

Written evidence submitted by Carers UK (ASCO104)

Carers UK submission to Health and Social Care Committee Inquiry on Adult Social Care Reform: The Cost of Inaction

1. About Carers UK

- 1.1 Carers UK is a charity set up to help the millions of people who care unpaid for family or friends. We are a membership organisation of carers, run by carers, for carers. We provide information and advice about caring alongside practical and emotional support for carers. We also campaign to make life better for carers and work to influence – using carers’ insights and lived experiences – policy makers, employers, and service providers, to help them improve carers' lives. We undertake research and engagement with carers, ensuring that there is the evidence to support the breadth and depth of carers’ voices and experience which must be at the heart of any decision-making.
- 1.2 Carers UK also set up and runs the Employers for Carers forum, which promotes good practice in supporting unpaid carers in the workplace. This has 230 members covering nearly 3 million employees.
- 1.3 Carers UK is also a member of, and co-chairs, the Care and Support Alliance¹.
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2. Summary

2.1 There are 4.7 million unpaid carers in England, who provide the bulk of support to people who are disabled, older or who have a chronic health condition and need support.² The value of their support is worth a staggering £152 billion a year in England, equivalent to a second NHS.³

2.2 Millions of people who have experience of providing unpaid care bear the negative effects of social care workforce shortages and a lack of funding for social care. Many currently caring face unrelenting demands and too often feel isolated, unsupported and undervalued while providing care for a family member. Importantly, a shortage of social care affects unpaid carers’ ability to work and negatively affects their health and wellbeing.

2.3 Many carers are not getting the support they need and are entitled to under the Care Act 2014. Some essential services remain unavailable to them that are inaccessible, unaffordable, or insufficient quality.

2.4 Research for Carers Week found that 62% of those who are currently providing or those who have previously provided unpaid care said that they had no choice in taking on the role because no other care options were available – this is around 10 million people.⁴ Given that a majority of unpaid carers do not

¹ <https://careandsupportalliance.com/about-us/>

² Census 2021

³ Valuing Carers 2021/22

have a choice about providing unpaid care and the negative impacts of providing unpaid care, there is an imperative for Government to ensure that families are better supported.

2.5 A lack of investment in social care:

- (i) Reduces a carer's ability to juggle work and care, impacting long term on pensions.
- (ii) Increases a carer's likelihood of being in poverty.
- (iii) Negatively affects carers' health and wellbeing, with poorer health and wellbeing outcomes – with carers putting off health treatments as a result.
- (iv) Reduces the ability to prevent health inequalities
- (v) Results in low numbers of carers getting vital breaks.
- (vi) Reduces support directly to unpaid carers, with carers' assessments which feel meaningless and poorer /reduced outcomes for unpaid carers.
- (vii) Increases carers' loneliness and isolation.
- (viii) Reduces gender and disability equality.
- (ix) Increases avoidable emergency admissions to the NHS.
- (x) Negatively impacts discharge from hospital placing additional pressure on unpaid carers.
- (xi) Negatively impacts directly on workers personal lives who work for the NHS and social care who are carers i.e. 1 in 3 workers juggling work and care.
- (xii) Reduces UK business/employer productivity through loss of staff or ill-health of staff in the workplace.
- (xiii) Increases public sector costs of benefits for carers who have no choice but to give up work to care, lost tax revenue and a decrease in family financial resilience throughout their lifetime.
- (xiv) Decreases the likelihood of successful outcomes for other policies such as the white paper; Get Britain Working.

2.6 Carers UK is calling on the Government to take urgent action on social care, including:

- (i) Developing a clear plan for social care reform, including improving availability, quality and affordability that sits alongside and works with the NHS 10 Year Plan.
- (ii) Recognising that social care support is fundamental for improving carers' ability to stay in and return to work and well as reducing health inequalities.
- (iii) Providing long-term, sustainable funding to ensure all carers and those they support can access high-quality social care services when they need them.
- (iv) Ensuring that Local Authorities have sufficient and sustainable funding to enable them to fulfil their duties to carers under the Care Act 2014.

