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Supporting people with dementia and their carers

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Health and Social Care Committee

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Executive Summary

Over three quarters of a million people in England live with dementia, a number that will grow exponentially, and every new diagnosis leaves another family facing a huge financial and psychological burden.

In 2015, the then Department of Health said England should become "the best country in the world for dementia care and support". There remains much progress necessary to achieve this ambition. The care system is a bureaucratic maze that patients and their families are expected to navigate at their most vulnerable and when in need of swift and effective support. England's 700,000 unpaid dementia carers too often face a lonely struggle to access care or even a full diagnosis for a loved one.

Through no fault of their own, people with dementia and their families, are at the sharp end of a system that does not work. Too often the NHS and social care can fail even in basic tasks such as the accurate and timely transfer of patient information. We concluded in our report, *Social care: funding and workforce*, that "the current system is unfair, confusing, demeaning, and frightening", and we heard no evidence in this inquiry to change our view.

This horrifying disease costs the nation almost £30 billion each year so the Government's commitment to increase funding and to reform social care is welcome. Significant additional investment is required alongside bold funding reform and a long-term plan for the social care sector. It is imperative that the Government makes good on its promise, not months or years from now, but within a matter of weeks.

Summary

Dementia is a horrifying and broad disease which includes a range of conditions associated with an ongoing decline of brain functioning.[1] The most common types are Alzheimer's disease and vascular dementia.[2] In 2019, there were an estimated 748,000 older people living with dementia in England and this number is predicted to grow exponentially by 2040.[3] In 2019, according to the London School of Economics and Political Science, the total cost of dementia in England was £29.5 billion, with the largest proportion of this spend going on social care (45.8%).[4]

In 2015, the then Department of Health's *Challenge on Dementia 2020* set the ambition for England to be "the best country in the world for dementia care and support and for people with dementia, their carers and families to live".[5] The evidence we heard during our inquiry indicates that there is still much progress to be made.

There are approximately 700,000 unpaid carers who play a vital role in supporting people with dementia.[6] We would like to acknowledge their tremendous contribution, especially over the pandemic period, when half spent over 100 hours a week caring for someone living with dementia.[7] However, in our inquiry, we heard that those living with dementia, their carers and families still face many challenges to access the critical care they deserve.

Instead of receiving integrated care across the health and social care system, those living with dementia and their carers are required to navigate complex and uncoordinated care pathways. The most vulnerable in our society are left at risk of falling through the gaps after receiving a diagnosis of dementia and their families and carers are left to grapple with burdensome bureaucracy in the system "set up to ration".[8]

In our report, *Social care: funding and workforce*, we concluded that "the current system is unfair, confusing, demeaning, and frightening".[9] We, like many others, have been calling for the Government to deliver on its promise of social care reform and we welcome the Government's announcement of additional funding on 7 September alongside the commitment to a social care White Paper this autumn. But the evidence we heard in our inquiry acts as a stark reminder that whilst important elements of social care reform remain undecided, people with dementia and their families continue to face a huge financial and psychological burden.

This short report builds on our previous recommendations on social care included in our reports on *Social care: funding and workforce*;[10] *Workforce burnout and resilience in*

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[1] Dementia UK, What is dementia?

[2] Dementia UK, What is dementia?

[3] London School of Economics and Political Science: Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040, November 2019, p. 3–4

[4] London School of Economics and Political Science: Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040, November 2019, p. 7

[5] Department of Health, Challenge on dementia 2020, February 2015, p. 3

[6] Q21 Fiona Carragher

[7] Alzheimer's Society, Worst hit: dementia during coronavirus. 2020

[8] Q20 Sarah Pickup

[9] House of Commons Health and Social Care Committee, Social care: funding and workforce, HC 206, para 89

[10] House of Commons Health and Social Care Committee, Social care: funding and workforce, HC 206

the NHS and social care;[11] and *The Government's White Paper proposals for the reform of Health and Social Care*.[12] It reiterates our position that significant additional financial investment for social care is required with bold reform of social care funding, alongside a long-term plan for the social care sector. We note that discussions within Government are reported to be at an advanced stage and we will be extremely disappointed if these plans are not brought forward by the end of the 2021.

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[11] House of Commons Health and Social Care Committee, Workforce burnout and resilience in the NHS and social care, HC 22

[12] House of Commons Health and Social Care Committee, The Government's White Paper proposals for the reform of Health and Social Care, HC 20

Introduction

1. In 2015, the then Government launched the *Challenge on Dementia 2020*.[13] The then Prime Minister, Rt Hon. David Cameron, stated that by 2020 he wanted England to be "the best country in the world for dementia care and support and for people with dementia, their carers and families to live".[14] However, in our inquiry we sought to shine a spotlight on critical issues that remain for people living with dementia, their carers and families and that prevent them from accessing the much needed care they deserve.

