



Research report November 2024

# **What needs to improve for social care to better support people with dementia?**

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nuffieldtrust

## About this report

This work forms one element of the UK China Health and Social Challenges Ageing Project, led by University College London (UCL) and funded by the National Natural Science Foundation of China (NSFC), the Economic and Social Research Council (ESRC) and the Medical Research Council (MRC) through the UK Research and Innovation Fund (UKRI) for International Collaboration.

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If you would like more information about getting support after a diagnosis of dementia, you can find information on the Alzheimer's Society website at [www.alzheimers.org.uk](http://www.alzheimers.org.uk).

If you are a carer of a person living with dementia, you can find help and information on the Dementia Carers Count website at <https://dementiacarers.org.uk/help-and-information>.

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# Key points

Exact numbers vary, but all modelling suggests there will be a large increase in the number of people living with dementia in the coming decades. There could be as many as 1.7 million people living with dementia in England and Wales alone by 2040, up from 900,000 across the UK currently.

Public, political and media debate about dementia tends to focus on disease-modifying treatments and the search for a cure. While it is crucial that those developments are supported, too little attention has been paid in recent years by policymakers and government to how people with dementia, and their – unpaid – carers, should be supported to live well for as long as possible.

Social care has a vital role to play in supporting people with dementia to live as independent and fulfilling a life as possible. This report, which is based on a literature review, document analysis, stakeholder interviews, a policy roundtable and site visits, considers how well prepared the social care sector is to meet the growing needs of people with dementia and their carers in terms of workforce and service provision.

The report finds that:

- While there are examples of excellence in dementia care within social care, it is not consistent across England. The following factors drive local variation in provision:
  - different approaches to commissioning and developing markets for care in local authorities (known as ‘market-shaping’)
  - a lack of clear national standards for what ‘good’ dementia support looks like
  - a lack of resources and prioritisation for long-term strategic planning
  - an absence of consistent training requirements for staff.

- Despite a policy focus on shifting care closer to home, as well as increasing numbers of people preferring care at home over residential care, there has been only patchy development of new or innovative services to meet changing needs, preferences and individual circumstances. A failure to reform the social care system and a long-standing challenging financial backdrop have limited the feasibility of investment in dementia-suitable care models.
- Wider factors, such as the suitability or adaptability of England’s housing stock for supporting people with dementia to live safely at home, also hamper the development of good social care for people with dementia.
- People living with dementia do not always have a good range of choices of appropriate care that is personalised around their own needs and preferences.
- Unpaid carers have increasingly been taking on more complex caring roles, yet have seen a contraction in the support available to them.

To a large extent, transforming social care for dementia depends on broader reform of the social care sector. But there are actions that could be taken within the constraints of the current system to improve the care available to those who need it. These include the following.

- **For local authorities:**
  - Fully exploit local authority market shaping and commissioning powers to develop and actively shape local markets that provide dementia-friendly support across a range of settings.
  - Proactively work with partners, including providers, the voluntary sector, people with dementia and their carers, to develop flexible services that are sensitive to a diverse range of individual needs, backgrounds, and preferences.
  - Improve access to carers’ assessments and ensure unpaid carers have access to high-quality information and training and are given clear guidance on how they can get support.

- Develop systematic data collection processes to enhance understanding of the prevalence of dementia, people's needs and who is providing unpaid care to someone with dementia.
- **For integrated care systems:**
  - Harness the role of integrated care systems in providing better coordination across all health and care services, especially at their interfaces. This will require integrated care systems having named dementia leads who work with local authorities, providers, and people, to strengthen strategic planning around the integration of dementia services.
  - Develop systematic data collection processes to understand the journey of people living with dementia across the whole health and social care system.
- **For national stakeholders (such as the Care Quality Commission, the Department of Health and Social Care and NHS England):**
  - Government and the regulator must take a more leading role in setting and signalling what principles underpin 'good' dementia care, and support improvement at a local level, being careful not to be so overly prescriptive as to undermine personalised care. This will require identifying promising areas of investment, developing national dementia strategies, and funding research into new models of care.
  - Government, supported by national workforce leads, should act to equip the workforce to provide a high standard of dementia care. This will involve exploring options for mandating dementia training for staff working in health and social care where evidence suggests it enhances care quality and experience and monitoring its impact and quality, while being mindful of the need to adapt it to different settings and population groups.
  - Government and NHS England should produce national guidance on and clear requirements for local data collection on dementia to improve the quality, scope, availability and rigour of data on both people with dementia and their carers to enhance understanding of incidence and needs.

All parts of the health and care system need to take urgent action to make sure not just that people with dementia are diagnosed swiftly but also that they are then well supported to live as fulfilling a life as possible, with access to social care and support that meets their needs and preferences. Action must also be taken to ensure that carers of people with dementia are supported well. Dementia needs to have a sufficiently high policy profile to effect this change.

# 1 Introduction

## Why does ‘good’ social care for people living with dementia matter?

‘Dementia’ is an umbrella term, used to describe a range of conditions causing loss of memory, language, problem-solving and other cognitive abilities. The Alzheimer’s Society estimates that there are around 982,000 people across the whole of the UK living with dementia, with or without a diagnosis.<sup>1</sup> In July 2024, there were around 490,000 people known to be living with a dementia diagnosis in England alone.<sup>2</sup> While dementia usually affects people in their later years, it can affect adults at any point in life. An estimated 70,000 people are living with early-onset dementia – with or without a diagnosis – across the UK,<sup>3</sup> of whom just over 15,000 in England have a formal diagnosis.<sup>2</sup>

There are varying estimates of the extent to which the number of people living with dementia will grow. The Chief Medical Officer for England’s latest annual report (for 2023) puts the number of people living with dementia at one in 10 people aged 80–84 and three in 10 people aged 90–94.<sup>4</sup> With an ageing population, in absolute terms, this means we could see between a million,<sup>5,6</sup> and 1.7 million people<sup>7</sup> living with dementia by 2040.\* This report forms part of a wider piece of work that University College London (UCL) is leading, which is modelling the future incidence of conditions, including dementia, to 2060.<sup>7</sup>

\* Some estimates forecast a decrease in the incidence and age-specific prevalence rates of dementia – see, for example, Watt T, Raymond A, Rachet-Jacquet L, Head A, Kypridemos C, Kelly E and Charlesworth A (2023) *Health in 2040: Projected patterns of illness in England*, The Health Foundation, [www.health.org.uk/publications/health-in-2040](http://www.health.org.uk/publications/health-in-2040), accessed 22 October 2024; Wittenberg R, Hu B, Barraza-Araiza L and Rehill A (2019) *Projections of Older People Living with Dementia and Costs of Dementia Care in the United Kingdom, 2019–2040*, London School of Economics and Political Science, [www.lse.ac.uk/cpec/assets/documents/cpec-working-paper-5.pdf](http://www.lse.ac.uk/cpec/assets/documents/cpec-working-paper-5.pdf). However, all research to date projects an increase in absolute numbers.



As England's demographics shift, we are also likely to see different profiles of people living with dementia, such as more people living with mild dementia for longer. We may see more people encountering dementia at a younger age, for instance due to better life expectancy for at-risk groups such as people with learning disabilities.<sup>8</sup> In addition, many people will live with dementia alongside other conditions such as mental ill health, chronic respiratory disease or cancer.<sup>9</sup>

While much public and media attention in relation to dementia focuses on promising developments in disease-modifying treatments and the search for a cure,<sup>10</sup> it would be unwise to rely solely on these treatments being available and widely accessible in the near future: there is still a long way to go before they are tested, regulated and widely available on the National Health Service (NHS).<sup>11</sup>

Social care can play a valuable role in supporting people with dementia and their unpaid carers to live as well as possible, throughout their journey with the disease. While not everyone with dementia and their carers will draw on social care, a large proportion will, and it is important that services can provide the right support and to adapt to changing needs and preferences. Dementia can affect people in different ways and to differing degrees, depending on the type and stage of the disease. For example, it can affect a person's ability to take care of themselves, for instance because of memory loss, confusion or challenges with communication, which can become difficult to manage as the disease evolves.<sup>12</sup> Box 1 provides examples of the sorts of services a person might draw on throughout this journey (we discuss this further in Chapter 2).

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**Box 1: Examples of social care for a person living with dementia and their carer**

Social care describes the care and support services that enable people and their carers to maximise their independence. At its best, it supports people to live fulfilling lives for as long as possible.

In the early stages of dementia, social care may include home care services, which might provide support with activities such as personal care, cleaning or preparing meals.<sup>13</sup> A person living with dementia and their carer might also visit services in their community, such as day services<sup>14</sup> and dementia cafés,<sup>15</sup> which provide peer support, information and advice, and downtime for carers. A person's carer may also use respite services, such as a short stay in a care home for the person with dementia, or a holiday, which can provide them with a break from their caring responsibilities.<sup>16</sup> These services can all play a role in preventing a person from deteriorating and their carer's needs from escalating, by both maintaining their quality of life and delaying the need for more intensive support.<sup>17</sup>

As dementia progresses, a person may no longer be able to live at home, usually because their needs can no longer be met safely. They may then require residential or nursing care.<sup>18</sup> Some care homes are dementia specific, for instance with more one-to-one staffing or interiors designed to keep people physically safe.

There are many other social care services that a person living with dementia and their carer may choose to draw on, for example assisted living services<sup>19</sup> or innovations such as assistive technology.<sup>20</sup> New models of dementia care are also developing in other countries, such as dementia villages in the Netherlands<sup>21</sup> and Green House communities in the United States.<sup>22</sup>

The choice(s) of social care services on which a person with dementia and their carer draw will depend on their needs and preferences, as well as practical considerations such as cost and accessibility.

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Data limitations mean it is difficult to gather a full picture of how people living with dementia access and use social care services, but we know that access to social care more generally is declining among older people.<sup>23</sup> Many people are left needing to pay for care themselves, or going without formal care at all – often relying on unpaid carers whose responsibilities are growing ever greater as the support available has declined.<sup>24</sup> It is estimated that one in three people will care for someone living with dementia in their lifetime,<sup>25</sup> and in 2021 there were around 700,000 carers for people living with dementia across the UK.<sup>26</sup> Yet the impact of having caring responsibilities for someone living with dementia is often overlooked.

The new government in Westminster, elected with a large majority, has promised to develop a long-term plan for health and social care, to create a National Care Service, to ‘ramp up’ dementia training for the adult social care workforce<sup>27</sup> and to shift care closer to home.<sup>28</sup> This is an opportunity to ensure that the voices of those with dementia and their carers feature prominently in these discussions.

This report makes the case for a renewed policy focus, at both national and local levels, on ensuring people with dementia are supported to live as well as possible through good social care. It discusses how to overcome the gaps and challenges that exist in the system in order to develop more consistent support that is tailored to the needs and preferences of people with dementia.

## Approach and methods

This report is the culmination of a short piece of research, conducted from October 2023 to March 2024, around what is needed at national and local levels to enable ‘good’ social care for people living with dementia. Our work was exploratory, and not exhaustive, but it sought to gather learning around the following research questions:

- **How prepared are local areas** with social care responsibilities (local authorities and integrated care systems) to support people living with dementia and their carers currently?

- **What gaps and challenges remain** to delivering good social care for people living with dementia and their carers?
- What levers and opportunities are there to ensure local areas with social care responsibilities are prepared **to meet the changing number and needs of people living with dementia** in the future?

This report draws on a **scoping literature review** and **policy synthesis** of around 30 key policy documents, reports and academic publications, published since 2010. We sought to identify literature focused on the provision of social care for people living with dementia and their carers, and we specifically searched for literature on the social care provider market and workforce in England. Our criteria for the inclusion of literature in our review and guiding questions for our analysis are outlined in the Appendix.

Due to the short scope of this report and limited available literature, we have not sought to formally assess the quality of the evidence we have used. However, we cite from academic peer-reviewed papers where these were available. While every effort was made to triangulate findings from the peer-reviewed papers with our other research methods (namely, stakeholder calls and a roundtable; see below), there is limited up-to-date academic evidence, and we have therefore drawn widely from grey literature. While the existing evidence helps us paint a picture of the experience of social care for people living with dementia and their carers, more research is therefore needed to fill those evidence gaps.

We also analysed a sample of local authority **market sustainability plans**, chosen to represent a range of areas with varying age, rural/urban and self-funder ratios. Market sustainability plans were submitted to the Department of Health and Social Care in March 2023 as part of the Market Sustainability and Fair Cost of Care Fund, and they are publicly available.<sup>29</sup> Details of the market sustainability plans and other local authority documents we reviewed are given in the Appendix. Market sustainability plans have been written as a wider assessment of local authorities' market sustainability and are therefore not specifically focused on dementia, and may have evolved since they were submitted in 2023. However, we reviewed them as a measure of how prominently dementia features as a concern for local authorities in their ability to shape markets that are responsive to local needs.