- (v) Developing a social care workforce strategy to ensure that there are enough skilled social care staff to provide social care, lessening the amount of unpaid care that family and friends are currently providing.
- (vi) Investing in carers' breaks so that carers are able to access the breaks they need and improve their mental and physical health and wellbeing.
- (vii) Developing a new National Carers Strategy, backed by significant investment, which sets out future commitments to supporting unpaid carers and identifies specific actions that focus on delivering tangible progress and additional support for carers, their families, and those they care for.
- (viii) Introducing a right to one week's paid Carer's Leave to ensure that unpaid carers with lower incomes are able to take leave to arrange or deliver short term planned care.

3. Committee Question 1. How much is inaction on adult social care reform costing the NHS and local authorities, and what impact does this have on patients and the public?

3.1 Inaction on adult social care reform is having a profound effect on unpaid carers, arguably the biggest impact. Census 2021 found that unpaid carers are providing more care than before. 1.5m unpaid carers across England and Wales are now providing over 50 hours of care every week, over 152,000 more than a decade ago.⁵ The amount of unpaid care provided is likely to be increasing due to the lack of affordable, reliable and good quality social care available, with families left to plug the gaps in formal provision. This has a significant impact on carers' ability to participate in paid work and contribute to the wider economy, as well as being able to look after their own health and wellbeing.

3.2 The amount of support directly received by unpaid carers in England is also falling. SALT data shows that in 2023-24, 360,815 carers were either supported or assessed/reviewed by the local authorities. However, 70% (252,875) of carers were only given information, advice and other universal services/signposting, or did not get any direct support at all. Local authority gross expenditure on support to carers was £183 million in 2023-24, a drop of 6.1% from £195 million in 2022-23.

Insufficient funding for social care is reducing unpaid carers' ability to work

3.3 Around 600 unpaid carers leave paid work every day because of providing unpaid care.⁶ With the right support this number could be reduced, including support with breaks, good replacement care and better workplace rights. Staying in work not only has advantages for carers' household finances but also for their own mental health and wellbeing.

A lack of social care and breaks contributes to carers' burnout and ill-health

3.4 The inaction on social care reform is a key factor contributing to the number of unpaid carers experiencing breakdowns and admissions to hospital, due to being run down and unable to take regular and sufficient breaks. ONS analysis found that the risk of one or more accident and emergency (A&E) attendances was higher for female unpaid carers who were providing increased hours of unpaid care,

⁵ <https://www.carersuk.org/press-releases/census-2021-data-shows-increase-in-substantial-unpaid-care-in-england-and-wales/>

⁶ <https://www.carersuk.org/media/no2lwyl/juggling-work-and-unpaid-care-report-final-web.pdf>

compared to female non-carers, after adjusting for demographic and socioeconomic characteristics.⁷ For a second year in a row, Directors of Adult Social Services ranked burnout as the number one contributing factor to increases in carer breakdown over the past 12 months.⁸

3.5 Many carers tell us they do not have enough breaks. This not only affects their health and wellbeing but also prevents them from seeking necessary treatment and tests when they do develop health issues of their own. Appointments are cancelled or not made until their condition gets worse.

3.6 In 2023, 47% of carers providing substantial care told Carers UK they needed more breaks or time off from caring. This increased to 58% for carers who said their health was bad or very bad. People caring for over 50 hours a week were much more likely to say they needed a break from caring compared to those caring for less than 50 hours (54% compared with 35%).⁹

A lack of social care impacts on unpaid carers ability to have health treatments

3.7 Carers often report how their physical and mental health has deteriorated since they started providing unpaid care. 59% of carers have developed a health condition since they started caring. 29% said they already had a health condition but this has been made worse by caring. Key things that carers said would have prevented this was getting a good nights' sleep (74%), regular breaks (72%), having more time to monitor their health and wellbeing and identify new symptoms (61%) and getting more practical support with caring (57%).

3.8 70% of carers have postponed or cancelled a health appointment, test, scan, or treatment because of caring. The top reason for this was not having support from family and friends to attend appointments (56%), followed by 43% who said they couldn't find suitable replacement care services, and 36% who said they didn't know what support they could access.¹⁰ By delaying their own treatment until their health deteriorates further is likely to cost the NHS and local authorities much more, both in treatment costs for more complex cases and also in the necessary social care provision when the carer is no longer able to cope and provide care.