2. Dementia encompasses a range of conditions all associated with an ongoing decline of brain functioning.[15] There are over 200 subtypes of dementia, with the most common being Alzheimer's disease and vascular dementia.[16] In 2019 there were an estimated 748,000 older people living with dementia in England, with a prevalence of 7.2%.[17] There are also around 40,000 people under the age of 65 living with dementia.[18] It is projected that the number of older people living with dementia in England will increase to around 1.35 million by 2040.[19]

3. In 2019, the total cost of dementia in England was £29.5 billion, with the largest proportion of this spend going on social care (45.8%).[20] The total cost of dementia care is projected to reach £80.4 billion by 2040.[21]

Calls for Social Care Reform

4. Many of those living with dementia and their families depend on the social care system for support. However, in our report, *Social care: funding and workforce*, we concluded that "the current system is unfair, confusing, demeaning, and frightening".[22]

5. In July 2019, Rt Hon. Boris Johnson MP, in his opening speech as Prime Minister, set out a clear commitment to tackle the long overdue challenge of reforming the social care system. He told the nation "we will fix the crisis in social care once and for all with a clear plan we have prepared".[23]

6. The Government has made its intention to bring forward its promised social care reforms clear through the recent introduction of the health and social care levy. While social care reform has been delayed by successive governments and we welcome the Government's commitment to tackling this issue, it is essential that the contents of the forthcoming White Paper include practical measures to improve the lives of families living with dementia. Witnesses giving evidence to our inquiry all agreed that social care reform

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[13] Department of Health, Challenge on dementia 2020, February 2015

[14] Department of Health, Challenge on dementia 2020, February 2015, p. 3

[15] NHS, About dementia;

[16] Dementia UK, What is dementia?

[17] London School of Economics and Political Science: Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040, November 2019, p. 3–4

[18] Alzheimer's Society, Who gets dementia?

[19] London School of Economics and Political Science: Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040, November 2019, p. 4

[20] London School of Economics and Political Science: Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040, November 2019, p. 7

[21] London School of Economics and Political Science: Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040, November 2019, p. 7

[22] House of Commons Health and Social Care Committee, Social care: funding and workforce, HC 206, para89

[23] Prime Minister's Office, 10 Downing Street, Boris Johnson's first speech as Prime Minister: 24 July 2019

was essential. We heard from Caroline Abrahams, Charity Director, Age UK, who told us that "[Age UK] think it is incredibly important that the Prime Minister fulfils his promise to bring forward proposals".[24] When asked about priorities for supporting people with dementia, Fiona Carragher, Director of Research and Influencing, Alzheimer's Society, told us "top of our list—is social care reform".[25]

7. In our report, *Social Care: Funding and Workforce*, we called for the Government to publish a 10-year plan for the social care sector as it has done for the NHS.[26] Caroline Abrahams, Charity Director, Age UK, reiterated the importance of this during our inquiry. She told us:

> The problems in social care are so many that a 10-year plan is a very good idea, because we are not going to fix them overnight; Rome was not built in a day. That would mean two or three Parliaments. It would mean a sustained push, and that is probably what we need.[27]

8. Helen Whately MP, then Minister of State for Care, Department of Health and Social Care, told us that there is a "once-in-a-generation opportunity to improve social care".[28] We heard from the Minster that reforms must be "ambitious and bold" and the Government is committed to bringing forward proposals this year.[29] However, as the plans for social care reform remain undecided, people with dementia and their families continue to face a huge financial burden and risk losing their homes. We wholeheartedly reiterate our previous sentiment that we will be extremely disappointed if these plans are not brought forward by the end of the calendar year.[30]

9. This report builds on previous work and recommendations related to the social care system in our recent reports. In Chapter 1, we consider the impact of the current social care funding structure on those living with dementia and explore options for social care funding reform. In Chapter 2, we consider what further action will be required to ensure all those living with dementia receive the personalised and quality care they deserve.

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[24] Q9 Caroline Abrahams

[25] Q7 Fiona Carragher

[26] House of Commons Health and Social Care Committee, Social care: funding and workforce, HC 206, para 37

[27] Q9 Caroline Abrahams

[28] Q49 Minister of State for Care, Department of Health and Social Care

[29] Q49 Minister of State for Care, Department of Health and Social Care

[30] House of Commons Health and Social Care Committee, The Government's White Paper proposals for the reform of Health and Social Care, HC 20, para 55

Chapter 1: Social care funding reform

10. Unlike the NHS, social care in England is not free for all those who need it. Whether a person living with dementia must contribute in part or in full towards the cost of their care principally depends on two factors: (i) whether their primary need for care is health related and (ii) if not, the person's financial means to contribute.[31]

11. Although in absolute terms the funding for social care has increased, so has demand, resulting in a significant amount of unmet need.[32] The Local Government Association (LGA) have highlighted the extent and impact of this underfunding:

> Years of significant underfunding coupled with rising demand and costs for care and support have combined to push adult social care services to breaking point. Over the past decade, adult social care cost pressures have increased by £8.5 billion and total funding has increased by £2.4 billion. This meant a gap of £6.1 billion needed to be managed […] This underfunding puts the workforce and unpaid family carers under further strain, creating unmet and under-met need and impacting on social care's ability to help mitigate demand pressures on the NHS.[33]

12. After considering the evidence from our *Social care: funding and workforce* inquiry we recommended social care funding must be increased by a minimum of £7 billion per year by 2023–24.[34]

13. We heard that 200,000 people with moderate and severe dementia in England do not get any kind of funded or professional support. They receive most of their support from informal carers, family members and friends.[35] Sarah Pickup, Deputy Chief Executive, Local Government Association, described a bureaucratic social care system "set up to ration":