We focus our analysis on local authorities, as they hold primary accountability for social care. However, we also discuss the role of integrated care systems as a gap and potential lever for improving the overall quality of dementia care and support, especially given the interconnected nature of health and social care needs for people living with dementia.<sup>30</sup>

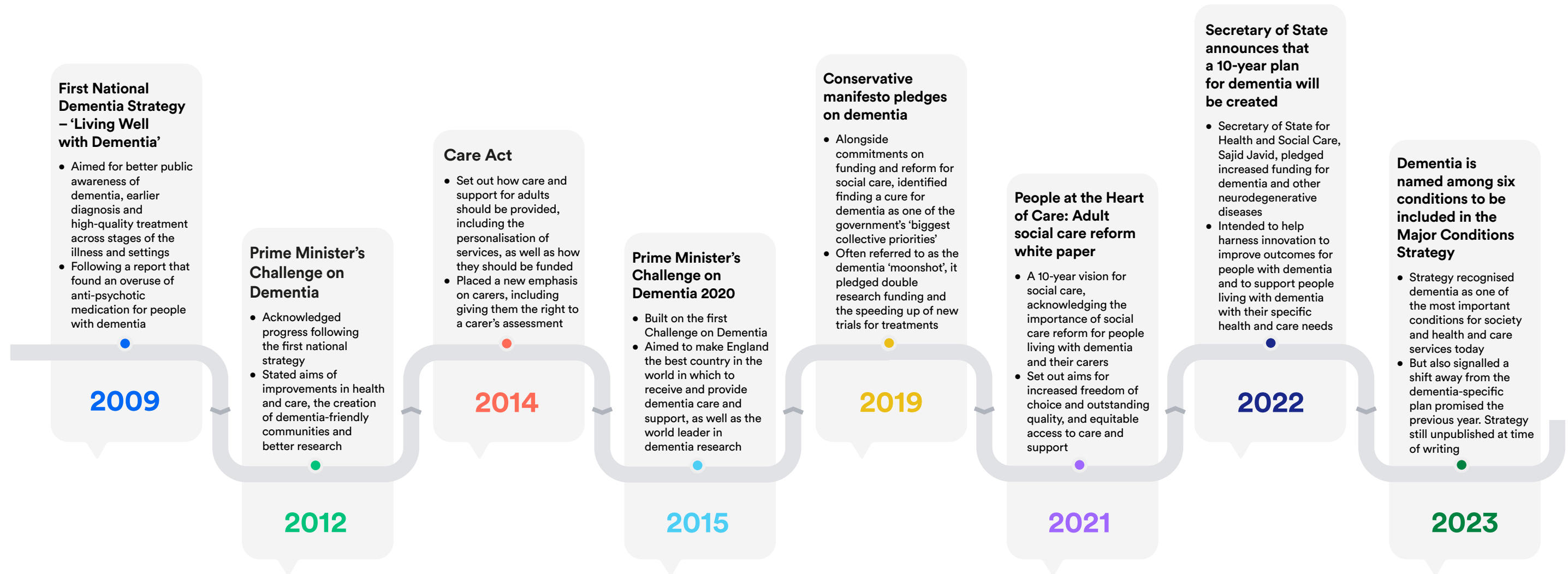
We supplemented our desk-based analysis with **scoping calls with stakeholders**, including local authorities, providers, carers, regulators, researchers and charities, and a **roundtable** of 15 participants from these sectors to gather a shared understanding of ‘good’ dementia care. We were also privileged to make two site visits and shadow several care settings that support people living with dementia at different stages of their journey. This provided us with insight into the wide variety of stories, needs and preferences that define the dementia journey of individuals with the disease and those providing vital care and support.

This research was funded as part of a wider project seeking to forecast the future incidence and prevalence of dementia, disability and cardiovascular disease in China and the UK to 2060, with the aim of adding to the evidence base for the development of appropriate policy responses to population ageing.<sup>31</sup> The project is funded by the National Natural Science Foundation of China (NSFC), the Economic and Social Research Council (ESRC) and the Medical Research Council (MRC) through the UK Research and Innovation Fund (UKRI) for International Collaboration.

## Policy context

In England, over the past 15 years, dementia has featured sporadically in policy ambitions across health and social care. And a lack of reform in social care has limited improvements in the quality of, and access to, dementia care. The timeline presented in Figure 1 shows the main policy announcements and milestones that have occurred during this period.

Figure 1: Timeline of main dementia policy announcements and milestones since 2009



In 2009, the first national dementia strategy – *Living Well with Dementia* – was published.<sup>32</sup> Then there was substantial momentum on dementia policy in the early- to mid-2010s, with two ‘challenges on dementia’ announced under then Prime Minister, David Cameron. The first of these, in 2012, was to make ‘major improvements’ to dementia care and research, including creating dementia-friendly communities, by 2015;<sup>33</sup> while the second, in 2015, was to make England the best country in the world in which to provide and receive dementia care and support, and the world leader on dementia care and research, by 2020.<sup>25</sup> While it is unclear to what extent these approaches have been successful in achieving their aims, they signalled a serious intent at the highest level to bring about change and to prioritise dementia. However, momentum was lost during the tumultuous years that followed.

A 10-year plan for dementia, announced by then Secretary of State for Health and Social Care, Sajid Javid, in 2022,<sup>34</sup> was subsequently scaled back to the inclusion of dementia in the ‘major conditions strategy’ – a strategy to improve outcomes for six major health conditions.<sup>9</sup> The final strategy was due to be published in late 2024 but it is unclear, at the time of writing, whether the current government will continue with this policy. The intended inclusion of dementia in the major conditions strategy recognised the importance of considering the impact that having two or more conditions at the same time (‘co-morbidities’) can have on people. However, this change of direction, alongside limited progress on the government’s wider strategy for social care reform,<sup>35</sup> has prompted concern that dementia is not being afforded the prominence it needs in policy.<sup>36,37</sup>

The past decade has witnessed multiple calls from stakeholders to take more proactive action on dementia. Issue-specific groups such as the All-Party Parliamentary Group (APPG) on Dementia and the Alzheimer’s Society have produced regular reports and campaigns to draw attention to issues such as:

- the role of dementia training for care workers<sup>38</sup>
- the health care and economic costs of dementia<sup>39</sup>
- the relationship between staffing levels, staff skills and the quality of dementia care.<sup>40</sup>

The Department of Health and Social Care, prompted by the second ‘challenge on dementia’ noted above,<sup>25</sup> commissioned and funded the Dementia Training Standards Framework, first released in 2015, which placed emphasis on person-centred care.<sup>41</sup> Despite these efforts, key groups – including local authorities,<sup>42</sup> the Chief Medical Officer for England<sup>4</sup> and the Care Quality Commission<sup>43</sup> – have increasingly identified the provision of good social care for people living with dementia as a challenge.

Many policy ambitions have lacked the political leadership, funding and follow-through on implementation to make the vision of a good social care system for people living with dementia a reality. Increasingly, stakeholder reports highlight the challenges people with dementia face in accessing good social care. To some extent, the challenges are due to the wider failure to bring about reform to social care as a whole. The 2024 Labour manifesto stated ambitions to create a National Care Service and to become a world leader in clinical trials, ‘putting Britain at the forefront of transforming treatment for dementia’.<sup>44</sup> But at the time of writing, it is unclear whether the new government will take forward the major conditions strategy and other elements of social care reform that have the potential to enable people with dementia to live as fulfilling a life as possible. While the Minister of State for Care, Stephen Kinnock, has stated intentions to expand dementia training for the care workforce,<sup>27</sup> whether any other specific activity in relation to care for those living with dementia is planned, including as part of plans to create a National Care Service, also remains unclear.

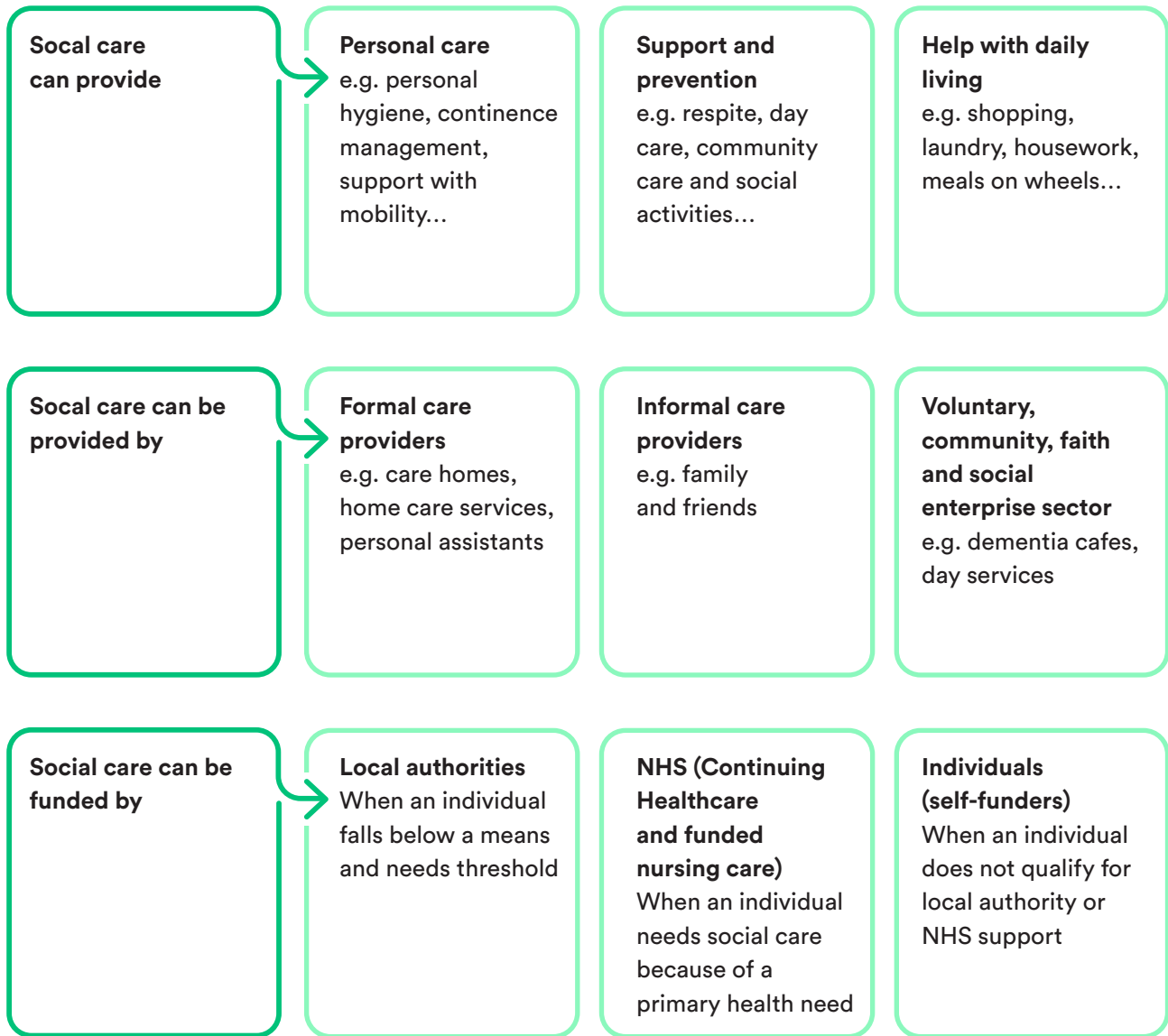


## 2 How is social care currently organised for people living with dementia?

Although health care services diagnose dementia (for example, in memory assessment services after referral from primary care<sup>45</sup>), for many people with dementia, social care provides most formal support throughout their illness. People living with dementia represent 70% of people living in care homes, and 60% of people who draw on home care.<sup>40</sup> Of course, many more people with dementia do not draw on formal support and unpaid carers care for them. The majority of this report focuses on the formal social care services that a person living with dementia and their carer may be able to access for support.

Social care, as described in the Care Act 2014, is intended to enable people in need of care and support, usually due to a long-term health condition, a disability or old age, to live as independent and fulfilling a life as possible.<sup>46</sup> Figure 2 outlines the range of activities that fall under the umbrella of social care. Access to social care can support people and their carers to manage the day-to-day and improve quality of life, and potentially has a preventative effect both in maintaining independence and delaying deterioration.<sup>17</sup>

Figure 2: Social care activities, providers and funding routes



Box 2 sets out the social care that people living with dementia in England may be entitled to.

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**Box 2: What social care are people living with dementia in England potentially entitled to?**<sup>24,47,48,49,50</sup>

A person with dementia – or symptoms of dementia that are limiting their ability to manage activities of daily living – is entitled to a local authority care assessment. A care assessment should identify a person’s needs and what support is required.

Carers over the age of 18 are entitled to a carer’s assessment, the outcome of which can entitle them to Carer’s Allowance, as well as training and signposting to local forms of support.

To access local authority funded support, a person with eligible needs will need to meet financial eligibility criteria (a means test). Anyone with means (including income, assets and savings) in excess of £23,250 is not eligible for local authority funded care, and may need to fund care themselves, or rely on unpaid carers.

People living with dementia may be found eligible to receive NHS Continuing Healthcare (CHC) if they have significant ongoing care needs arising from a primary health need. In these cases, the NHS may fund their health and social care needs entirely. However, eligibility for what constitutes a primary health need is inconsistent across England and having dementia does not automatically mean a person is eligible. Latest data shows only one in five of all people who had been assessed for Continuing Healthcare were found to be eligible.<sup>51</sup>

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Local authorities hold the main responsibility for social care, including ensuring the development of adequate care and support for local residents, whether state funded or not. This duty, set out in the Care Act 2014, is known as ‘market-shaping’,<sup>52</sup> and includes the market management of all public, not-for-profit and for-profit providers. This market-shaping duty should ensure that people living with dementia and their carers find care and support that

meet their needs. We reflect on the challenges that local authorities face in executing this duty in the next chapter.

Good social care is reliant on a skilled workforce, including not just those who work with people on a day-to-day basis, but also registered managers, social workers and all health and social care professions with which a person is likely to interact throughout their dementia journey. Staff who work with people living with dementia make up a large proportion of the social care workforce: in 2023–24, there were approximately 925,000 filled posts within services catered to people living with dementia, or more than half of the 1.59 million strong social care workforce.<sup>53</sup> Of those posts, most work in residential (420,000) and home care (400,000). In the next chapter we discuss the challenges employers encounter in finding staff with the right experience or skills to meet the needs of people living with dementia.

As well as often requiring input from social care, many people with dementia have ongoing and often complex health needs. Some of these may relate to dementia itself. Other people will have co-existing long-term health conditions such as diabetes or cardiovascular disease,<sup>9</sup> which rely on a range of services across health and social care. For instance, government research has found that:

- 44% of people living with dementia have a diagnosis of hypertension
- 17–20% have a diagnosis of diabetes, stroke, coronary heart disease or depression
- 9–11% have a diagnosis of Parkinson’s disease, chronic obstructive pulmonary disease (COPD) or asthma.<sup>54</sup>

Whether living in their own home, in an independent living home or other supported living environment, or in a care home, people living with dementia will regularly interact with health care. It is therefore essential that health and social care services collaborate with each other. Primary care services are key to supporting day-to-day wellbeing, identifying when someone’s dementia is getting worse, managing other conditions, as well as providing support to carers. Community mental health services also have a key role in providing treatment and care and support to people living with dementia.<sup>55</sup>

## 3 What are the gaps and challenges?

This chapter explores some of the main barriers to people living with dementia and their carers consistently benefiting from good social care that is coordinated with health and wider services and can enable them to lead fulfilling lives.