A shortage of social care increases emergency admissions or unplanned visits to hospital

3.9 In our State of Caring survey 2022 we asked carers whether the person they cared for had experienced an emergency admission or unplanned visit to hospital in the last year, and whether anything could have prevented this.¹¹ 16% said more support from social care services could have prevented this, and 22% said higher quality and more reliable care and support could have prevented this.

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<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/bulletins/unpaidcareexpectancyandhealthoutcomesofunpaidcarersengland/april2024#:~:text=General%20health%20status,based%20on%20age%2Dadjusted%20percentages>.

⁸ <https://www.adass.org.uk/wp-content/uploads/2024/07/ADASS-Spring-Survey-2024-FINAL-1.pdf>

⁹ State of Caring Survey on health, 2023.

¹⁰ Survey with carers conducted in November 2024, including 450 responses.

¹¹ <https://www.carersuk.org/media/p4kblx5n/cukstateofcaring2022report.pdf>

3.10 Almost all carers providing substantial care feel that there should be social care reform that runs alongside healthcare reform. Carers UK ran a survey for unpaid carers in November 2024 as part of the NHS 10 Year Plan engagement. 97% of carers said it was 'very important' that the future of adult social care is considered alongside the future of the NHS. The main issues with social care services that carers said are affecting them now are social care services not linking up properly with the NHS (51%) and poor coordination of care services (50%). When we asked carers what they were worried about in the future, the main concerns were services being reduced or cut (48%) and rising charges for social care services (45%).

3.11 It is clear from carers' views that an investment in social care would improve carers' well-being and health, as well as supporting the NHS.

4. Committee Question 2. What NHS and local authority service reforms are not happening as a result of adult social care pressures, and what benefits are patients and the public missing out on?

4.1 The lack of focus on social care reform has an impact on the quality of services offered by the NHS. The lack of social care provision means that there are delays in hospital discharge which in turn affects waiting times for treatment for other patients. The NHS is already under considerable pressure, operating at near its full capacity, especially during the winter months.

4.2 These higher waiting times mean that it is difficult to prevent conditions from getting worse and costing the NHS more due to increased complexity and severity. Even when carers can find replacement care to allow them to attend appointments, waiting times in the NHS often mean a delay in treatment. Just under a third (30%) of carers waiting for hospital treatment or assessment for themselves had been waiting for over a year.¹² More complex cases are also more likely to end up being admitted to hospital and needing increased medication.

5. Committee Question 3. What is the cost of inaction to individuals and how might people's lives change with action on adult social care reform?

5.1 The cost of inaction for unpaid carers is significant and enduring in terms of health, wellbeing, paid work, finances and income. Their lives could be significantly improved with more investment in adult social care reform. Carers UK's State of Caring 2023 survey found that 47% of carers said they needed more breaks or time off from caring. 44% of carers said they had put off health treatment because of their caring role.¹³ 36% of carers disagreed that the social care support they could access met their needs and the needs of the person they care for. 50% of carers said they were receiving support with their caring roles from family and friends – a higher proportion than those receiving support from social care services (37%).

5.2 Significant numbers of carers experience challenges with their mental health and wellbeing and the lack of support from social care to allow them to take sufficient breaks is likely to be exacerbating this. Over three quarters (79%) of carers feel stressed or anxious, and half of carers (49%) feel depressed. Most worryingly, over a third of carers (36%) whose mental health was bad or very bad said they had thoughts related to self-harm or suicide.¹⁴

¹² State of Caring, 2022.

¹³ https://www.carersuk.org/media/xgwlj0gn/soc23-health-report_web.pdf

¹⁴ https://www.carersuk.org/media/xgwlj0gn/soc23-health-report_web.pdf

5.3 The pressure to discharge patients from hospital is also resulting in poor practice towards carers where the law and policy guidance is not always being followed. Only 14% of unpaid carers providing substantial care said that they received sufficient support to protect the health and wellbeing of the person they cared for and their own. Only 14% said that they felt under no pressure to care and felt fully supported. Only 18% had a carer's assessment at the point of hospital discharge¹⁵, despite guidance and the Care Act 2014.