> First of all, you cross the care eligibility threshold. Then you cross the means-tested eligibility threshold. Then, if your needs really rise, you end up in the continuing healthcare system [CHC]. We know that areas set budget targets to reduce their spend on CHC when they have tight budgets […] There are criteria, but all criteria are open to interpretation, and there can be a real battle […] We have to find a way to fund the system adequately so that you can meet the needs of people who have really high needs, and also invest in preparing people, and helping people set themselves up for the future. It does not have to be bureaucratic. The bureaucracy is all about managing the system as it is established in law.[36]

14. The Government's 2019 general election manifesto included a pledge to "guarantee that no one needing care has to sell their home to pay for it".[37] However, until the new cap is introduced, those with dementia continue to face unlimited costs for their social care.

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[31] House of Commons Library, Dementia: policy, services and statistics, May 2021

[32] King's Fund, Adult Social Care Funding and Eligibility

[33] Local Government Association, Social care reform and the social care workforce, House of Commons, 18 March 2021, March 2021

[34] House of Commons Health and Social Care Committee, Social care: funding and workforce, HC 206, para 104

[35] Q8 Fiona Carragher

[36] Q20 Sarah Pickup

[37] The Conversative and Unionist Party Manifesto 2019, p.12

Alzheimer's Society refer to this as the 'dementia tax' and highlight the unfair burden placed on people with dementia compared to other long-term health conditions:

> People with dementia who have assets including their house over £23,250 in England are often paying hundreds of thousands of pounds for their care. We estimate that a typical person's bill for dementia care would take 125 years to save for. Currently, too many people with dementia and their families are buckling under the inordinate pressure of paying for their dementia care bill.
>
> For many other long-term health conditions, such as cancer and heart disease, medical treatments are available for free on the NHS. However, these treatments don't yet exist for dementia, meaning that it is costly social care, as opposed to free treatments on the NHS, that people with dementia are forced to pay for to get support. It should not be the case that because you develop one condition over another, you can be left bankrupted by care costs. This is not a fair system and Alzheimer's Society has been calling for an end to this 'dementia tax' for the last eleven years.[38]

15. Jonathan Freeman opened our inquiry with a powerful personal testimony reflecting on his experience of supporting his mother, Gillian, when she was diagnosed with dementia. Jonathan described the harrowing experience of selling his mother's home to fund her care:

> I had no choice but to sell her home to make sure that we could continue to pay the fees. […] I wanted to be there to support my mum. I did not want to have to spend my time worrying about her finances and arguing with bureaucracies for what I think should be a basic right.[39]

16. In our report, *Social care: funding and workforce*, we explored options for longer term reform of social care funding to prevent families facing catastrophic costs.[40] This included a lifetime cap on care costs at £46,000 as recommended by Sir Andrew Dilnot, which is estimated to cost £3.1 billion in 2023–24.[41] However, despite the Care Act 2014 including provisions to implement a cap, it has not been introduced to date. The cap on care costs proposed by the Government on 7 September 2021 was the far higher figure of £86,000. Whilst this is estimated to help 150,000 families annually, those with more modest assets and high care needs will still risk losing a high proportion of their wealth in future.[42] The Health Foundation has estimated that an individual whose house is valued at £125,000 would still risk losing almost half of their housing wealth.[43]

17. When considering who should cover the costs of social care, we heard from Caroline Abrahams, Charity Director, Age UK, who said that "it is all of us". She explained:

> We are all going to have to pay more if we are to have a decent social care

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[38] Alzheimer's Society, Dementia Tax

[39] Q1 Jonathan Freeman

[40] House of Commons Health and Social Care Committee, Social care: funding and workforce, HC206, paras 74–102

[41] Commission on Funding of Care and Support, Fairer Care Funding, July 2011; Oral evidence taken on 14 July 2020, HC (2019–21) 206, Q141 [Sir Andrew Dilnot]

[42] HM Government, Building Back Better: Our plan for Health and Social Care. September 2021

[43] The Health Foundation, Social care cap a bold step forward but funding won't 'fix' social care or tackle the NHS backlog. September 2021.

> system. This is often just viewed as an older people's issue, but it is not. Obviously, there are younger people with disabilities. You can fall down the stairs tomorrow and have a serious brain injury at 30 and need long-term care […] When we have talked to older people about this, they have no objection, once the arguments are explained, to paying a small amount, maybe at the time of their death.
>
> This is politically very difficult […] but it is a matter of looking at where people are best placed to contribute. People are in different situations. Not everyone can pay more out of their income, but maybe they could pay from their assets. The point is that we all need to pay because it is something from which our whole society would benefit.[44]

18. On 7 September, the Government announced there would be a new health and social care levy that would raise £12 billion annually. We welcome this announcement. We expect that the Government will provide more clarity on core funding for social care when it publishes its White Paper to deliver the transformation needed for families living with dementia. But for the next three years the health and social care levy will increase the social care budget by less than £2 billion a year and there is no clarity about what it will increase to after that. Until the Government reveals those details, we remain concerned that there will be not be enough core funding for social care to deliver the transformation needed for families living with dementia.