### Care provision does not always meet the needs of people from diverse backgrounds

There is a major gap around the development of dementia care that is sensitive to people's individual needs, backgrounds and experiences. The limited availability of care that can meet people's cultural needs is well reported.<sup>25,40,43</sup> The second Prime Minister's 'challenge on dementia' launched in 2015 recognised the importance of being able to tailor dementia services to diverse and intersecting needs,<sup>25</sup> but we heard in our conversations with stakeholders that there is still a long way to go to meet this aspiration. There is also a growing need to develop services that can best support people with young-onset dementia, many of whom will currently be drawing on services that may be more catered to a different generation and set of experiences.<sup>4</sup>

Language, ethnicity, sexual orientation, past experiences and the interactions of dementia with other conditions such as learning disabilities are among the many factors that make up a person's life and these need to be well understood and supported.<sup>4,40,56</sup> Commissioners, providers and policy-makers are limited in their understanding of how people of different backgrounds and experiences are accessing dementia services due to a lack of good-quality data on inequalities.<sup>57</sup> Addressing this gap will be essential if services that can meet people's needs and preferences are to be available and accessible. There is also evidence that access to services that are sensitive

to a person's previous negative experiences in health and care, for instance due to stereotyping or discrimination, is important to avoid worsening their condition or creating anxiety and mistrust.<sup>43</sup> Box 3 highlights the varying extents to which local authorities are concerned about their ability to meet a range of diverse needs and preferences among people living with dementia.

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**Box 3: Are local authorities concerned about their ability to provide care and support for people living with dementia that can meet diverse needs and preferences?**

Our analysis of local authority market sustainability plans found variation in the extent to which local authorities have expressed concerns around their ability to provide care for people living with dementia, or whether they have set a specific dementia strategy to shape local provision.

Some areas, usually those that serve a greater share of older people among their population, have made significant investments into local dementia services, recognising that many of their residents will be likely, at some point, to develop dementia or take on caring duties for someone living with dementia. Other areas have taken limited action to change how they cater to the needs of their residents living with dementia but are growing increasingly concerned about their ability to meet rising demand for services.

Only a limited number of the market sustainability plans we reviewed mentioned developing services that could cater to specific backgrounds and experiences. Several mentioned the need to develop services that could cater to co-morbidities, such as having specialist bariatric beds. Camden is one example of a local authority explicitly seeking to cater to diverse cultural needs, with small community social enterprises that 'specialise in meeting the cultural needs of local communities and support less than 10 residents'.

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## Most people living with dementia want to live at home for as long as possible, but the development of community infrastructure has not kept pace with demand

Research has found that many people living with dementia want to live at home for as long as possible, and to die at home.<sup>58</sup> A long-standing policy ambition to shift care closer to home has matched this shift in preferences.<sup>59</sup> While this is not always possible for those experiencing the most severe effects of dementia, growing numbers of people will not need complex care for most of their dementia journey, especially as new disease-modifying treatments start to help people with mild-to-moderate dementia.<sup>60</sup> Around two-thirds of people diagnosed with dementia live at home.<sup>25,61</sup> This proportion is likely to grow with shifting preferences and new treatments. Box 4 provides examples of what local authorities are planning to develop so that they have more or better home care and other community services for people living with dementia.

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### Box 4: What are local authorities planning around the development of home care for people living with dementia?

Our analysis of a subsection of local authority market sustainability plans found that many local authorities have developed specific home care strategies, including plans to ‘transform the economy of dementia care provision to ensure that people can return home [from hospital] as much as possible’ (Bexley). Some areas have also sought to empower people with dementia to live more independently through:

- maximising the use of community assets to promote early intervention and prevention to support people to live at home, particularly through reablement and local groups and activities to support independence (East Riding of Yorkshire)
- supporting people living with dementia and their carers to act as individual employers to improve access to direct payments (Norfolk)

- developing alternative models of care and support, such as ‘extra care’ units\* (Cheshire East, Wigan, Wirral) – for instance, Wigan was planning to increase the number of extra care apartments it had from 170 to 275 over the course of a year.

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However, the incompatibility of much of England’s housing stock with dementia complicates ambitions to keep people in their own homes. For example, homes may be laid out in a way that is disorientating for someone with dementia or unsafe to navigate.<sup>62</sup> Significant additional formal and informal care costs exist as a result of the current state of housing stock.<sup>63</sup> Although there is scope to adapt existing homes to the needs of people with dementia, this is challenging and costly, and homes vary in the extent to which they can be adapted to an adequate standard. Features such as signage and handrails may be easier to retrofit, and new technologies, such as devices using artificial intelligence to predict falls,<sup>64</sup> can decrease certain types of risk. Research on people’s homes has found that fixing unsafe situations could save up to £1.1 billion a year in formal care, and a further £3.5 billion related to unpaid care.<sup>63</sup> However, the width of corridors and other structural features are difficult to alter in existing homes.<sup>62</sup> Furthermore, housing strategies are not reliably ensuring that homes built in the future will be safe for those who develop dementia to continue living in them.<sup>65</sup>

Home care is vital to supporting large numbers of people living with dementia in their own homes. But many home care providers struggle to operate a sustainable service at the rates that local authorities pay them.<sup>66</sup> One consequence of this has been compression in the length of home care visits, which can make it difficult for home care workers to provide people with the care and support they need.<sup>58</sup> As dementia (or any other condition the individual is also living with) becomes more advanced, a person’s needs may become too complex for home care services in their local area to enable them to live at home with safety and dignity, ultimately forcing them into another setting.

\* Extra care housing is purpose-built housing for older people, with staff available who can help with personal care and household needs.



Community support is an important resource for many people living at home with dementia and their carers. There are a range of community services, such as day centres, dementia cafés and support from volunteers, some of which local authorities commission or provide, while the voluntary and community sector fully provide others. Better support in the community has been identified as enabling independent living for longer.<sup>67</sup> However, in recent years, funding for such initiatives has been squeezed. Stakeholders have raised concerns around their ability to afford to keep running them, and charities and media stories have echoed this.<sup>68,69,70,71</sup>

Another challenge is that services are not distributed according to population needs. Whether support is accessible (and when this is available or what form it takes) can be heavily dependent on where somebody lives. Community support can go beyond specific services to broader initiatives such as dementia-friendly communities,<sup>72</sup> which are far from commonplace. But an overreliance on voluntary support in the context of inadequate social care funding is concerning, with volunteers having to take on more complex care roles.<sup>73</sup> Volunteers may have highly variable support, experience or training in dementia care, further driving inconsistency.

Extra care settings can be a suitable option for people with dementia who can no longer live in their own homes. These settings can provide more independence and familiarity than a residential or nursing care environment, and have been associated with improvements in self-reported limitations and cognition.<sup>74</sup> The support provided in these settings is, however, not sufficient to cope with the most complex needs, and the evidence base on how to best to use extra care settings for those living with dementia is limited.<sup>75</sup> Also, there has been limited development of these settings so that they cater to the needs of people living with dementia. This means that many people with dementia are faced with limited choice in the type of care they can arrange to support their independence,<sup>25,65</sup> although it should be noted that not all people with dementia have had positive experiences in extra care accommodation.<sup>77</sup>

To summarise, England is not currently well placed to consistently support people living with dementia to remain in their own homes or communities for as long as possible. Yet there is evidence that people with dementia living at home tend to experience a higher quality of life than those in nursing care settings, even when accounting for the severity of dementia.<sup>78</sup> It is important

to reiterate that everybody experiences dementia differently, no setting is the best for everyone and equitable access to the largest number of options possible is fundamental to meeting the ambition of personalised care.

## Local authorities struggle to incentivise provision for complex dementia

People living with more complex dementia may require assistance or close supervision during day-to-day activities to maintain their wellbeing and prevent any risk of harm. Care homes can often be the best option to meet these needs. However, financial pressures and a lack of proactive commissioning have hindered investment in settings that can support the requirements of complex dementia. People's choice of care home can therefore be constrained, or not appropriate to meet their needs.<sup>4</sup> This can lead to insufficient levels of care, delayed hospital discharge and out-of-area placements, all contributing to negative impacts on people's physical and mental wellbeing.

We heard from stakeholders that, historically, complex dementia needs were met in specialist dementia residential nursing homes, which require more intensive staffing arrangements, such as one-to-one care.<sup>79</sup> However, despite their market-shaping duty, described in Chapter 2, a majority of local authorities (67%) report that they struggle to incentivise provision that can meet more complex demand and have an oversupply of care homes set up to provide 'standard' care.<sup>42</sup> As one local authority market sustainability plan explains, 'the term "dementia specialism" is becoming a thing of the past as any care home in the future will need to be able to meet most dementia care needs as standard'.<sup>80</sup>

As such, a large proportion of care homes originally set up to provide only 'standard' care are increasingly being asked to support residents with much more complex needs. Yet providers can be reluctant to take on people with complex needs, citing:

- limits to their own expertise
- an unwillingness to take on risk

- insufficient staffing or skills
- the funding provided for an individual not being reflective of the actual costs of providing their care.<sup>81,82</sup>

Existing physical infrastructure – for example, the size of rooms and the width of corridors – is one barrier that can prevent providers from moving from standard to more complex provision. Less than half of social care accommodation has been purpose-built.<sup>83</sup> The challenges of maintaining adequate environments to support people living with dementia mean some homes are downgrading their registration from nursing to residential.<sup>84</sup>

There are limited incentives for providers to invest in developing or adapting infrastructure to meet complex dementia needs, even when they are aware of changing market demands. Low levels of state funding and a reliance on self-funders limit profit margins and opportunities for major capital investments.<sup>52,82</sup> Major adaptations to existing facilities or the construction of new specialised facilities are expensive, and likely to be unattractive or unfeasible for many providers within this financial climate.

In some cases, a lack of guidance on best practice in designing dementia-specific infrastructure compounds the lack of financial incentives to develop provision that caters to people’s dementia needs. One local authority commissioner gave an example of a newly built care home for people with dementia that had long and featureless (hence disorientating) corridors. There is reasonable evidence on best practice related to physical infrastructure for people with dementia, but providers do not always adopt it.<sup>76</sup> Inconsistent implementation between providers suggests that knowledge is not sufficiently shared, or that regulators and commissioners do not define standards of ‘good’ dementia care well enough or enforce them.

Local authorities face challenges in ascertaining the full picture of need, and hold limited drivers for improvement and innovation.<sup>52</sup> The unstable financial and policy environment has led to a consequent lack of trust between commissioners and providers that undermines a willingness to work together to develop provision for complex dementia needs.<sup>82</sup> Stakeholders reported that local authority commissioners do not sufficiently signal to the market when, where and what specialist provision is needed. They wanted

to see local authorities more consistently using estimates of future need to signal to providers what types of care, and how much of it, they would seek to commission in the longer term.

Box 5 outlines what local authorities are doing to develop better provision for people with complex dementia needs.

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**Box 5: What are local authorities doing to develop care home provision to support complex dementia care?**

Of the market sustainability plans we reviewed, we found that many local authorities are seeking to reposition their market away from ‘standard’ residential care towards a more responsive market that can cater to a complex range of needs, including specialist dementia care and support. These local authorities have been working strategically with their providers to signal the need for more bespoke dementia provision and have provided support to adapt existing provision towards this (for example, Isle of Wight, Norfolk, Wigan, Wirral), through for example:

- proactively supporting care homes in the form of multidisciplinary support teams wrapped around the home (Bexley)
  - encouraging providers to register for dementia care with the Care Quality Commission and develop the necessary staffing arrangements (Bexley, Norfolk)
  - using commissioning levers such as block contracts to incentivise new developments that are fit for purpose to suit local need (Cornwall)
  - bringing provision back in-house to have certainty about the availability of bespoke provision (Kingston-Upon-Hull).
-

## There are not enough staff with the right skills to support the needs and preferences of people living with dementia

Adequate staffing levels and a good mix of skills and knowledge are fundamental cornerstones in the provision of good dementia care. Dementia is a condition that is not only encountered in specialist dementia settings: only 1% of the staff who work with people with dementia work in these settings.<sup>53</sup> This highlights the importance of fostering good support for all staff and opportunities for skills development across all social care services. Indeed, Skills for Care's workforce strategy for adult social care in England acknowledges that the rise in the number of people living with dementia will necessitate a changing skill mix among those who provide care.<sup>85</sup>

The challenges of recruitment and retention across the social care sector are well known, with a recent Skills for Care report on the state of the workforce highlighting 131,000 vacant posts at any one time.<sup>53</sup> Many providers of dementia care have experienced difficulties in recruiting staff with specialist skill sets. Previous research suggests there is insufficient expertise around navigating key moments in the life of a person living with dementia, notably around the end of life.<sup>58</sup> Local authorities have also reported that their care homes are unable to recruit the right staff, such as nurses. Market sustainability plans that we reviewed, such as that of Camden, highlight that the challenges of recruiting the right staff mix and expertise have threatened the viability and ability of local providers to provide good care, particularly around the recruitment of nursing staff.<sup>86</sup> The increased vulnerability and often complex needs of people living with dementia, especially for those with more advanced forms of the disease, will require higher staff-to-resident ratios and a different mix of skills and experience compared with those for some other groups.<sup>87</sup>

In Box 6 we discuss which strategies local authorities are pursuing to develop dementia skills among their local workforces.

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**Box 6: How are local authorities planning to develop the dementia skills of their social care workforce?**

In the market sustainability plans we reviewed, local authorities highlighted activities to boost recruitment and retention in general but were less consistent in specifically relating these activities to dementia. Examples included:

- attracting more staff by introducing sector-specific minimum wage rates for care workers that sit above National Living Wage rates (East Riding of Yorkshire, Wirral)
- driving recruitment locally and overseas, and offering accommodation for staff (Isle of Wight)
- upskilling existing staff around personal care, moving and handling, and dementia awareness (Gloucestershire)
- funding training to develop the skills of care staff in managing greater complexity or to meet current and future need (Isle of Wight, Norfolk, Wigan).

The guidance accompanying the market sustainability plans did not specifically ask about workforce challenges relating to dementia, so our analysis might not have captured other activities that local authorities are doing to develop a skilled workforce specifically dedicated to supporting people with the disease. However, given the likely growth in complex dementia needs, it is surprising that local authorities are not consistently developing the right types of staffing and skill mix to cater to dementia needs as part of their wider workforce planning for market sustainability.