5.4 Good quality, accessible and affordable social care is essential to supporting unpaid carers to continue with some paid work or be able to return to work and to their careers. 69% of carers who are employees said that more affordable, accessible and reliable replacement care for the person they care for would help them to juggle work and care.¹⁶ 50% of carers who had given up work to care said that not being able to find suitable replacement care for the person they care prevented them from returning to work, and 39% said that not being able to find affordable replacement care prevented them from returning to work.¹⁷ Getting social care right is therefore paramount to also supporting more carers to return to and stay in work, supporting carers to maintaining their workplace skills as well as supporting the wider economy. The Government's ambition of achieving an 80% employment rate won't be able to be possible without a focus on and prioritisation of social care provision to support the 5.8 million unpaid carers across the UK.

5.5 Being out of work also increases carers risk of falling into poverty, as well as the financial position of their wider household. Unpaid carers have a 50% higher risk of living in poverty compared to non-carers and being out of work is the strongest predictor of poverty for this group.¹⁸

5.6 The lower (£14,250) and upper (£23,250) savings limits in social care eligibility assessments have not changed for many years, in line with inflation, since at least the 2010 Spending Review.^{19,20} The consequence of this is that more people are now required to fund their own social care and fewer people are eligible for state support. The cost of care is often being paid out of people's disability related benefits. The cost of care itself has also increased in recent years, putting more pressure on households with disabilities as well as on unpaid carers who need to take a break.

5.7 Carers are not properly having their rights addressed under the Care Act 2014. The central ambition of the Care Act 2014 under s. 1 is to improve and promote wellbeing. Carers UK will be publishing new findings in 2025 which looks at the extent to which unpaid carers' are getting carers' assessments and the outcomes set out in those assessments. Our published work to date has found support for carers falling short, as a result of underfunding of social care.

¹⁵ State of Caring 2023, impact of caring on health, Carers UK, November 2023

¹⁶ <https://www.carersuk.org/media/qslsly1mc/state-of-caring-employment-web-2024.pdf>

¹⁷ <https://www.carersuk.org/media/qslsly1mc/state-of-caring-employment-web-2024.pdf>

¹⁸ https://www.carersuk.org/media/dnxerxqv/poverty_financial_hardship_uk_web.pdf

¹⁹ https://assets.publishing.service.gov.uk/media/5a7ce2a8e5274a2c9a484b61/dh_123875.pdf

²⁰ <https://www.gov.uk/government/publications/social-care-charging-for-local-authorities-2024-to-2025/social-care-charging-for-care-and-support-local-authority-circular#:~:text=A%20person%20with%20assets%20below,for%20the%20lower%20capital%20limit.>

6. Q4. Where in the system is the cost of inaction on adult social care reform being borne the most?

6.1 Unpaid carers are arguably bearing the biggest cost in many ways, in particular in terms of paid work, financially and in terms of their health and wellbeing. They are providing more care than ever before in order to plug gaps in social care and are facing the consequences of this, in terms of their own health and wellbeing as well as their ability to participate in paid work and live free of serious poverty. Unpaid care is disproportionately provided by women. There has been an increase in the number of people providing substantial care (more than 50 hours per week) between 2011 and 2021 to a total of over 1.5 million people.²¹

6.2 The impact of a lack of support from social care can have significant implications on carer finances. Carers who are not well supported and cannot find reliable and affordable replacement care may need to make the difficult decision to give up or cut down their paid work. This comes with significant risks for their own financial wellbeing as well as the income level of the whole household. Being out of work is the single strongest quantitative predictor of poverty for unpaid carers.²² 70% of carers who had given up work to care said they were worried about living costs and whether they can manage in future. Furthermore, carers who were looking after the home/family/dependents full time were more likely to have bad or very bad mental health than those in employment (44% vs 35%).²³

6.3 A significant number of unpaid carers are affected by serious financial hardship: 1.2 million unpaid carers live in poverty, and 400,000 live in deep poverty in the UK. The poverty rate for unpaid carers is 50% higher than for those who do not provide care (27% vs 18%).²⁴

6.4 A lack of support and access to social care services was also found to be one of the key drivers of poverty, according to research by Carers UK and WPI Economics.²⁵ The research found that social services currently struggle to meet the demand for paid care. Having access to affordable and accessible care services, which carers can rely on while they go to work is essential for many people juggling work and care. The high cost and lack of paid care provision leaves many unpaid carers no choice but to provide the care themselves.