19. **We conclude, in line with our report on *Social care: funding and workforce*, the current social care system is "unfair and confusing". Those living with dementia remain unprotected from unlimited costs and navigating the system is burdensome for those providing support. This is unacceptable and it is therefore essential the Government's White Paper addresses these issues with full reform of the social care system**.

20. **We are disappointed that the Government has not provided greater funding for social care in the next three years from the new health and social care levy, with no clarity about what proportion of the levy will go to social care after that period. However, the Government has pledged to look at the wider issue of social care funding at the upcoming spending review and it is essential that the starting point for the social care funding increase must be an additional £7 billion per year by 2023–24 to cover demographic changes, uplift staff pay in line with the National Minimum Wage and to protect people who face catastrophic social care costs.**

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[44] Q15 Caroline Abrahams

Chapter 2: Providing appropriate care and support for people with dementia

Diagnosis and post-diagnostic support

21. The *Challenge on Dementia 2020* set out a strategy for improving diagnosis rates and reducing variation across the country.[45] The national ambition is that two thirds of the estimated number of people with dementia in England should receive a diagnosis with appropriate post-diagnostic support.[46] However, Fiona Carragher, Director of Research and Influencing, Alzheimer's Society, told us that diagnosis remains a problem and whilst this target had previously been achieved, the rate had fallen:

> We have significant issues with diagnosis. The diagnosis rate dropped from only 67.4%, which is not great, to 61% in the last year. There is a huge amount to do around diagnosis and post-diagnostic support.[47]

22. John O'Doherty was diagnosed with dementia in 2016 and currently lives with his wife at home. John's powerful testimony highlighted the challenges some face in getting a diagnosis and the importance of receiving a timely diagnosis:

> I had been going to my GP for a number of years because I knew my personality was changing […] I continued to go to see my GP, but nothing was happening. It got to the stage where I went to see the doctor with my wife, and I had a complete and utter meltdown in the surgery. As a result of that, I was referred to a psychiatrist, who did a memory test. He said that he was a bit concerned about the memory test. I had a brain scan […] I was there with my wife, and I was told that I had mixed cortical and subcortical vascular dementia. […] the actual diagnosis was vindication. I knew I had dementia. All the signals were there. I knew people who had dementia, and I felt that I was not being listened to at all. Being given that diagnosis was giving me a chance. I could move on with my life. I could make decisions.[48]

23. When John received his diagnosis, he told us that he felt let down by his post-diagnostic support:

> As for my support, to call it poor would be complimenting it. For example, I went for an appointment to go to a post-diagnostic support group with my wife. I agreed to do it because I wanted to learn as much as I could, to develop strategy and friendships. […] I waited and waited […] but I heard nothing. […] Obviously, I lost complete faith in the system, to be let down so much like that.[49]

24. Receiving an early diagnosis can help those living with dementia and their carers plan ongoing care. Jonathan Freeman also described "a real battle" getting a diagnosis for his mother, Gillian.[50] By the time they received the diagnosis, Jonathan told us Gillian's

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[45] Department of Health, Challenge on dementia 2020, February 2015

[46] NHS England, Dementia

[47] Q7 Fiona Carragher

[48] Q6 John O'Doherty

[49] Q6 John O'Doherty

[50] Q1 Jonathan Freeman

dementia was "pretty far advanced" and the late diagnosis meant placing her in a care home "without being able to prepare her properly for that".[51]

25. Helen Whately MP, then Minister of State for Care at the Department of Health and Social Care, recognised "early diagnosis as crucial to make sure that the individual gets the support they need and, really importantly, that those caring for them can access support as well".[52] In response to the falling diagnosis rate, the Minister told us "NHS England is spending £17 million to bring that back up and to take steps to increase the diagnosis rate again".[53]

The importance of integrated care

26. We heard from Fiona Carragher that "if ever there was a group of people who cross between the NHS and the social care system to get the support and care they need, it is people with dementia".[54] However, we have heard that achieving good integrated care remains a serious and concerning challenge. For example, Jonathan Freeman told us:

> You are focusing on dementia and social care, but it is very often about the interface with the health service and the health sector. That lack of integration was certainly what I witnessed. […] You get caught in the gap in the middle.[55]

27. The Department of Health and Social Care's *Joint declaration on post-diagnostic dementia care* and support is a shared commitment between the Government, the healthcare system, the social care sector, the third sector and other relevant partners to deliver better quality post-diagnostic support for people affected by dementia.[56] However, Alzheimer's Society's recent report, *From diagnosis to end of life: The lived experiences of dementia care and support*, highlighted that despite guidance being in place for dementia care responsibilities remain unclear and it is difficult to establish whether guidance is being followed, particularly post diagnosis.[57] Furthermore, Sarah Pickup, Deputy Chief Executive, Local Government Association, emphasised the need to address the gap between diagnosis and ongoing post-diagnostic support:

> When you have the diagnosis, sometimes there is no treatment the health service can offer you, and you do not yet cross the eligibility threshold for social care. We have to move away from a post-diagnostic gap, and enable people to have information and advice, as well as a go-to person to support and advise them.[58]

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[51] Q1 Jonathan Freeman

[52] Q70 Minister of State for Care, Department of Health and Social Care

[53] Q70 Minister of State for Care, Department of Health and Social Care

[54] Q35 Fiona Carragher

[55] Q2 Jonathan Freeman

[56] Department of Health and Social Care, Joint declaration on post-diagnostic dementia care and support, January 2016