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Dementia training is not mandatory for social care staff but was the most taken-up non-mandatory topic among social care staff in 2022/23 (45% of all non-mandatory training).<sup>88</sup> More recent data (not directly comparable) from the 2024 Skills for Care report on the state of adult social care sector and workforce suggest that 29% of staff in workplaces reporting training information have undergone some form of dementia training in the past

year (2023/24).<sup>53</sup> However, existing training is reported as being often too focused on the medical aspects of the condition, desk-based or lacking interactivity.<sup>25,65,76</sup> Understaffing and busy schedules also mean that some staff may not be given adequate time to take part in dementia training in the most beneficial way.

We heard from our roundtable attendees and stakeholder conversations that there is a need for staff working with people living with dementia to have the right skills and experience. However, it was stressed that taking an overly standardised approach to training would be detrimental as dementia care needs to be flexible around a person’s identity, life story, changing needs and experience, and not defined only by their condition.<sup>41,89</sup> This is particularly important given the inequalities in accessing care and support for dementia that is reflective of a person’s cultural and personal needs.<sup>40</sup> A recent Alzheimer’s Society report outlines the many benefits of good-quality dementia training:

- better care for people living with dementia and their carers
- more confidence and job satisfaction among staff
- improved management of dementia among providers
- wider system benefits due to earlier intervention.<sup>38</sup>

It is necessary to improve training and support for a broad range of staff groups, not just care workers. A majority of staff working in the health and social care sector will interact with people living with dementia at various points, yet understanding of dementia and its different forms among health and care professionals is patchy.<sup>90</sup> We heard from our conversations that some key staff groups, such as social workers, did not systematically have training or placement experience in how to arrange support for people living with dementia, which has an impact on people’s choices and experiences. We also heard that unpaid carers can find hospital settings challenging due to staff having a poor understanding of and support for dementia, even when a ward has dedicated dementia-aware staff members. There is a clear need for a more consistent and collaborative approach to ensuring that staff across health and social care have the confidence to support people living with dementia, however their needs may present.<sup>90</sup> The Oliver McGowan Mandatory Training on Learning Disability and Autism is an example of driving consistency in the



uptake of training through a statutory requirement on employers to provide this to staff in health and care.<sup>91</sup>

Continued pressures on services are likely contributing to difficulties in recruiting and retaining a value-driven workforce that has the relational skills to offer the best support to people living with dementia. Tight schedules and understaffing can prevent staff from having the time to build good and trusting relationships with the people they support, and gathering a full understanding of a person's life needs and preferences, which are so important to providing good dementia care.<sup>40,76</sup> There is evidence that relational care, which involves fostering meaningful relationships between all those involved in a person's care and support, has a positive impact on both those who draw on care and care workers,<sup>92</sup> but an overstretched workforce is not well placed to deliver this. There also is scope for managers to provide better support and clarity around job roles for staff working with people living with dementia, as these are known to have an impact on staff satisfaction and, in turn, the care they provide.<sup>58</sup>

## Unpaid dementia carers are consistently forgotten and have poor access to support services

People living with dementia who are not deemed eligible for public funding need to fund their care themselves, or go without any formal care at all, relying partially or entirely on informal care, typically from members of their immediate family. Even those who are eligible for publicly funded care are often supported by unpaid carers. Yet unpaid carers frequently go without the care and support they need to enable them to manage their caring responsibilities. Reasons that unpaid carers cite for not accessing services include:

- a lack of information
- a lack of support in accessing services
- the perceived unsuitability of services.<sup>93</sup>



Analysis by the Alzheimer’s Society and Carnall Farrar has found that the biggest cost associated with dementia for both the state and individuals is the cost of providing unpaid care, as the caring responsibilities of supporting someone with dementia may affect the carer’s ability to participate in society economically through work.<sup>39</sup> Carers UK estimates that 600 unpaid carers a day quit their jobs due to the difficulties of managing work and caring responsibilities,<sup>94</sup> leaving many in a position of poverty – 75% struggle with managing living costs.<sup>95</sup>

The self-reported quality of life of unpaid carers generally has been in decline over the past decade, driven largely by the lack of support both for the person they are caring for and for themselves.<sup>96</sup> In the Alzheimer’s Society and Carnall Farrar research, a majority of unpaid dementia carers reported that they suffer from a health condition themselves, and nearly 95% observed an adverse impact on their own health as a result of their caring role.<sup>39</sup>

A 2023 Dementia Carers Count survey of 1,314 carers supporting a friend or family member with dementia found that 89% had reached crisis point at least once, with more than a quarter trying to manage crises often. It also found that only half had had a carer’s assessment.<sup>97</sup> There has been a fall in the number of carers receiving some form of direct financial support, with 13,000 fewer getting this support in 2020/21 than six years previously.<sup>24</sup> Many report feeling trapped by their responsibilities. Also, 70% of carers want more support than they currently receive,<sup>39</sup> but are not always aware of what support is available for them to access. With the erosion of many carers’ support services in the aftermath of the Covid-19 pandemic,<sup>59</sup> access to respite often only happens at the point of carer breakdown, with long-term implications for the welfare of both the carer and the person living with dementia.

We heard from our roundtable that carers’ priorities include having:

- a single point of contact
- access to support groups
- access to training and education
- clearer information and advice
- more regular respite
- more inclusion of their voices
- financial support.

Additionally, carers want support that is flexible, responsive and tailored to their changing needs. Without good support, carer breakdown can occur more rapidly, and without any alternatives, can lead to unplanned admissions to hospital or care homes for the person living with dementia, some of which can end up being premature and irreversible.<sup>98</sup>

## People living with dementia do not always experience joined up care

People living with dementia experience difficulties with the coordination of services across health and social care from the very beginning of their dementia journey, despite better integration of services having been an ambition published in the *Prime Minister's Challenge on Dementia* nearly a decade ago.<sup>25</sup> Diagnoses of dementia are inconsistent, with wide variation across England.<sup>30,57</sup> We heard that, in the absence of a formal diagnosis, many turn to local community support but are then disadvantaged by not having access to treatments and services that can help them manage the day-to-day. Others also highlighted the 'cliff edge' that people face after a diagnosis, with limited join up of health and social care services and poor information about what to do next, at a very distressing time. A lack of coordination with wider services – such as housing, the voluntary and community sector, transport and leisure services – compounds this.<sup>4</sup>

Our stakeholders told us that people can also struggle to access preventive care and support services, which have the potential to help a person manage the early stages of dementia for longer and spot early signs of deterioration. Without this, many people enter formal care at critical junctures, such as after episodes of incontinence, where carer breakdown can quickly occur.<sup>99</sup>

In addition, a lack of suitable care within the community can lead to delays in hospital discharge and see people having long stays in hospital, despite being medically fit to leave. Also, people with dementia are frequently admitted to hospital in an unplanned way: one study in London found that around 77% of people living with dementia had at least one unplanned admission to hospital, particularly when they were approaching the end of life.<sup>100</sup> Unplanned admissions and delayed discharges can cause people with dementia to be inactive in hospital for long periods in time, leading them to experience a

physical and cognitive decline (known as deconditioning), which can further affect their wellbeing.<sup>60,99</sup>

We also heard from care providers that Continuing Healthcare (CHC) funding that the NHS provides for eligible people with dementia is too low, inconsistent across integrated care boards and often fails to rise in line with cost increases. Nuffield Trust research has found that, across social care more generally, the number of standard Continuing Healthcare assessments fell from 16.5 per 50,000 people in mid-2017 to 12.6 per 50,000 people in March 2024.<sup>51</sup>

Box 7 outlines how some local authorities are looking to develop more coordinated services for people with dementia.

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**Box 7: How are local authorities seeking to develop more joined-up services around dementia?**

Many of the market sustainability plans we reviewed gave examples of how local authorities are choosing to work with integrated care systems to ensure that services for people living with dementia are more coordinated. These included:

- strengthening reablement or rehabilitation after a stay in hospital, through providing short-term services to maximise independence (time-limited packages to prevent the need for long-term support<sup>101</sup>) (Bexley, Gloucestershire, Wirral)
  - developing specialist rehabilitation and recovery beds for people living with dementia and other complex needs after a hospital stay (Leeds)
  - co-developing or co-commissioning services for people living with dementia, such as:
    - having specialist services with joint funding arrangements for people with acute or complex needs that require more intensive care (Isle of Wight)
    - developing a shared understanding of future nursing demand (Norfolk)
    - working with home care providers to stabilise the market (Cornwall).
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## 4 What actions are needed now to ensure that people living with dementia and their carers benefit from ‘good’ social care?

Given the projected increase by 2040 – at least in absolute terms – in the number of people who will be living with dementia and the number who will be caring for someone who does, it is essential that opportunities are harnessed now to ensure that local areas are prepared to support growing and changing needs and preferences. The Chief Medical Officer for England’s latest annual report (for 2023) notes that ‘central and local government (the State) have the principal responsibility for environmental factors which can delay or prevent the probability of early ageing’.<sup>4</sup> Dementia is a major driving factor of illness in older age, and increasingly among younger demographics too. This chapter outlines the opportunities and levers at local and national levels that can be drawn on to deliver good social care for people living with dementia and their carers. However, we acknowledge the interdependence of factors at both levels.

## Local-level priorities

### **Local authorities should use market-shaping and commissioning powers fully to create a market for social care that is dementia and carer friendly**

Creating a vibrant market for social care that can support people living with dementia and their carers will require local authorities to be proactive about developing services alongside providers that are reflective of people's preferences, choices and diversity, and flexible enough to cater to these as they evolve. This might include setting local dementia strategies that are co-produced with residents and clearly signal to providers the types of service and innovation needed to create a dementia-friendly market. It is vital that any new development of dementia care and support takes account of local population needs, paying particular attention to ensuring that underserved populations can access services that cater to diverse backgrounds and preferences. Local authorities may wish to develop certain services in-house, or alongside integrated care system partners (see below), such as reablement or preventive services.

Developing good social care for people living with dementia will likely require some upfront investment to shape local provision and strengthen the workforce, for instance via targeted fee increases for providers who are willing to develop more bespoke dementia skills among their staff.<sup>42</sup> As an example, Leeds used a 'Dementia Transition Fund' to pay for time-limited one-to-one staffing to support care homes taking on residents discharged from hospital with complex dementia needs.<sup>60</sup>

As a matter of urgency, local authorities should seek to improve access to carers' assessments and ensure they are tailored to the needs of those caring for people with dementia and regularly reviewed. Efforts to reinstate carer support services such as respite would help to ensure that these are preventive and not just accessed as a last resort or in a crisis. In particular, respite that can be flexible and adapted to the specificity of dementia needs, for instance during the night-time, is of particular value to carers.<sup>102</sup> More generally, there is also a need for local authorities to develop better training, signposting and resources for carers so they are better empowered to fulfil their caring responsibilities. One example is to consider how unpaid carers can be

supported to maintain employment alongside their caring responsibilities, for instance ensuring that care and support services for the person living with dementia are accessible during working hours.<sup>94</sup>

The current financial environment remains challenging. Investing in better care and support for people living with dementia will require some consideration around which priorities are likely to require most investment and have the most potential to create meaningful change, and transparency from local commissioners around trade-offs or changes to current arrangements. Some local authorities are targeting dementia training towards improving the quality of outcomes for those living at home, given the likely growth in demand for home-based support, for instance via the Homecare Association's 'Train a Trainer on Dementia' programme.<sup>42</sup> The ability of local authorities to provide much-needed long-term certainty of investment will of course be dependent on a sustainable funding source at a national level, to avoid exacerbating existing disparities in funding levels across England.<sup>103</sup>

And, while more consistent investment in building dementia-friendly social care markets is clearly necessary, our stakeholders told us that there are many lower-cost interventions that can have positive impacts on the day-to-day lives of people living with dementia and their carers, such as dementia-friendly cafés or day centres. Other examples include local alliances in rural areas and the development of age-friendly communities.<sup>4</sup> We heard that community initiatives have the potential to act as hubs for everyone involved in a person's journey with dementia, including the person themselves, their carers, GPs and other clinical professionals, and social workers.

### **Integrated care systems should embed more coordinated approaches to dementia care that give an equal voice to social care**

The inception of integrated care systems has brought many opportunities for more coordinated approaches to care, but in many places this potential has yet to be realised for people living with dementia and their carers. There is a wide and complex range of actors who need to come together across the health and care pathway to provide a seamless experience for someone with dementia, and the leadership and prioritisation needed to bring these partners together to drive improvements to dementia care is inconsistent.<sup>30</sup>

While local authorities hold primary responsibility for social care, integrated care systems are uniquely positioned to provide better coordination across all services, especially at their interfaces – for instance around hospital discharge into social care, reablement or respite. Stakeholders reflected that, where this is not already the case, having a named dementia lead and an evidence-based strategy at integrated care system level can help foster accountability and prioritise improvements to dementia care and support across the integrated care system patch.

The King’s Fund has recently published research that explored the role of integrated care systems in improving current inequalities around dementia diagnosis.<sup>30</sup> The research found that integrated care systems can act as a vehicle for better coordination around diagnosis, for instance through:

- creating a shared vision and collaboration
- sharing good practice
- working across larger geographies
- addressing health inequalities among underserved groups
- having cross-system leadership to enable these improvements.

Much of this learning applies more widely to the role of integrated care systems in driving good health and social care, wrapping around people living with dementia and their carers. This will require each integrated care board to have dementia leads who have the appropriate seniority, visibility and leverage across all partners to meaningfully co-produce dementia strategies – not just with commissioners and dementia leads in local authorities, but also with care providers, the voluntary and community sector, and people – to build a shared vision and willingness to take on joint opportunities and risk.

There are key gains to be made in integrated care systems and local authorities working with partners to bring new options to the social care market that reflect people’s needs and preferences, particularly around specialist services, which may require a more complex infrastructure and workforce mix. There is a potential role for integrated care systems to ensure that all professions in health and care are well equipped to understand the different types of dementia and feel confident to support a wide range of needs and preferences, for instance through training hubs for a range of staff roles across the integrated care system patch.



## National-level priorities

### Government and the regulator must take a more leading role in signalling what ‘good’ dementia care looks like

There are pockets of excellent care for people living with dementia.<sup>76</sup> However, especially in a scenario where there is a growing need for new and varied types of care that can support a range of dementia needs, it is vital that best practice is shared effectively. There must also be clarity on who is responsible for this. Striking a balance between raising standards and maintaining flexibility will be key – seeing individuals as individuals rather than their disease is paramount.

