches that respect individual preferences and needs are consistently more effective than one-size-fits-all models. Emerging solutions are showing promise. Multigenerational housing is gaining recognition

as a strategy to address both the housing and social care crises. Advancements in robotics and assistive technologies also offer opportunities to deliver more personalised, affordable, and accessible care while easing the burden on the health and care workforce. A key issue in the current NHS approach is that assessments often focus on determining whether someone qualifies for care rather than identifying the specific type of care needed or how best to support that individual over time. This results in fragmented and reactive service provision, rather than proactive, adaptive support. Alongside this there is a fragmentation across services for those living with neurodegenerative diseases where there is a lack of coordination across health care, medical care, housing, financial and mental health support services.

Conclusion: A Preferable Future by 2040

Drawing from both primary and secondary research, a vision for a more desirable future in 2040 includes:

- A cultural shift toward valuing care, wellbeing, and ageing with dignity particularly for those with neurodegenerative diseases.
- Technological advancements that enhance care delivery and reduce pressure on the workforce.
- A reframing of care as a public good, shared across society rather than the sole responsibility of individuals or families.
- Customisable care pathways tailored to each person's evolving needs and preferences.
- A diverse ecosystem of 4-5 adaptable, holistic care models, offering flexible and inclusive options throughout all stages of diagnosis.
- Integrated support systems from diagnosis through end-of-life, ensuring

- continuity of care and dignity at every stage.

Policy Recommendations and implications

1. Redesign NHS care assessments to be needs based and patient led

Shift from eligibility-focused assessments to customisable, evolving evaluations that give individuals agency to co-create their own care plans. Assessments should adapt over time to reflect changing needs and preferences.

2. Invest in diverse and adaptable care models

Support the development and scaling of 4-5 holistic models including multigenerational housing, tech-integrated home care, and small, nature-integrated community homes that provide flexibility across all stages of disease progression.

3. Recognise and support unpaid carers as essential parts of the care system

Provide emotional, and respite support to unpaid carers through mental health services, and accessible short-term care programs. Introduce a time banking system to provide compensation and recognition for carers' contributions.

4. Leverage assistive technologies and robotics to enhance care delivery

Fund research, development and implementation pilots programmes for emerging technologies that reduce workforce strain and enable more personalised, affordable care.

5. Reframe care as a public good through public engagement and policy reform

Launch a national campaign and policy review that shifts public perception of care towards shared responsibility, dignity, and long-term investment.

6. Establish a national strategy to

coordinate neurodegenerative care Co-ordinate a cross-departmental strategy aligning medical care, social care, housing, and technology to ensure integrated, seamless support for individuals.

Immediate Next Steps

1. Redesign NHS Care Assessments to Be Needs-Based and person-led

2. Invest in Diverse and Adaptable Care Models

3. Recognise and Support Unpaid Carers

Broader Implications

If these recommendations are not addressed, the UK risks deepening health inequalities within the neurodegenerative space, increasing systemic strain on the NHS and social care, and placing greater emotional and financial burdens on families. Conversely, implementing these actions would lead to a care system that is more resilient, future-proof, and capable of supporting people with neurodegenerative conditions to live a better quality of life with access to the support they need.

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