[57] Alzheimer's Society, From diagnosis to end of life: The lived experiences of dementia care and support, October 2020, p.10

[58] Q11 Sarah Pickup

28. Reflecting on integrated care system arrangement, Sarah Pickup also told us:

> What you need to deliver those kinds of support, without the passing backwards and forwards, according to who is responsible for funding, is pooled budgets. You need pooled budgets focused on need […] it is about pooling of teams, funding and services, and focusing on what people need and not on whose responsibility it is today to fund a particular piece of the jigsaw.[59]

29. **We have heard of the importance of receiving a timely diagnosis for people with dementia and their carers. We appreciate that the covid-19 pandemic will undoubtably have played a part in the recent decline in diagnosis rates which was previously on target. We also welcome the funding NHS England and Improvement has committed to bring the diagnosis rate back to the target of two thirds of those estimated to have dementia.**

30. **However, the evidence we have taken has made it clear that improving diagnosis alone is not sufficient: people living with dementia and their carers need appropriate post-diagnostic support throughout the rest of their life. We are clear that there should be no gap between receiving a diagnosis and providing both immediate support and planning longer-term care for someone with dementia. People with dementia and their carers should not be left to fall through the cracks of an uncoordinated and complex pathway across the health and social care system.**

31. ***We recommend the Department of Health and Social Care and NHS England and Improvement use the White Paper to develop clear guidance on the care and support those living with dementia and their carers should expect to receive from diagnosis through to lifelong post-diagnostic support. This guidance must encourage integrated working across the health and social care system while also establishing clear responsibilities for Integrated Care Systems in coordinating care. Alongside this, there must be appropriate data collection along the whole dementia pathway to monitor activity and support improvement. We expect an update on this work by the end of November 2021.***

Providing quality and personalised care

32. The Alzheimer's Society states that social care reform must be centred around providing quality and personalised care within an integrated health and social care system:

> We know the time to act on social care reform is now. Whilst any reform is subject to the examination of complex funding options, Alzheimer's Society firmly believes that long term reform must first be rooted in the recognition of what good quality care looks like, how it becomes truly personalised for people with dementia and their carers in real terms, and how it can be provided consistently for people using it within a sustainable system integrated with healthcare.[60]

33. The 'Wellbeing Principle' of the *Care Act 2014* in England clearly outlines the quality

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[59] Q36 Sarah Pickup

[60] Alzheimer's Society, A Future for Personalised Care, March 2021, p.3

of care all those requiring social care should expect to experience.[61] However, Caroline Abrahams, Charity Director, Age UK, told us:

> We are miles away from fulfilling the Care Act 2014. It was a piece of legislation that came about as a great vision and a great process and which was never resourced. Again, part of it absolutely comes back to money.[62]

34. Fiona Carragher, Director of Research and Influencing, Alzheimer's Society, told us "the central principles [of personalised care] are giving people choice and control; supporting the individual to choose and set their own goals—what matters to them; and recognising the importance of relationships".[63] Ms Carragher explained that improving care needs to be built on the existing evidence. She highlighted:

> Really good evidence has come out of academic centres such as the Centre of Excellence at the University of Exeter. We have things like cognitive rehabilitation in the NICE guidance for dementia care. There is huge patchy uptake of this across the country. There are some things that we know can be done, and should be done, but they are not there across the country.[64]

35. Fiona Carragher emphasised that "funding is at the heart" of improving uptake of good practice and emphasised the importance of "early and accurate diagnosis" and "workforce training".[65]

Workforce and training

36. We heard from Jonathan Freeman about the difference having a supportive carer who understood his mother's needs meant for her care:

> Dementia is so cruel. She could not communicate in any meaningful way, or verbally with me. She knew she could not, and that was incredibly painful for her […] One young carer realised, in a way that I had not, that he could communicate with mum in French because foreign language is stored in a different part of the brain. It was absolutely miraculous; that is incredible care.[66]

37. He went on to emphasise the importance of "investing in leadership and talent development in our workforce in a way that we are not, across the whole sector developing talent within the social care workforce".[67]

38. Sarah Pickup pointedly highlighted "there is a specialism, which is about supporting people to live their life, and we need to recognise that".[68] She told us that the workforce was 'at the heart' of improving care:

> It is about training, but it is also about career progression and recognising someone's skills, particularly if you think about the dementia pathway.