There are clear opportunities to drive some consistency, for example in creating dementia-friendly environments,<sup>76</sup> and in setting out key principles for communicating clearly and comfortably to somebody suffering from memory loss.<sup>104</sup> For example, West Yorkshire Combined Authority has recently published criteria for ‘dementia-ready’ housing to help local housing and community services to build or refurbish housing stock to better meet the needs of people living with dementia.<sup>105</sup> This type of guidance could be beneficial at a national level – with a role for the Department of Health and Social Care to develop this, bringing in relevant expertise from across government, sector leaders and people who draw on care.

In addition, examples of innovative approaches to care may be a source of useful learning for England, such as the Green House model or dementia villages, in which typical facilities, care services and living environments are designed and arranged so that a person living with dementia and their carers can navigate them easily. It is worth noting, however, that the evidence base on such approaches is still limited and there is a need to fund more evaluations to strengthen it.<sup>106,107</sup> Access to best practice should enable better-quality care and increase the confidence of providers to cater to people with dementia.

At the time of writing, it remains unclear whether the new government will maintain plans for the publication of the major conditions strategy, started under the previous administration. However, the Care Quality Commission (CQC) has recognised its role to support better approaches to personalised



care, rooted in learning more about people's lives,<sup>43</sup> and has committed to the development of a dementia strategy. In the wake of the Dash review of the CQC, the role of the regulator is firmly under the spotlight.<sup>108</sup> Our previous work has also outlined shortcomings in the way the CQC currently operates, including weak levers to drive change and a lack of substantial support for struggling providers to improve.<sup>52</sup>

As the CQC redefines its role following the recommendations of the Dash review, there is an opportunity for the regulator to take better account of the needs of those who deliver and benefit from care and support for dementia. The CQC's dementia strategy could underpin this and help providers across England increase their understanding of what 'good' dementia care looks like and serve as a useful lever for establishing baseline standards, and a platform from which services could strive for improvement. Importantly, the CQC should take an active role in helping all providers move towards exceptional standards of dementia care. Funding and focused research to grow the evidence base on dementia care would unlock additional benefits to this approach, especially in terms of harnessing emerging technologies effectively.

We heard from social care providers and other stakeholders that there was appetite for sharing examples of good practice in dementia care rather than more prescriptive guidelines, which could be embedded as part of the CQC's dementia strategy. National leadership is also needed to address inequalities in outcomes for individuals from diverse backgrounds, including those from different age groups, cultural, ethnic and language backgrounds, and with protected characteristics, to ensure that individual needs and preferences can be respected across a range of care and support settings. Steps to address this issue may include guidance for providers to adapt care for people with different religious, cultural or linguistic backgrounds, those with early-onset dementia, LGBTQ+ people and so on. This aligns with the Department of Health and Social Care's 2022 ambition for more person-centred dementia care.<sup>34</sup>

## **Government and national workforce bodies should take leadership on equipping the workforce to provide a high standard of dementia care**

The case for solving the social care sector's broader workforce challenges to enable better access to high-quality care is well acknowledged.<sup>109</sup> Steps to achieve this have been taken with the publication of Skills for Care's workforce strategy, which urges a package of reform that includes better pay and progression opportunities, better working conditions and an improvement in the social value placed on care work.<sup>85,110</sup> The Department of Health and Social Care now has a role to build on this and develop a comprehensive workforce strategy for social care staff, which would lead to many opportunities for tangible improvements to dementia care. For instance, higher staff satisfaction has been associated with better dementia care.<sup>76</sup> And, while Skills for Care's workforce strategy recognises the paucity of evidence around the registration of care staff, there is potential for such an initiative to be used as a vehicle for implementing better training standards.<sup>109</sup>

There have also been calls for training across all care groups.<sup>76</sup> The Alzheimer's Society has recently called for mandatory dementia training for all social care staff as a key priority,<sup>38</sup> and the Skills for Care workforce strategy also called for sector-wide dementia training that is aligned to the Dementia Training Standards Framework.<sup>38,111</sup> As a minimum, the All-Party Parliamentary Group on Dementia has called for better national oversight of training levels, for instance through the use of National Institute for Health and Care Excellence (NICE) guidelines.<sup>40</sup> The Department of Health and Social Care has previously provided specific targeted investment aimed at supporting dementia skills development, including for NHS staff, which sets a precedent for future national investment in staff training.<sup>25</sup> The Department of Health and Social Care and other national actors, for example the CQC and Skills for Care, will need to determine where there may be value in mandatory training for wider staff groups, such as CQC inspectors.<sup>90</sup> The new Minister of State for Care's commitment to accompanying the new Fair Pay Agreement for the sector with expanded dementia training appears to honour these calls, although the scope, content and quality of this are yet to be made clear.<sup>27</sup>

Challenges spreading dementia training more consistently include the cost and time needed to complete this, as well as concerns about the quality

of training and its transferability to real-life care contexts. While there is a high degree of support for mandatory training, careful thought needs to be given to which staff groups should be prioritised and how best to roll it out more widely. There is also a lack of consistency and quality assurance for training that social care providers currently offer. There is a role for national bodies to develop a more coordinated approach to dementia training. For instance, Skills for Care, alongside the CQC and the Department of Health and Social Care, intends to work over the coming years to ensure that training for the sector overall is better aligned with best practice, and that the correct mandatory training requirements are in place.<sup>85</sup>

Stakeholders made clear that, at a minimum, any dementia training should include:

- recognition of the early signs of dementia
- understanding of variations in signs and progression in different forms of dementia
- the countering of any stigma around dementia and those affected by it
- personalised care
- end-of-life care
- supporting the friends and family of people with dementia.

There should be standardisation to the extent that all training is delivered in line with the evidence on what is effective and covers these minimum expectations. Simultaneously, there is an opportunity to design training to better equip individuals to deliver care that is person-centred, such as through an understanding of the way in which the needs of people with dementia might differ, and a focus on meaningful contact with their friends and family.

### **Government must prioritise better and more consistent support for unpaid carers**

The previous government's *People at the Heart of Care* White Paper for social care included policies to support unpaid carers, with up to £25 million pledged to boost services for them.<sup>67</sup> The Carer's Leave Act 2023 obliges employers to give employees who are carers up to five days' unpaid leave per year.<sup>112</sup> Despite this, support for unpaid carers in general does not go far enough. The £25 million that the previous government pledged for unpaid carers

expires in March 2025 and there have been calls for long-term, sustainable funding that is well targeted at what this group need most.<sup>113</sup> Previous Nuffield Trust research has found that a far greater financial commitment would be necessary to come close to addressing the shortfall in support for the millions currently providing unpaid care in England.<sup>24</sup> This research also identified the need for greater accountability towards unpaid carers in central government, as well as the need for a more collaborative approach to support for unpaid carers between a range of government stakeholders.<sup>24</sup>

More specifically to dementia, there is an opportunity for national actors to help to bridge the information gaps that unpaid carers often experience. One action could be to ensure a more consistent offer of training for dementia carers nationally – some organisations currently offer this but it is far from universal. The National Institute for Health and Care Excellence has suggested joint dementia training sessions for care professionals and unpaid carers, which may be a good opportunity to build shared understanding of what is necessary to provide good care.<sup>89</sup> We heard from stakeholders that it is important for unpaid carers to know what may happen as dementia advances, including potential impacts on care and support needs, as unexpected deteriorations in loved ones’ conditions and independence are often a cause of distress.

National leadership is needed to improve consistency in support and access to information after a dementia diagnosis. Many people who have been newly diagnosed with dementia and their family and friends feel abandoned by the system after this life-changing moment.<sup>114</sup> Key actions could include ensuring that all people in this situation have a clear touchpoint from day one and that they receive a comprehensive package of information on what to expect and what support is available for them. Carer representatives in our research wanted the development of a national carers’ strategy, as exists in Scotland<sup>115</sup> and Wales,<sup>116</sup> which outlines the rights that carers are entitled to and what they should expect from the system. This would not be entirely specific to dementia carers but would need to clearly address, and recognise the unique challenges of, dementia care. The Department of Health and Social Care is best placed to lead national policy on supporting carers but should coordinate action with other bodies that have a duty to support carers, including the Department for Work and Pensions and NHS England.<sup>24</sup>

## Government and NHS England should collect more data on people living with dementia

Data currently collected around dementia are incomplete. Some of our understanding of dementia relies on surveys such as the English Longitudinal Study of Ageing (ELSA), but this only captures information on people living in their own homes.<sup>117</sup> Such surveys therefore exclude people living in care homes, many of whom have the highest forms of dementia need. In addition, the NHS currently does not have a record of what residential setting 45% of patients with dementia live in, which makes it difficult to provide targeted care.<sup>39</sup> There are also poor data in social care more generally,<sup>59</sup> and a limited understanding of how people identifying under one or several protected characteristics draw on services and what specific needs they have.<sup>43</sup> We therefore have a limited ability to build a full picture of dementia provision in social care, how access is spread unequally and how needs and preferences have changed and fluctuated over time. This in turn has had an impact on planning and the development of future services.

However, the Department of Health and Social Care is implementing a new person-level data collection covering adult social care. This could provide the basis for improved understanding of social care access for people with dementia, if this data is linked to health data at local and national levels. There is an opportunity to invest in data collection that allows us to quantify and observe people's experiences across their dementia journey, regardless of where in England they live or what type of care they receive. This would provide commissioners and providers with the best possible picture for developing services that are responsive to the needs of the populations they serve, and paint a clearer picture of inequalities in outcomes. The CQC has identified a role for itself in driving research about varying outcomes across different groups of people with dementia.<sup>43</sup>

## 5 Conclusions

The number of people living with dementia will grow, at least in absolute terms, in the next decade. A large proportion of these will draw on some form of social care, whether supported by the state, paying for it themselves or supported by unpaid carers. However, it is clear from our research that not all social care is suitable for people with dementia. While there are examples of excellent care and support, this is not a consistent picture, with much of what is offered falling short of flexible, person-centred care, staffed by people who do not have the right skills and experience. Many local authorities face challenges in commissioning strategically for dementia care. Funding constraints and limited investment incentives for infrastructure are also a widespread barrier. Workforce and skills shortages then compound these issues.

In the course of this work, a consistent theme among people we spoke to was that there is a worrying inertia among policy-makers and politicians, despite the inevitable rise in the number of people the system will need to support in future. Many of the underlying deficiencies in social care for people with dementia are rooted in long-standing dysfunctions of the wider social care sector. The current government has promised to build a National Care Service and there is hope that it will create a more functional system. As part of that, it is essential that the specifics of dementia care are considered and built in.

However, the creation of a National Care Service feels like a distant and ill-defined prospect at present and, while it is important to influence and engage with that process, it is equally important that stakeholders in the social care sector take action to improve care for people with dementia in the more immediate term. One sign of positive intent is the government's commitment to deliver more dementia training to the social care workforce, alongside reformed pay and terms and conditions, but this needs to be designed and targeted effectively.<sup>27</sup> Public bodies at local and national levels have a responsibility to use their existing powers to move towards dementia provision of consistently good quality. These include:

- local authority and integrated care system action to more proactively create local care markets that can meet dementia needs
- better national government support to define and share good practice
- better signposting to services and support at all levels of the system, including by professionals who span the health and care boundary, to ensure people with dementia and their carers can access what is available.

The financial health of the social care sector will ultimately determine how well people with dementia are supported. In the short term, there is a need for national government leadership to put the social care sector on a sustainable footing, accompanied by investment and a clear long-term implementation plan to better equip England for the growing number of people that will be living with dementia in the future. In the longer term, as plans for the National Care Service develop, it will be important to recognise that social care for people with dementia cannot operate in isolation. While the scope of this work has focused on social care for this group, it is essential that future policy recognises the interconnectedness of social care with other policy areas – health, housing, benefits and employment – which are all crucial to ensuring that people with dementia and their carers are well supported.

# Appendix: Detailed methodology

For this report we set out the following detailed questions to guide our scoping analysis:

- 1 How prepared are local areas with social care responsibilities (local authorities and integrated care systems) to support people with dementia currently?
  - a What do current policies set out for local areas with social care responsibilities in relation to the provider market and the workforce?
  - b What provision exists for people with dementia in local areas with social care responsibilities?
  - c What staff skill mix exists for people with dementia in local areas with social care responsibilities?
  - d How adequate is the provision and staff skills mix for care and support for people with dementia currently?
- 2 To what extent are key stakeholders recognising the growing incidence of dementia as a major issue?
- 3 What is happening and needs to happen for local areas with social care responsibilities to be prepared to meet the needs of people with dementia in the future?
  - a What activities are key stakeholders undertaking to shape social care markets to better respond to the needs of people with dementia?
  - b What activities are key stakeholders undertaking to build a sustainable workforce that can respond to the needs of people with dementia?
  - c At what level do these activities need to happen? What can facilitate the activities?



Table A1 outlines how we sought to answer these questions through our research activities.

**Table A1: The questions that our research activities sought to answer**

Activities	What questions they sought to answer
Literature review and policy synthesis	1, 2
Review of market sustainability plans	1, 2, 3a, 3b
Stakeholder calls and site visits	1d, 2, 3a, 3b
Roundtable	3

## Literature review and policy synthesis

We reviewed around 30 documents as part of our scoping literature review and policy synthesis. The criteria for inclusion of literature into the review were as follows:

- Include literature focused on dementia and social care. (Due to scope limitations, we did not include literature on health services relating to dementia except where it covered integration with social care.)
- Specifically include literature focusing on the social care provider market and the workforce in relation to dementia.
- Literature must be academic publications, grey literature or government policy publications published since 2010.

We identified our primary literature through a keyword search using terms such as ‘dementia’, ‘policy’, ‘England’, ‘care home’, ‘homecare’ and ‘carers’ in general academic databases, including Google Scholar. We also analysed all UK government publications on dementia published since 2010. We then employed a snowballing approach to find other relevant documents, which were cited in our initial literature search or mentioned by stakeholders.

We analysed the literature using a framework approach, structured around the questions guiding our analysis, as set out at the beginning of this Appendix.