6.5 The economic value of contributions made by unpaid carers in the UK is now £184 billion a year. This new research shows there has been a huge increase in the value of unpaid care in the UK – up by £64.9 billion since 2011 – a 29% increase. This increase is because families are providing more hours of care than ever before in all four nations.²⁶ The combined NHS budget across all four nations of the UK was approximately £189 billion - this means that unpaid carers are providing care equivalent to the budget of a second NHS in the UK. This value of unpaid care is also over four times the amount of publicly funded spending on adult social care services.²⁷

²¹ Census 2021.

²² https://www.carersuk.org/media/dnxerxqv/poverty_financial_hardship_uk_web.pdf

²³ State of caring on employment, 2024.

²⁴ https://www.carersuk.org/media/dnxerxqv/poverty_financial_hardship_uk_web.pdf

²⁵ Ibid

²⁶ <https://www.carersuk.org/reports/valuing-carers/>

²⁷ <https://www.carersuk.org/reports/valuing-carers/>

6.6 The complexity of need is increasing. Over 400,000 people are waiting for care to begin, or an assessment of their needs. This challenging financial situation, coupled with the increasing complexity of need, means that Directors of Adult Social Care are losing confidence in delivering on their legal duties. 90% of Directors indicated that they are either partially confident or have no confidence that their budgets will be sufficient to fully meet their statutory duties in 2024/25.²⁸

6.7 88% of Directors agreed that unpaid carers are coming forward with an increased level of need in their local area over the past year. Directors ranked burnout as the number one contributing factor to increases in carer breakdown over the past 12 months.²⁹

6.8 Pressures on budgets mean that many unpaid carers are not getting enough support with their caring role beyond signposting. In 2023-24, 360,815 carers were either [supported or assessed/reviewed](#) by the local authorities. However, 70% (252,875) of carers were only given information, advice and other universal services/signposting, or did not get any direct support at all.³⁰

7. Committee Question 5. What contribution does adult social care make to the economy and HM Treasury and how might this change with action on reform?

7.1 Having a reliable, affordable and high-quality social care system would improve unpaid carers' ability to work, particularly in tandem with other support in workplace rights such as the introduction of paid Carer's Leave by the Government. It would also improve UK employers' productivity and reduce business costs.

7.2 Carers UK set up and runs an employer forum, Employers for Carers, promoting good practice in supporting carers within the workplace. This has over 230 members covering nearly 3 million employees. 63% of employers responding to the Employers for Carers survey said a key issue for their employees is navigating the social care system can be challenging and easy access to information on support is particularly important to the health and wellbeing of working carers who are often time poor and under considerable pressure.³¹

7.3 We have already set out the evidence from unpaid carers about the importance of social care in supporting them to stay in work and supports their health and wellbeing. A lack of social care then directly impacts on employers when this is not in place. The impact of staff turnover, absence, and stress because of juggling work and caring unsupported could be costing UK businesses over £3.5 billion every year, so there are significant savings to be made by better supporting employees to combine work and caring.³²

7.4 Between 2010-2020, people aged 46-65 were the largest age group to become unpaid carers. 41% of people who became unpaid carers were in this age group (Petrillo and Bennett, 2022).³³ Women have a

²⁸ <https://www.adass.org.uk/wp-content/uploads/2024/07/ADASS-Spring-Survey-2024-FINAL-1.pdf>

²⁹ <https://www.adass.org.uk/wp-content/uploads/2024/07/ADASS-Spring-Survey-2024-FINAL-1.pdf>

³⁰ [Carers support by local authorities - NHS England Digital](#)

³¹ Supporting Carer Health and Wellbeing in the Workplace, Carers UK and Employers for Carers, 2020.