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[61] Care Act 2014, Promoting individual wellbeing
[62] Q27 Caroline Abrahams
[63] Q28 Fiona Carragher
[64] Q28 Fiona Carragher
[65] Q29 Fiona Carragher
[66] Q1 Jonathan Freeman
[67] Q48 Jonathan Freeman
[68] Q30 Sarah Pickup

> Understanding how you might try different tactics to communicate with someone as their dementia advances is a really skilled job. You cannot expect someone to be a minimum wage care worker, develop those skills and not be rewarded, yet we do.[69]

39. Alzheimer's Society's recent report, *A Future for Personalised Care*, highlighted a vacancy rate of 7.3% within the social care sector and annual turnover rate of 38.1%.[70] Fiona Carragher explained to us the negative impact of an unstable social care workforce for people with dementia:

> One of the major issues we have is not only vacancy rates, but high turnover of staff, which means that that relationship is hard to build. If you are only going in for a short period of time in a domiciliary care setting, it is hard to build a relationship and understand what the individual with dementia needs.[71]

Monitoring the quality of care in care homes

40. In 2014, 39% of those over 65 living with dementia were living in care homes. The average prevalence of people living with dementia in care homes had risen from 56% in 2002 to 70% in 2013.[72]

41. In October 2014, the Care Quality Commission's (CQC) report, *Cracks in the pathway: People's experiences of dementia care as they move between care homes and hospital*, found that whilst many hospitals and care homes deliver excellent care, the quality of care for people with dementia varied greatly.[73] The CQC found that some hospitals and care homes did not comprehensively identify all of a person's care needs, and there was variable or poor staff understanding and knowledge of dementia care:

> The quality of dementia care across providers is variable, and transitions between services need to be improved. People with dementia are likely to experience poor care at some point along their care pathway, but they have the right to expect good care and it is unacceptable that they should receive a variable quality of care.[74]

The CQC inspected 129 care homes and found aspects of variable or poor care across more than 90% of care homes.[75]

42. In commenting on this matter, Helen Whately MP, then Minister of State for Care at the Department of Health and Social Care told us that:

> [The Department] are going to implement an assurance oversight system that the CQC will take the lead on. That will look at local authorities'

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[69] Q30 Sarah Pickup

[70] Alzheimer's Society, A Future for Personalised Care, March 2021, p.29

[71] Q43 Fiona Carragher

[72] Dementia Statistics Hub

[73] Care Quality Commission, Cracks in the pathway: People's experiences of dementia care as they move between care homes and hospitals, October 2014

[74] Care Quality Commission, Cracks in the pathway: People's experiences of dementia care as they move between care homes and hospitals, October 2014 , p.9

[75] Care Quality Commission, Cracks in the pathway: People's experiences of dementia care as they move between care homes and hospitals, October 2014 , p.6–7

> commissioning of social care and give much greater visibility than we have at the moment of the extent to which the *Care Act 2014* is being put into practice, versus the gaps between the aspiration and the reality.[76]

43. **As emphasised by Alzheimer's Society and other key stakeholders, social care reform must be "rooted in the recognition of what good quality care looks like" and create a system where people with dementia are able to receive personalised care. We support this and believe that an essential foundation to this is a sustainable skilled and valued workforce. Reforms to deliver this must be a core part of the forthcoming White Paper including a focused effort to reducing the 30% turnover rates typical in the sector with a more strategic approach to social care pay, progression and conditions. We expect the Government's recent commitment of £500 million to be spent on the social care workforce is unlikely to address these issues.**

Supporting people with dementia and their carers in the community

44. A survey commissioned by Alzheimer's Society in 2014 found 85% of people would rather stay living at home if diagnosed with dementia.[77] The charity, Age UK, has highlighted that with right the support in place many people living with dementia can continue to live in the community:

> At the moment, two thirds of people with dementia live in the community, one third of whom live on their own. With the right support and services, people with dementia can lead fulfilling lives independently in their own homes. Essential to this is good access to everyday services such as banking, shops or transport for people with dementia and cognitive impairment and their carers. However, too often those services do not meet their needs and there are still examples of prejudice against dementia where people feel patronised or discriminated against.[78]

45. During our inquiry, we heard that there are approximately 700,000 unpaid carers for people with dementia in the UK.[79] All those giving evidence acknowledged the significant contribution of carers in supporting those with dementia and the importance of acknowledging and supporting this contribution in the social care reforms. Sarah Pickup told us that "we need to make sure that any reforms have carers in there and that they are not to one side".[80] Research from Alzheimer's Society has shown that half of carers spent over 100 hours a week caring for someone with dementia during the pandemic.[81]

46. Building on this, Fiona Carragher told us:

> One of the things that can be done for family carers is that, in the context of the reform and the long-term vision, they are seen to play a key role […] what really matters for people with dementia are those relationships […] It is their relationships with their loved ones and with the community. It is giving carers the support that they need, cutting down the bureaucracy

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[76] Q59 Minister of State for Care, Department of Health and Social Care

[77] Dementia Statistics Hub, Perceptions of dementia

[78] Age UK, Living well with dementia (England), March 2016

[79] Q21 Fiona Carragher

[80] Q23 Sarah Pickup

[81] Alzheimer's Society, Worst hit: dementia during coronavirus. 2020

> and helping with the navigation through the system, so that they can do the thing they want to do, which is to have a loving relationship with someone with dementia.[82]

47. Most carers do not get any respite for the care they provide, and because many are not identified by their GP or by a hospital dealing with the person needing care, their caring work goes completely unacknowledged. The then Minister of State for Care indicated that the current register of carers is inadequate.[83]

48. **Unless carers are identified they cannot be supported. The Government must consider strengthening its current register by placing a new duty on the NHS to identify carers and promote their health and wellbeing.**

49. Very few carers receive respite despite the fact that without them our social care system would not be able to function. Many carers have been left without financial support during the pandemic and have had to shoulder the burden of considerable additional costs. Caroline Abrahams told us:

> There is, first, an issue about money. If you give up work to care, as many people do, you are consigning yourself to be poor later in life. We must do something about carer's allowance. We ought to be trying to support carers to keep working, if they can, alongside caring. To do that, we need a different approach to flexible working, which may have been accelerated, helpfully, by the pandemic.[84]

50. **It is welcome that the Government has stated that booster vaccinations will be offered to carers. More needs to be done to support carers in other ways. The Government's carer's action plan expired at the end of last year. It is critical that a National Carers' Strategy based on that consulted on in 2016 is published as soon as possible so that carers can continue to play their vital role in supporting people with dementia.**

51. Our witnesses also highlighted that supporting people with dementia involves going further than just the health and social care system.[85] For example, Sarah Pickup told us:

> There is a wider role for local government. It is not just about integration of health and social care. It is about people living their lives in communities.[86]

52. Fiona Carragher supported this and encouraged the Government to look wider than the Department of Health and Social Care when considering its future strategy for dementia:

> We now have a moment, with the Government considering their new dementia strategy. This is very much led by DHSC, but we would seek at Alzheimer's Society for it to be a cross-Government initiative, thinking not only about housing, but about transport and about how it links to BEIS, so that we have the breakthrough innovations and research that we need. There is a clear moment now to think about the transformation not only of

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[82] Q21 Fiona Carragher

[83] Q50 Minister of State for Care, Department of Health and Social Care

[84] Q22 Caroline Abrahams

[85] See, for example: Q37 Sarah Pickup; and Q39 Fiona Carragher

[86] Q37 Sarah Pickup

> the health and social care piece but of wider Government initiatives around dementia.[87]

53. In 2014, Public Health England and the Alzheimer's Society launched a campaign to recruit 'Dementia Friends' who are able to recognise the symptoms and support people with dementia. As of January 2019, there were 2.78 million Dementia Friends.[88] The Government and the Alzheimer's Society also encouraged communities to become 'dementia-friendly' with the ambition that over half of people will be living in dementia-friendly communities by 2020. As of January 2019, there were 412 such communities in England.[89] However, Fiona Carragher told us:

> There is a lot more to do around that. At Alzheimer's Society we are very proud to run flagship initiatives around it, but we need to do more to be aware and to have inclusive mixed housing stock. There are great examples in parts of Europe, where young and old are living together so that there is a link to the community. For us, it is about moving it towards an inclusivity agenda, as well as just an awareness piece.[90]

54. **With many people preferring to stay living at home if diagnosed with dementia, it is vital that any future Government strategies for dementia support this becoming a reality. Initiatives such as Dementia Friends and dementia-friendly communities have successfully increased awareness of dementia but more needs to be done for those living with dementia to be included in their local communities.**

55. ***Ensuring inclusivity for those living with dementia goes beyond the health and social care system. We heard that, for example, achieving inclusivity requires changes to housing and transport. Therefore, we recommended that the Government's new dementia strategy must include cross-departmental initiatives to ensure people with dementia are able to remain connected to their community.***

56. **Unpaid carers play a vital role in supporting people with dementia. We would like to acknowledge their tremendous contribution, especially over the pandemic period and we welcome the eventual inclusion of provisions in the Health and Care Bill relating to carers. The Government must consider unpaid carers in their White Paper for social care reform. To ensure reforms enable unpaid carers to better support those living with dementia, the Government must provide unpaid carers with the opportunity to contribute to any plans for reform. Carers deserve our support as well as our thanks. The Government must bring forward a National Carers' Strategy by the end of March 2022 with the aim of offering improved support for people providing care and should improve the Carers register.**

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[87] Q39 Fiona Carragher

[88] Department of Health and Social Care, Dementia 2020 Challenge: 2018 Review Phase 1, February 2019, para 1.3

[89] Department of Health and Social Care, Dementia 2020 Challenge: 2018 Review Phase 1, February 2019, para 1.3

[90] Q41 Fiona Carragher

Conclusions and recommendations

Social care funding reform

1. We conclude, in line with our report on *Social care: funding and workforce*, the current social care system is "unfair and confusing". Those living with dementia remain unprotected from unlimited costs and navigating the system is burdensome for those providing support. This is unacceptable and it is therefore essential the Government's White Paper addresses these issues with full reform of the social care system. (Paragraph 19)

2. We are disappointed that the Government has not provided greater funding for social care in the next three years from the new health and social care levy, with no clarity about what proportion of the levy will go to social care after that period. However, the Government has pledged to look at the wider issue of social care funding at the upcoming spending review and it is essential that the starting point for the social care funding increase must be an additional £7 billion per year by 2023–24 to cover demographic changes, uplift staff pay in line with the National Minimum Wage and to protect people who face catastrophic social care costs. (Paragraph 20)

Providing appropriate care and support for people with dementia

3. We have heard of the importance of receiving a timely diagnosis for people with dementia and their carers. We appreciate that the covid-19 pandemic will undoubtably have played a part in the recent decline in diagnosis rates which was previously on target. We also welcome the funding NHS England and Improvement has committed to bring the diagnosis rate back to the target of two thirds of those estimated to have dementia. (Paragraph 29)