Due to the limited scope of the work, we did not formally review the quality of the evidence we cite throughout this report. While we sought to draw from peer-reviewed literature as much as possible, we were limited by what has been published and we therefore refer to a wide range of publications, including grey literature. Within the report, we draw attention to the limitations of the evidence base and the need to expand it over time.

## **Review of market sustainability plans**

To support our literature review and policy synthesis, we analysed a subset of the 152 market sustainability plans listed on the GOV.UK website (n=14, around 10%), to understand to what extent local areas were considering dementia as part of their planning. Table A2 outlines how we sampled the plans to include in the review.

**Table A2: Sampling criteria for our review of market sustainability plans**

Criteria	Sampling
Region	<p>Include one from each region of England:</p> <ul style="list-style-type: none"> <li>• East Midlands</li> <li>• East of England</li> <li>• London</li> <li>• North East</li> <li>• North West</li> <li>• South East</li> <li>• South West</li> <li>• West Midlands</li> <li>• Yorkshire and the Humber</li> </ul>
Rural/urban classification	<p>In line with the Office for National Statistics' (ONS's) Rural Urban Classification,<sup>118</sup> include a spread of:</p> <ul style="list-style-type: none"> <li>• mainly rural</li> <li>• largely rural</li> <li>• urban with significant rural</li> <li>• urban city and town</li> <li>• urban with minor conurbation</li> <li>• urban with major conurbation</li> </ul>
Self-funder ratio	<p>In line with the ONS's classification of self-funder ratios,<sup>119</sup> include a spread of:</p> <ul style="list-style-type: none"> <li>• a low percentage of self-funders (&lt;30%)</li> <li>• a medium percentage of self-funders (30–50%)</li> <li>• a high percentage of self-funders (&gt;50%)</li> </ul>
Over-65 ratio	<p>In line with the ONS's classification of the ratios of people aged 65 and over,<sup>120</sup> include a spread of:</p> <ul style="list-style-type: none"> <li>• a low percentage of people 65 and over (&lt;10%)</li> <li>• a medium percentage of people aged over 65 (10–20%)</li> <li>• a high percentage of people aged over 65 (&gt;20%)</li> </ul>

Note: For local authority market sustainability plans, see Department of Health and Social Care (2024).<sup>29</sup>

We reviewed the market sustainability plans of the following local authorities:

- London Borough of Bexley
- London Borough of Camden
- Cheshire East
- Cornwall
- East Riding of Yorkshire
- Gloucestershire
- Isle of Wight
- Kingston upon Hull
- Norfolk
- Rutland
- Slough
- Solihull
- Wigan
- Wirral.

We also reviewed a small number of additional local authority documents, such as market positioning statements, as stakeholders referred us to these.

We analysed the plans and accompanying documents using the same framework approach as for our scoping literature review, structured around our guiding questions.

## Stakeholder calls, a roundtable and site visits

To identify relevant stakeholders, we followed a ‘bullseye’ stakeholder mapping approach, based on guidance that the STRiDE project – led by the Care Policy and Evaluation Centre at the London School of Economics and Political Science – has developed (<https://stride-dementia.org>). This enabled us to map out stakeholders at national and local levels, including arm’s-length bodies, government and policy officials, charities, care providers, academia, think tanks, workforce representatives and people who draw on care and their carers. We then prioritised who to approach for the 10 scoping calls we undertook and identified 15 stakeholders to invite to our roundtable. We analysed the notes from the roundtable using the same framework approach as for our scoping literature review, structured around our guiding questions.

Through our stakeholder scoping calls, we were able to arrange two site visits to care settings that support people living with dementia at different stages of their journey, during which we shadowed staff.

# References

1. Alzheimer's Society (2024) 'What are the costs of dementia diagnosis and care in the UK?'. [www.alzheimers.org.uk/about-us/policy-and-influencing/dementia-scale-impact-numbers](http://www.alzheimers.org.uk/about-us/policy-and-influencing/dementia-scale-impact-numbers). Accessed 22 October 2024.
2. NHS Digital (2024) 'Primary care dementia data, July 2024'. <https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data/july-2024>. Accessed 22 October 2024.
3. Alzheimer's Society (no date) 'Young-onset dementia'. [www.alzheimers.org.uk/about-dementia/types-dementia/young-onset-dementia](http://www.alzheimers.org.uk/about-dementia/types-dementia/young-onset-dementia). Accessed 22 October 2024.
4. Department of Health and Social Care (2023) *Chief Medical Officer's Annual Report 2023: Health in an ageing society*. GOV.UK. <https://assets.publishing.service.gov.uk/media/6674096b64e554df3bd0dbc6/chief-medical-officers-annual-report-2023-web-accessible.pdf>.
5. Watt T, Raymond A, Ratchet-Jacquet L, Head A, Kypridemos C, Kelly E and Charlesworth A (2023) *Health in 2040: Projected patterns of illness in England*. The Health Foundation. [www.health.org.uk/publications/health-in-2040](http://www.health.org.uk/publications/health-in-2040). Accessed 22 October 2024.
6. Wittenberg R, Hu B, Barraza-Araiza L and Rehill A (2019) *Projections of Older People Living with Dementia and Costs of Dementia Care in the United Kingdom, 2019-2040*. London School of Economics and Political Science. [www.lse.ac.uk/cpec/assets/documents/cpec-working-paper-5.pdf](http://www.lse.ac.uk/cpec/assets/documents/cpec-working-paper-5.pdf).
7. Chen Y, Bandosz P, Stoye G, Liu Y, Wu Y, Lobanov-Rostovsky S, French E, Kivimaki M, Livingston G, Liao J and Brunner EJ (2023) 'Dementia incidence trend in England and Wales, 2002-19, and projection for dementia burden to 2040: analysis of data from the English Longitudinal Study of Ageing', *The Lancet: Public Health* 8(11), E859-E867. [www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(23\)00214-1/fulltext](http://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(23)00214-1/fulltext). Accessed 25 October 2024.
8. Dementia UK (no date) 'Young onset dementia: facts and figures'. [www.dementiauk.org/information-and-support/young-onset-dementia/young-onset-dementia-facts-and-figures](http://www.dementiauk.org/information-and-support/young-onset-dementia/young-onset-dementia-facts-and-figures). Accessed 22 October 2024.

9. Department of Health and Social Care (2023) 'Major conditions strategy: case for change and our strategic framework'. [www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework/major-conditions-strategy-case-for-change-and-our-strategic-framework--2](http://www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework/major-conditions-strategy-case-for-change-and-our-strategic-framework--2). Accessed 22 October 2024.
10. See, for example, Gregory A (2024) 'Hundreds of thousands face being denied revolutionary new dementia drugs in England', *The Guardian*, 5 April. [www.theguardian.com/society/2024/apr/05/dementia-patients-england-nhs-may-be-denied-access-new-drugs](http://www.theguardian.com/society/2024/apr/05/dementia-patients-england-nhs-may-be-denied-access-new-drugs). Accessed 22 October 2024.
11. Walshe F (2024) 'First drug to slow Alzheimer's too costly for NHS'. [www.bbc.co.uk/news/articles/c75nry66y52o](http://www.bbc.co.uk/news/articles/c75nry66y52o). Accessed 22 October 2024.
12. Alzheimer's Society (no date) 'Dementia symptoms'. <https://alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/dementia-symptoms>. Accessed 22 October 2024.
13. Alzheimer's Society (2019) 'Choosing homecare: where do I start finding the right agency?'. [www.alzheimers.org.uk/dementia-together-magazine/feb-mar-2019/choosing-homecare-where-do-i-start-finding-right-agency](http://www.alzheimers.org.uk/dementia-together-magazine/feb-mar-2019/choosing-homecare-where-do-i-start-finding-right-agency). Accessed 22 October 2024.
14. Alzheimer's Society (no date) 'Day service – spend the day doing something you enjoy'. [www.alzheimers.org.uk/get-support/your-support-services/day-service](http://www.alzheimers.org.uk/get-support/your-support-services/day-service). Accessed 22 October 2024.
15. Alzheimer's Society (no date) 'Dementia café – information and advice for people in a relaxed setting'. [www.alzheimers.org.uk/get-support/your-dementia-support-services/dementia-cafe](http://www.alzheimers.org.uk/get-support/your-dementia-support-services/dementia-cafe). Accessed 22 October 2024.
16. Alzheimer's Society (no date) 'Replacement care (respite care) in England'. [www.alzheimers.org.uk/get-support/help-dementia-care/replacement-care-respite-care-england](http://www.alzheimers.org.uk/get-support/help-dementia-care/replacement-care-respite-care-england). Accessed 22 October 2024.
17. Social Care Institute for Excellence (2021) 'Prevention in social care'. [www.scie.org.uk/integrated-care/prevention-in-social-care](http://www.scie.org.uk/integrated-care/prevention-in-social-care). Accessed 22 October 2024.
18. Alzheimer's Society (no date) 'Care homes: when is the right time and who decides?'. [www.alzheimers.org.uk/get-support/help-dementia-care/care-homes-who-decides-when](http://www.alzheimers.org.uk/get-support/help-dementia-care/care-homes-who-decides-when). Accessed 22 October 2024.

19. Age UK (no date) 'Assisted living and extra care housing'. [www.ageuk.org.uk/information-advice/care/housing-options/assisted-living-and-extra-care-housing](http://www.ageuk.org.uk/information-advice/care/housing-options/assisted-living-and-extra-care-housing). Accessed 22 October 2024.
20. Dementia UK (2023) 'Living aids and assistive technology for a person living with dementia'. [www.dementiauk.org/information-and-support/living-with-dementia/living-aids-and-assistive-technology](http://www.dementiauk.org/information-and-support/living-with-dementia/living-aids-and-assistive-technology). Accessed 22 October 2024.
21. Rinaldi G (2024) 'Hogeweyk to Hawick: the Dutch dementia village studied by the Borders'. [www.bbc.co.uk/news/uk-scotland-south-scotland-64648948](http://www.bbc.co.uk/news/uk-scotland-south-scotland-64648948). Accessed 22 October 2024.
22. The Green House Project (2024) *Eldercare: Made for this moment*. The Green House Project. <https://thegreenhouseproject.org/wp-content/uploads/Green-House-Project-Brochure-2024.pdf>.
23. Schlepper L and Dodsworth E (2023) 'The decline of publicly funded social care for older adults'. [www.nuffieldtrust.org.uk/resource/the-decline-of-publicly-funded-social-care-for-older-adults](http://www.nuffieldtrust.org.uk/resource/the-decline-of-publicly-funded-social-care-for-older-adults). Accessed 22 October 2024.
24. Paddison C and Crellin N (2022) *Falling Short: How far have we come in improving support for unpaid carers in England?* Nuffield Trust. [www.nuffieldtrust.org.uk/research/falling-short-how-far-have-we-come-in-improving-support-for-unpaid-carers-in-england](http://www.nuffieldtrust.org.uk/research/falling-short-how-far-have-we-come-in-improving-support-for-unpaid-carers-in-england). Accessed 22 October 2024.
25. Department of Health and Social Care and Prime Minister's Office (2015) *Prime Minister's Challenge on Dementia 2020*. GOV.UK. [www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020](http://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020). Accessed 22 October 2024.
26. Alzheimer's Society (2021) *Stabilise, Energise, Realise: A long-term plan for social care*. Alzheimer's Society. [www.alzheimers.org.uk/sites/default/files/2021-09/stabilise-energise-realise.pdf](http://www.alzheimers.org.uk/sites/default/files/2021-09/stabilise-energise-realise.pdf).
27. UK Parliament (2024) 'Adult social care: volume 754: debated on Tuesday 15 October 2024'. *Hansard*. <https://hansard.parliament.uk/commons/2024-10-15/debates/6E4CB94A-708E-4C08-B290-4B6BE7E0F3D9/AdultSocialCare>. Accessed 22 October 2024.
28. Labour Party (no date) 'Build an NHS fit for the future'. <https://labour.org.uk/change/build-an-nhs-fit-for-the-future>. Accessed 22 October 2024.

29. Department of Health and Social Care (2024) 'Cost of care reports and market sustainability plans by local authority'. [www.gov.uk/government/publications/market-sustainability-and-fair-cost-of-care-fund-2022-to-2023-guidance/cost-of-care-reports-and-market-sustainability-plans-by-local-authority](http://www.gov.uk/government/publications/market-sustainability-and-fair-cost-of-care-fund-2022-to-2023-guidance/cost-of-care-reports-and-market-sustainability-plans-by-local-authority). Accessed 22 October 2024.
30. Morris L, Livsey K and Naylor C (2024) 'The role of integrated care systems in improving dementia diagnosis'. [www.kingsfund.org.uk/insight-and-analysis/long-reads/role-integrated-care-systems-improving-dementia-diagnosis](http://www.kingsfund.org.uk/insight-and-analysis/long-reads/role-integrated-care-systems-improving-dementia-diagnosis). Accessed 22 October 2024.
31. Institute of Epidemiology and Health Care (no date) 'UK-China Health and Social Challenges Ageing Project (UKCHASCAP)'. [www.ucl.ac.uk/epidemiology-health-care/research/epidemiology-and-public-health/research/uk-china-health-and-social-challenges-ageing#:~:text=Currently%20there%20are%20173M%20people,due%20to%20rapid%20population%20ageing](http://www.ucl.ac.uk/epidemiology-health-care/research/epidemiology-and-public-health/research/uk-china-health-and-social-challenges-ageing#:~:text=Currently%20there%20are%20173M%20people,due%20to%20rapid%20population%20ageing). Accessed 25 October 2024.
32. Department of Health (2009) *Living Well with Dementia: A national dementia strategy*. GOV.UK. [www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy](http://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy). Accessed 28 October 2024.
33. Department of Health (2012) *Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015*. Department of Health. [https://assets.publishing.service.gov.uk/media/5a7c8d5240f0b62aff6c2789/dh\\_133176.pdf](https://assets.publishing.service.gov.uk/media/5a7c8d5240f0b62aff6c2789/dh_133176.pdf).
34. Department of Health and Social Care (2022) 'Health secretary announces 10-year plan for dementia'. [www.gov.uk/government/news/health-secretary-announces-10-year-plan-for-dementia](http://www.gov.uk/government/news/health-secretary-announces-10-year-plan-for-dementia). Accessed 22 October 2024.
35. National Audit Office (2023) *Reforming Adult Social Care in England*. National Audit Office. [www.nao.org.uk/reports/reforming-adult-social-care-in-england](http://www.nao.org.uk/reports/reforming-adult-social-care-in-england). Accessed 22 October 2024.
36. Benham-Hertz S (no date) 'The government's major conditions strategy must deliver for people with dementia'. [www.alzheimersresearchuk.org/news/the-governments-major-conditions-strategy-must-deliver-for-people-with-dementia](http://www.alzheimersresearchuk.org/news/the-governments-major-conditions-strategy-must-deliver-for-people-with-dementia). Accessed 22 October 2024.