<https://www.employersforcarers.org/media/cxnflyrq/supporting-carer-health-and-wellbeing-in-the-workplace.pdf>

³² The business case for supporting unpaid carers, Employers for Carers.

https://www.employersforcarers.org/media/zjkj3zrw/business_case_new.pdf

³³ Petrillo, M., Bennett, M.R., and Pryce, G. (2022) Cycles of caring: transitions in and out of unpaid care. London:

50:50 chance of providing unpaid care by the time they are 46, men by the time they are 57 – 11 years later.³⁴ Women are significantly more likely to working part-time juggling work and long term care. The impact of a lack of adult social care in promoting unpaid carers' employment has a distinctively gendered impact. Caring is a factor in a significant number of over-50s giving up work to care. With every rise in the state pension age, more people of working age will be juggling work and care.

7.5 25% of unpaid carers providing substantial care in our State of Caring 2024 survey said that they had taken lower paid work or turned down a promotion due to the demands of caring, working below their potential.³⁵

7.6 Analysis by Age UK, building on work by the LSE, has estimated that the value to the economy of carers being able to work is £5.3 billion.³⁶

7.7 For UK businesses there are significant productivity costs through the loss of unpaid carers as employees. It costs on average a year's salary to replace an employee, with a combination of logistical costs i.e. direct costs of replacement and productivity costs whilst the new worker reaches optimal productivity.³⁷ There is also a productivity impact on colleagues working in teams with absences, for example across the NHS and social care where there are large vacancy rates. Given that 1 in 3 NHS workers is also an unpaid carer³⁸ – many of whom will rely on good quality adult social care in order to juggle work and care, there are wider implications for some of the Government targets and missions if there is not a dedicated programme for supporting unpaid carers in the workplace and good investment in social care. The NHS 10 Year Plan must have a strong set of programme recommendations for supporting the NHS workforce where they are juggling work and care.

7.8 Better investment and reform in social care would:

- Promote equality for women in particular.
- Reduce business and employer costs in relation to ill-health brought about by the stress of caring.
- Increase business and employer productivity through staff retention.
- Increase the talent pool from which employers are able to recruit.
- Increase the working span of individuals, enabling them to contribute more to pensions during their working life.
- Alongside a targeted programme of support for NHS staff, reduce staff turnover.
- Make the aspirations and rights of the Care Act 2014 a reality.

Carers UK.

³⁴ Dr Yanan Zhang and Dr Matthew R. Bennett, "Will I Care? The Likelihood of being a carer in adult life, Carers UK and University of Birmingham, Centre for Care.

³⁵ Carers UK, State of Caring 2024, impact on employment. <https://www.carersuk.org/media/qjsly1mc/state-of-caring-employment-web-2024.pdf>

³⁶ Supporting working carers; the benefits to family, business and the economy, HM Government, Carers UK and Employers for Carers. 2013

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/232303/Supporting_Working_Carers_Final_Report_accessible.pdf

³⁷ <https://www.oxfordeconomics.com/wp-content/uploads/2023/05/cost-brain-drain-report.pdf> 2014

³⁸ NHS Staff Survey 2023

8. Committee Question 6. To what extent are the costs of inaction on adult social care reform considered by the Government when evaluating policies, including within the Budget and Spending Reviews? How should these costs be assessed and evaluated?

8.1 Unfortunately, we do not know exactly which costs are considered as part of the process of Government's evaluation of policies and allocation of funding to social care because there is a lack of transparency. The Government needs to be more open and transparent with the social care sector so that we can understand the scale of the problem and work together to agree a plan. We fully support the Access Social Care campaign for greater transparency on Government decision-making in this area.

8.2 There is also a lack of alignment between the policies of different Government departments which are often working at cross purposes, with contradictory priorities. For example, whilst the Department for Work and Pensions has the ambition to get more people back into work, there is no urgent action to ensure that the social care sector is there to support unpaid carers to return to and stay in paid work alongside their caring role. Whilst it is encouraging that the Get Britain Working White Paper has been published by Secretaries of State from four separate government departments, including the Secretary of State for Health and Social Care, we believe there needs to be a definitive plan for social care which aligns with the above paper.

December 2024