4. However, the evidence we have taken has made it clear that improving diagnosis alone is not sufficient: people living with dementia and their carers need appropriate post-diagnostic support throughout the rest of their life. We are clear that there should be no gap between receiving a diagnosis and providing both immediate support and planning longer-term care for someone with dementia. People with dementia and their carers should not be left to fall through the cracks of an uncoordinated and complex pathway across the health and social care system. (Paragraph 30)

5. *We recommend the Department of Health and Social Care and NHS England and Improvement use the White Paper to develop clear guidance on the care and support those living with dementia and their carers should expect to receive from diagnosis through to lifelong post-diagnostic support. This guidance must encourage integrated working across the health and social care system while also establishing clear responsibilities for Integrated Care Systems in coordinating care. Alongside this, there must be appropriate data collection along the whole dementia pathway to monitor activity and support improvement. We expect an update on this work by the end of November 2021.* (Paragraph 31)

6. As emphasised by Alzheimer's Society and other key stakeholders, social care reform must be "rooted in the recognition of what good quality care looks like" and

create a system where people with dementia are able to receive personalised care. We support this and believe that an essential foundation to this is a sustainable skilled and valued workforce. Reforms to deliver this must be a core part of the forthcoming White Paper including a focused effort to reducing the 30% turnover rates typical in the sector with a more strategic approach to social care pay, progression and conditions. We expect the Government's recent commitment of £500 million to be spent on the social care workforce is unlikely to address these issues. (Paragraph 43)

7. With many people preferring to stay living at home if diagnosed with dementia, it is vital that any future Government strategies for dementia support this becoming a reality. Initiatives such as Dementia Friends and dementia-friendly communities have successfully increased awareness of dementia but more needs to be done for those living with dementia to be included in their local communities. (Paragraph 54)

8. *Ensuring inclusivity for those living with dementia goes beyond the health and social care system. We heard that, for example, achieving inclusivity requires changes to housing and transport. Therefore, we recommended that the Government's new dementia strategy must include cross-departmental initiatives to ensure people with dementia are able to remain connected to their community.* (Paragraph 55)

9. Unpaid carers play a vital role in supporting people with dementia. We would like to acknowledge their tremendous contribution, especially over the pandemic period and we welcome the eventual inclusion of provisions in the Health and Care Bill relating to carers. The Government must consider unpaid carers in their White Paper for social care reform. To ensure reforms enable unpaid carers to better support those living with dementia, the Government must provide unpaid carers with the opportunity to contribute to any plans for reform. Carers deserve our support as well as our thanks. The Government must bring forward a National Carers' Strategy by the end of March 2022 with the aim of offering improved support for people providing care and should improve the Carers register. (Paragraph 56)

Formal minutes

Tuesday 19 October 2021

Members present:

1. Jeremy Hunt, in the Chair
2. Dr Luke Evans
3. Barbara Keeley
4. Anum Qaisar-Javed
5. Dean Russell
6. Laura Trott

Draft Report (*Supporting people with dementia and their carers*), proposed by the Chair, brought up and read.

Ordered, That the draft Report be read a second time, paragraph by paragraph.

Summary agreed to.

Paragraphs 1 to 56 agreed to.

Resolved, That the Report be the Seventh Report of the Committee to the House.

Ordered, That the Chair make the Report to the House.

Ordered, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

Adjourned till Tuesday 26 October 2021 at 9.00 am

Witnesses

The following witnesses gave evidence. Transcripts can be viewed on the inquiry publications page of the Committee's website.

Tuesday 18 May 2021

Johnathan, an individual with lived experience; **John**, an individual with lived experience	Q1–6
Fiona Carragher, Director of Research and Influencing, Alzheimer's Society; **Caroline Abrahams**, Charity Director, Age UK; **Sarah Pickup**, Deputy Chief Executive, Local Government Association	Q7–48

Tuesday 25 May 2021

Helen Whately MP, Minister of State for Care, Department of Health and Social Care; **Tom Surrey**, Director of Adult Social Care Policy, Department of Health and Social Care	Q49–81

List of Reports from the Committee during the current Parliament

All publications from the Committee are available on the publications page of the Committee's website.

Session 2021–22

Number	Title	Reference
1st	The Government's White Paper proposals for the reform of Health and Social Care	HC 20
2nd	Workforce burnout and resilience in the NHS and social care	HC 22
3rd	Pre-appointment hearing for the Chair of the Food Standards Agency	HC 232
4th	The safety of maternity services in England	HC 19
5th	The treatment of autistic people and individuals with learning disabilities	HC 21
6th	Coronavirus: lessons learned to date	HC 92
1st Special	The Health and Social Care Committee's Expert Panel: Evaluation of the Government's progress against its policy commitments in the area of maternity services in England	HC 18

Session 2019–21

Number	Title	Reference
1st	Appointment of the Chair of NICE	HC 175
2nd	Delivering core NHS and care services during the pandemic and beyond	HC 320
3rd	Social care: funding and workforce	HC 206
4th	Appointment of the National Data Guardian	HC 1311
1st Special	Process for independent evaluation of progress on Government commitments	HC 633
2nd Special	Delivering core NHS and care services during the pandemic and beyond: Government Response to the Committee's Second Report of Session 2019–21	HC 1149
3rd Special	Drugs policy: Government Response to the Committees First Report of Session 2019	HC 1178