37. Hullah N (2023) 'Awaiting a 10-year dementia plan for England'. [www.alzheimers.org.uk/get-support/publications-and-factsheets/dementia-together/awaiting-10-year-dementia-plan-england](http://www.alzheimers.org.uk/get-support/publications-and-factsheets/dementia-together/awaiting-10-year-dementia-plan-england). Accessed 22 October 2024.
38. Alzheimer's Society report due to be published w/c 12th Nov.
39. Alzheimer's Society and Carnall Farrar (2024) *The Economic Impact of Dementia*. Module 1: Annual costs of dementia. Alzheimer's Society. [www.alzheimers.org.uk/sites/default/files/2024-05/the-annual-costs-of-dementia.pdf](http://www.alzheimers.org.uk/sites/default/files/2024-05/the-annual-costs-of-dementia.pdf).
40. All-Party Parliamentary Group on Dementia (2022) *Workforce Matters: Putting people affected by dementia at the heart of care*. APPG on Dementia. [www.alzheimers.org.uk/sites/default/files/2022-09/APPG%20on%20Dementia%20Workforce%20Matters%20Report%202022.pdf](http://www.alzheimers.org.uk/sites/default/files/2022-09/APPG%20on%20Dementia%20Workforce%20Matters%20Report%202022.pdf).
41. Skills for Health, Skills for Care and Health Education England (2018) *Dementia Training Standards Framework*. Skills for Health. [www.skillsforhealth.org.uk/wp-content/uploads/2021/01/Dementia-Core-Skills-Education-and-Training-Framework.pdf](http://www.skillsforhealth.org.uk/wp-content/uploads/2021/01/Dementia-Core-Skills-Education-and-Training-Framework.pdf).
42. Department of Health and Social Care (2023) 'Local authority market sustainability plans: insights report'. [www.gov.uk/government/publications/local-authority-market-sustainability-plans-insights-report](http://www.gov.uk/government/publications/local-authority-market-sustainability-plans-insights-report). Accessed 22 October 2024.
43. Care Quality Commission (2023) 'Rapid literature review: dementia inequalities'. [www.cqc.org.uk/about-us/transparency/external-reports-research/rapid-literature-review-dementia-inequalities](http://www.cqc.org.uk/about-us/transparency/external-reports-research/rapid-literature-review-dementia-inequalities). Accessed 22 October 2024.
44. Labour Party (2024) *Change: Labour Party manifesto 2024*. Labour Party. <https://labour.org.uk/wp-content/uploads/2024/06/Change-Labour-Party-Manifesto-2024-large-print.pdf>.
45. Alzheimer's Society (no date) 'How to get a dementia diagnosis'. [www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/dementia-diagnosis/how-to-get-dementia-diagnosis](http://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/dementia-diagnosis/how-to-get-dementia-diagnosis). Accessed 22 October 2024.
46. HM Government (2014) 'Care Act 2014'. [www.legislation.gov.uk/ukpga/2014/23/section/1](http://www.legislation.gov.uk/ukpga/2014/23/section/1). Accessed 22 October 2024.

47. Alzheimer's Society (no date) 'The care needs assessment: support for people with dementia'. [www.alzheimers.org.uk/get-support/legal-financial/dementia-care-needs-assessment](http://www.alzheimers.org.uk/get-support/legal-financial/dementia-care-needs-assessment). Accessed 22 October 2024.
48. Alzheimer's Society (no date) 'The carer's assessment: support for carers'. [www.alzheimers.org.uk/get-support/legal-financial/carers-assessment](http://www.alzheimers.org.uk/get-support/legal-financial/carers-assessment). Accessed 22 October 2024.
49. Dodsworth E and Oung C (2023) 'Offer and eligibility: who can access state-funded adult care and what are people entitled to?'. [www.nuffieldtrust.org.uk/news-item/offer-and-eligibility-who-can-access-state-funded-adult-care-and-what-are-people-entitled-to-1](http://www.nuffieldtrust.org.uk/news-item/offer-and-eligibility-who-can-access-state-funded-adult-care-and-what-are-people-entitled-to-1). Accessed 22 October 2024.
50. NHS (no date) 'Carer's assessments'. [www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carers-assessments](http://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carers-assessments). Accessed 22 October 2024.
51. Hutchings R, Davies M and Curry N (2024) 'Falling through the gaps: a closer look at NHS Continuing Healthcare'. [www.nuffieldtrust.org.uk/resource/falling-through-the-gaps-a-closer-look-at-nhs-continuing-healthcare](http://www.nuffieldtrust.org.uk/resource/falling-through-the-gaps-a-closer-look-at-nhs-continuing-healthcare). Accessed 22 October 2024.
52. Curry N and Oung C (2021) *Fractured and Forgotten: The social care provider market in England*. Nuffield Trust. [www.nuffieldtrust.org.uk/sites/default/files/2021-04/nuffield-trust-social-care-provider-market-web1.pdf](http://www.nuffieldtrust.org.uk/sites/default/files/2021-04/nuffield-trust-social-care-provider-market-web1.pdf).
53. Skills for Care (2024) *The State of the Adult Social Care Sector and Workforce in England 2024*. Skills for Care. [www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/The-state-of-the-adult-social-care-sector-and-workforce-in-England-2024.pdf](http://www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/The-state-of-the-adult-social-care-sector-and-workforce-in-England-2024.pdf).
54. Public Health England (2019) 'Dementia: comorbidities in patients – data briefing'. [www.gov.uk/government/publications/dementia-comorbidities-in-patients/dementia-comorbidities-in-patients-data-briefing](http://www.gov.uk/government/publications/dementia-comorbidities-in-patients/dementia-comorbidities-in-patients-data-briefing). Accessed 22 October 2024.
55. Alzheimer's Society (no date) 'Nurses'. [www.alzheimers.org.uk/get-support/help-dementia-care/nurses](http://www.alzheimers.org.uk/get-support/help-dementia-care/nurses). Accessed 22 October 2024.
56. Alzheimer's Society (no date) 'Learning disabilities and dementia'. [www.alzheimers.org.uk/about-dementia/types-dementia/learning-disabilities-dementia](http://www.alzheimers.org.uk/about-dementia/types-dementia/learning-disabilities-dementia). Accessed 22 October 2024.

57. Hodgson S, Hayes H, Cubi-Molla P and Garau M (2024) 'Inequalities in dementia: unveiling the evidence and forging a path towards greater understanding'. [www.ohe.org/publications/inequalities-in-dementia](http://www.ohe.org/publications/inequalities-in-dementia). Accessed 22 October 2024.
58. D'Astous V, Abrams R, Vandrevalla T, Samsi K and Manthorpe J (2019) 'Gaps in understanding the experiences of homecare workers providing care for people with dementia up to the end of life: a systematic review', *Dementia* 18(3), 970-89. <https://journals.sagepub.com/doi/10.1177/1471301217699354>. Accessed 22 October 2024.
59. Curry N, Oung C, Hemmings N, Comas-Herrera A and Byrd W (2023) *Building a Resilient Social Care System in England: What can be learnt from the first wave of Covid-19?* Nuffield Trust. [www.nuffieldtrust.org.uk/sites/default/files/2023-05/Building%20a%20resilient%20social%20care%20system%20in%20England.pdf](http://www.nuffieldtrust.org.uk/sites/default/files/2023-05/Building%20a%20resilient%20social%20care%20system%20in%20England.pdf).
60. Leeds City Council (2019) *Living with Dementia in Leeds – Our Strategy 2020–25*. Leeds City Council. <https://democracy.leeds.gov.uk/documents/s210565/Living%20with%20Dementia%20in%20Leeds%20Report%20Appendix%208.1%20250920.pdf>.
61. Parkin E and Baker C (2021) *Dementia: Policy, services and statistics*. Briefing paper. House of Commons Library. <https://researchbriefings.files.parliament.uk/documents/SN07007/SN07007.pdf>.
62. Alzheimer's Society (2020) *Dementia-friendly Housing Guide*. Alzheimer's Society. [www.alzheimers.org.uk/sites/default/files/2020-06/Dementia%20Friendly%20Housing\\_Guide.pdf](http://www.alzheimers.org.uk/sites/default/files/2020-06/Dementia%20Friendly%20Housing_Guide.pdf).
63. Centre for Ageing Better (2024) *Counting the Cost: The case for making older people's homes safe*. Centre for Ageing Better. <https://ageing-better.org.uk/sites/default/files/2024-05/Counting-the-cost-report.pdf>.
64. Matuszyk M (2024) 'How artificial intelligence can help people affected by dementia'. [www.alzheimers.org.uk/blog/artificial-intelligence-ai-dementia](http://www.alzheimers.org.uk/blog/artificial-intelligence-ai-dementia). Accessed 22 October 2024.
65. All-Party Parliamentary Group on Dementia (2019) *Hidden No More: Dementia and disability*. APPG on Dementia. [www.alzheimers.org.uk/sites/default/files/2019-06/APPG\\_on\\_Dementia\\_2019\\_report\\_Hidden\\_no\\_more\\_dementia\\_and\\_disability\\_media.pdf](http://www.alzheimers.org.uk/sites/default/files/2019-06/APPG_on_Dementia_2019_report_Hidden_no_more_dementia_and_disability_media.pdf).

66. Homecare Association (2023) *A Minimum Price for Homecare: April 2024 to March 2025*. Homecare Association. [www.homecareassociation.org.uk/resource/homecare-association-publishes-minimum-price-for-homecare-2024-25.html](http://www.homecareassociation.org.uk/resource/homecare-association-publishes-minimum-price-for-homecare-2024-25.html). Accessed 22 October 2024.
67. Department of Health and Social Care (2021) *People at the Heart of Care: Adult social care reform white paper*. GOV.UK. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1061870/people-at-the-heart-of-care-asc-reform-accessible-with-correction-slip.pdf).
68. Charity Finance Group (2022) 'Charities face cliff edge, warns Civil Society Group'. [https://cfg.org.uk/news/charities\\_face\\_cliff\\_edge\\_civil\\_society\\_group\\_warns\\_government](https://cfg.org.uk/news/charities_face_cliff_edge_civil_society_group_warns_government). Accessed 22 October 2024.
69. Maslin E and Mistry P (2024) 'Fears care centre will close without fresh funding'. [www.bbc.co.uk/news/articles/c722gg96454o](http://www.bbc.co.uk/news/articles/c722gg96454o). Accessed 22 October 2024.
70. Barlow M and Torr G (2024) 'Daughter "horrified" at Derbyshire dementia day centre closure threat'. [www.bbc.co.uk/news/uk-england-derbyshire-68906849](http://www.bbc.co.uk/news/uk-england-derbyshire-68906849). Accessed 22 October 2024.
71. BBC News (2024) 'Families need more dementia support warns expert'. [www.bbc.co.uk/news/articles/c2qvv527q69o](http://www.bbc.co.uk/news/articles/c2qvv527q69o). Accessed 22 October 2024.
72. Alzheimer's Society (no date) 'What is a dementia-friendly community?'. [www.alzheimers.org.uk/get-involved/dementia-friendly-resources/what-dementia-friendly-community](http://www.alzheimers.org.uk/get-involved/dementia-friendly-resources/what-dementia-friendly-community). Accessed 22 October 2024.
73. Cameron A, Johnson EK, Lloyd L, Willis P and Smith R (2021) 'The contribution of volunteers in social care services for older people', *Voluntary Sector Review* 13(2), 260–77. <https://bristoluniversitypressdigital.com/view/journals/vsr/13/2/article-p260.xml>. Accessed 22 October 2024.
74. Holland C, Boukouvalas A, Wallis S, Clarkesmith D, Cooke R, Liddell L and Kay A (2016) 'Transition from community dwelling to retirement village in older adults: cognitive functioning and psychological health outcomes'. *Ageing and Society* 37, 1499–526. [www.cambridge.org/core/journals/ageing-and-society/article/transition-from-community-dwelling-to-retirement-village-in-older-adults-cognitive-functioning-and-psychological-health-outcomes/B93C2CEC5194E5631746B2542E19AABA](http://www.cambridge.org/core/journals/ageing-and-society/article/transition-from-community-dwelling-to-retirement-village-in-older-adults-cognitive-functioning-and-psychological-health-outcomes/B93C2CEC5194E5631746B2542E19AABA). Accessed 26 October 2024.

75. Housing and Dementia Research Consortium (2021) *HDRC Survey: Provisions for people living with dementia in extra care housing settings in the UK*. Housing LIN. [www.housinglin.org.uk/\\_assets/Resources/Housing/OtherOrganisation/HDRC-provisions-for-dementia-in-ECH-summary-report\\_final.pdf](http://www.housinglin.org.uk/_assets/Resources/Housing/OtherOrganisation/HDRC-provisions-for-dementia-in-ECH-summary-report_final.pdf).
76. Tadd W, Woods R, O’Neill M, Windle G, Read S, Seddon D, Hall C and Bayer T (2012) *Promoting Excellence in All Care Homes*. Cardiff University. [https://orca.cardiff.ac.uk/id/eprint/113154/1/PEACHReport\\_2012.pdf](https://orca.cardiff.ac.uk/id/eprint/113154/1/PEACHReport_2012.pdf).
77. Evans SC, Atkinson T, Cameron A, Johnson EK, Smith R, Darton R, Porteus J and Lloyd L (2020) ‘Can extra care housing support the changing needs of older people living with dementia?’, *Dementia* 19(5), 1492–508. <https://kar.kent.ac.uk/69079/1/Can%20Extra%20Care%20Housing%20support%20the%20changing%20needs%20of%20older%20people%20living%20with%20dementia.pdf>.
78. Olsen C, Pedersen I, Bergland A, Enders-Slegers M-J, Jøranson N, Calogiuri G and Ihlebaek C (2016) ‘Differences in quality of life in home-dwelling persons and nursing home residents with dementia – a cross-sectional study’, *BMC Geriatrics* 11(16), 147. <https://pubmed.ncbi.nlm.nih.gov/27400744>. Accessed 22 October 2024.
79. Care Quality Commission (2023) *The State of Health Care and Adult Social Care in England 2022/23*. Care Quality Commission. [www.cqc.org.uk/sites/default/files/2023-10/20231020\\_stateofcare2223\\_print.pdf](http://www.cqc.org.uk/sites/default/files/2023-10/20231020_stateofcare2223_print.pdf).
80. Gloucestershire County Council (2023) ‘Gloucestershire market sustainability plan 2023’. [www.gloucestershire.gov.uk/media/ouvpr53e/gloucestershire-market-sustainability-plan-2023-final.pdf](http://www.gloucestershire.gov.uk/media/ouvpr53e/gloucestershire-market-sustainability-plan-2023-final.pdf).
81. Alzheimer’s Society (2018) *Dementia – the True Cost: Fixing the care crisis*. Alzheimer’s Society. [www.alzheimers.org.uk/sites/default/files/2018-05/Dementia%20the%20true%20cost%20-%20Alzheimers%20Society%20report.pdf](http://www.alzheimers.org.uk/sites/default/files/2018-05/Dementia%20the%20true%20cost%20-%20Alzheimers%20Society%20report.pdf).
82. Hoddinott S and Davies N (2023) *Adult Social Care: Short-term support and long-term stability*. Institute for Government. [www.instituteforgovernment.org.uk/sites/default/files/2023-03/adult-social-care-short-term-long-term\\_0.pdf](http://www.instituteforgovernment.org.uk/sites/default/files/2023-03/adult-social-care-short-term-long-term_0.pdf).
83. National Audit Office (2021) *The Adult Social Care Market in England*. National Audit Office. [www.nao.org.uk/wp-content/uploads/2021/03/The-adult-social-care-market-in-England.pdf](http://www.nao.org.uk/wp-content/uploads/2021/03/The-adult-social-care-market-in-England.pdf).

84. Lobont C (2023) 'Heading for the door: the changing role of nurses in social care'. [www.nursinginpractice.com/community-nursing/heading-for-the-door-the-changing-role-of-nurses-in-social-care](http://www.nursinginpractice.com/community-nursing/heading-for-the-door-the-changing-role-of-nurses-in-social-care). Accessed 22 October 2024.
85. Skills for Care (2024) *A Workforce Strategy for Adult Social Care in England*. Skills for Care. [www.skillsforcare.org.uk/Workforce-Strategy/resources/Supporting-resources/A-Workforce-Strategy-for-Adult-Social-Care-in-England.pdf](http://www.skillsforcare.org.uk/Workforce-Strategy/resources/Supporting-resources/A-Workforce-Strategy-for-Adult-Social-Care-in-England.pdf).
86. London Borough of Camden (2023) 'Market sustainability plan'. [www.camden.gov.uk/documents/20142/0/Market+Sustainability+Plan+-+Camden.pdf/fc4398f6-37b2-67a6-1501-76260d85aeae?t=1679572904657](http://www.camden.gov.uk/documents/20142/0/Market+Sustainability+Plan+-+Camden.pdf/fc4398f6-37b2-67a6-1501-76260d85aeae?t=1679572904657). Accessed 22 October 2024.
87. Skills for Care (no date) *Guide to Safe Staffing*. Skills for Care. [www.skillsforcare.org.uk/resources/documents/Support-for-leaders-and-managers/good-and-outstanding-care/Improve-your-CQC-rating/Guide-to-safe-staffing.pdf](http://www.skillsforcare.org.uk/resources/documents/Support-for-leaders-and-managers/good-and-outstanding-care/Improve-your-CQC-rating/Guide-to-safe-staffing.pdf).
88. Skills for Care (2023) *The State of the Adult Social Care Sector and Workforce 2023*. Skills for Care. [www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/The-State-of-the-Adult-Social-Care-Sector-and-Workforce-2023.pdf](http://www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/The-State-of-the-Adult-Social-Care-Sector-and-Workforce-2023.pdf).
89. National Institute for Health and Care Excellence (2018) 'Dementia: assessment, management and support for people living with dementia and their carers'. Guideline [NG97]. [www.nice.org.uk/guidance/ng97](http://www.nice.org.uk/guidance/ng97). Accessed 22 October 2024.
90. Care Quality Commission (2014) *Cracks in the Pathway: People's experiences of dementia care as they move between care homes and hospitals*. Care Quality Commission. [www.cqc.org.uk/sites/default/files/20141009\\_cracks\\_in\\_the\\_pathway\\_final\\_0.pdf](http://www.cqc.org.uk/sites/default/files/20141009_cracks_in_the_pathway_final_0.pdf).
91. NHS England (2024) 'The Oliver McGowan Mandatory Training on Learning Disability and Autism'. [www.hee.nhs.uk/our-work/learning-disability/current-projects/oliver-mcgowan-mandatory-training-learning-disability-autism](http://www.hee.nhs.uk/our-work/learning-disability/current-projects/oliver-mcgowan-mandatory-training-learning-disability-autism). Accessed 22 October 2024.
92. Gopinath M, de Lappe J, Larkin M and Wilson A (2023) *The Value and Practice of Relational Care with Older People*. The Open University. [https://oro.open.ac.uk/88675/8/Relational%20care%20report\\_ORO%20VERSION%20EDIT.pdf](https://oro.open.ac.uk/88675/8/Relational%20care%20report_ORO%20VERSION%20EDIT.pdf).



93. Giebel C, Robertson S, Beaulen A, Zwakhalen S, Allen D and Verbeek H (2021) “Nobody seems to know where to even turn to”: barriers in accessing and utilising dementia care services in England and the Netherlands’, *International Journal of Environmental Research and Public Health* 18(22), 12233. <https://doi.org/10.3390/ijerph182212233>. Accessed 26 October 2024
94. Carers UK (no date) ‘Juggling work and unpaid care’. [www.carersuk.org/policy-and-research/our-areas-of-policy-work/juggling-work-and-unpaid-care](http://www.carersuk.org/policy-and-research/our-areas-of-policy-work/juggling-work-and-unpaid-care). Accessed 22 October 2024.
95. Carers UK (2023) ‘State of Caring survey 2023’. [www.carersuk.org/policy-and-research/state-of-caring-survey](http://www.carersuk.org/policy-and-research/state-of-caring-survey). Accessed 22 October 2024.
96. Schlepper L and Dodsworth E (2023) ‘The decline of publicly funded social care for older adults’. [www.nuffieldtrust.org.uk/resource/the-decline-of-publicly-funded-social-care-for-older-adults](http://www.nuffieldtrust.org.uk/resource/the-decline-of-publicly-funded-social-care-for-older-adults). Accessed 22 October 2024.
97. Dementia Carers Count (2023) *Invisible: 2023 Dementia Carers Count Survey findings*. Dementia Carers Count. <https://dementiacarers.org.uk/wp-content/uploads/2022/05/Invisible-2023-Report.pdf>.
98. Carers Trust (2015) *Caring about Older Carers: Providing support for people caring later in life*. Carers Trust. <https://carers.org/downloads/resources-pdfs/caring-about-older-carers/caring-about-older-carers.pdf>.
99. NHS England (2024) ‘RightCare dementia scenario’. [www.england.nhs.uk/long-read/rightcare-dementia-scenario](http://www.england.nhs.uk/long-read/rightcare-dementia-scenario). Accessed 22 October 2024.
100. Yorganci E, Stewart R, Sampson EL and Sleeman KE (2022) ‘Patterns of unplanned hospital admissions among people with dementia: from diagnosis to the end of life’, *Age and Ageing* 51(5). <https://doi.org/10.1093/ageing/afac098>. Accessed 26 October 2024.
101. Social Care Institute for Excellence (2020) ‘Reablement: a guide for carers and family’. [www.scie.org.uk/integrated-care/intermediate-care-reablement/reablement-guide](http://www.scie.org.uk/integrated-care/intermediate-care-reablement/reablement-guide). Accessed 22 October 2024.
102. Dementia Carers Count (2024) ‘Manifesto for dementia carers’. <https://dementiacarers.org.uk/blog/manifesto-for-dementia-carers>. Accessed 22 October 2024.
103. Curry N, Oung C, Crellin N and Dodsworth E (2024) *What Health and Care Need from the Next Government: Adult social care*. Nuffield Trust. [www.nuffieldtrust.org.uk/sites/default/files/2024-04/Nuffield%20Trust%20-%20General%20election%20-%20social%20care%20tests\\_WEB.pdf](http://www.nuffieldtrust.org.uk/sites/default/files/2024-04/Nuffield%20Trust%20-%20General%20election%20-%20social%20care%20tests_WEB.pdf).

104. Alzheimer's Society (no date) 'Practical tips for supporting someone with memory loss'. [www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/memory-loss-support-tips](http://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/memory-loss-support-tips). Accessed 22 October 2024.
105. West Yorkshire Combined Authority (no date) *Dementia-ready Housing Design Criteria for General Needs Housing*. West Yorkshire Combined Authority. [www.westyorks-ca.gov.uk/media/12886/dementia-ready-housing-guidance.pdf](http://www.westyorks-ca.gov.uk/media/12886/dementia-ready-housing-guidance.pdf).
106. Zimmerman S, Bowers BJ, Cohen LW, Grabowski DC, Horn SD, Kemper P and THRIVE Research Collaborative (2016) 'New evidence on the Green House model of nursing home care: synthesis of findings and implications for policy, practice, and research', *Health Services Research* 51(suppl 1), 475–96. doi:10.1111/1475-6773.12430.
107. Pedro C, Duarte M, Jorge B and Freitas D (2020) '440 – dementia villages: rethinking dementia care', *International Psychogeriatrics* 32(S1), 158.
108. Bliss A and Jones E (2024) 'Dash review of the CQC: what you need to know'. [www.nhsconfed.org/publications/dash-review-cqc](http://www.nhsconfed.org/publications/dash-review-cqc). Accessed 22 October 2024.
109. Hemmings N, Oung C and Schlepper L (2022) *New Horizons: What can England learn from the professionalisation of care workers in other countries?*. Nuffield Trust. [www.nuffieldtrust.org.uk/sites/default/files/2022-09/1662995727-nuffield-trust-new-horizons-web.pdf](http://www.nuffieldtrust.org.uk/sites/default/files/2022-09/1662995727-nuffield-trust-new-horizons-web.pdf).
110. Hemmings N, Allen L, Lobont C, Burale H, Thorlby R, Alderwick A and Curry N (2024) *From Ambition to Reality: National policy options to improve care worker pay in England*. The Health Foundation and Nuffield Trust. [www.nuffieldtrust.org.uk/sites/default/files/2024-07/Nuffield%20Trust%20and%20Health%20Fdn%20-%20Care%20worker%20pay\\_WEB.pdf](http://www.nuffieldtrust.org.uk/sites/default/files/2024-07/Nuffield%20Trust%20and%20Health%20Fdn%20-%20Care%20worker%20pay_WEB.pdf).
111. Skills for Care (2024) 'A workforce strategy for adult social care in England: recommendations and commitments: train'. [www.skillsforcare.org.uk/Workforce-Strategy/Recommendations-and-commitments/Train.aspx](http://www.skillsforcare.org.uk/Workforce-Strategy/Recommendations-and-commitments/Train.aspx). Accessed 22 October 2024.
112. Department for Business, Energy and Industrial Strategy and Russell D (2022) 'Boost for carers who will receive new unpaid leave entitlement under government-backed law'. [www.gov.uk/government/news/boost-for-carers-who-will-receive-new-unpaid-leave-entitlement-under-government-backed-law](http://www.gov.uk/government/news/boost-for-carers-who-will-receive-new-unpaid-leave-entitlement-under-government-backed-law). Accessed 22 October 2024.



113. Carers UK (2023) 'Carers UK responds to DHSC launch of £25 million fund for carers'. [www.carersuk.org/press-releases/carers-uk-responds-to-dhsc-launch-of-25-million-fund-for-carers](http://www.carersuk.org/press-releases/carers-uk-responds-to-dhsc-launch-of-25-million-fund-for-carers). Accessed 22 October 2024.
114. Alzheimer's Society (2022) 'Three in five people affected by dementia struggled with too little support over last year'. [www.alzheimers.org.uk/news/2022-06-29/three-five-people-affected-dementia-struggled-too-little-support-over-last-year](http://www.alzheimers.org.uk/news/2022-06-29/three-five-people-affected-dementia-struggled-too-little-support-over-last-year). Accessed 22 October 2024.
115. Scottish Government (2022) 'National carers strategy'. [www.gov.scot/publications/national-carers-strategy/pages/5](http://www.gov.scot/publications/national-carers-strategy/pages/5). Accessed 22 October 2024.
116. Welsh Government (2021) *Strategy for Unpaid Carers*. Welsh Government. [www.gov.wales/sites/default/files/publications/2021-03/unpaid-carers-strategy.pdf](http://www.gov.wales/sites/default/files/publications/2021-03/unpaid-carers-strategy.pdf).
117. Institute for Fiscal Studies (no date) 'English Longitudinal Study of Ageing (ELSA) user guide for the wave 1 core dataset version 3'. [https://ifs.org.uk/sites/default/files/output\\_url\\_files/wave\\_1\\_user\\_guide.pdf](https://ifs.org.uk/sites/default/files/output_url_files/wave_1_user_guide.pdf).
118. Department for Environment, Food and Rural Affairs (2016, updated 2021) 'Rural Urban Classification'. [www.gov.uk/government/collections/rural-urban-classification](http://www.gov.uk/government/collections/rural-urban-classification). Accessed 24 October 2024.
119. Office for National Statistics (2023) 'Care homes and estimating the self-funding population, England: 2022 to 2023'. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/articles/carehomesandestimatingtheselffundingpopulationengland/2022to2023>. Accessed 6th November 2024.
120. Office for National Statistics (no date) 'Estimates of the population for the UK, England, Wales and Northern Ireland: Mid-2021 edition of this dataset'. <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland>. Accessed October 2023.

**Nuffield Trust is an independent health and social care think tank. We aim to improve the quality of health care in the UK by providing evidence-based research and policy analysis and informing and generating debate.**

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