

## Written evidence submitted by Carers Trust (ASC0122)

### Health and Social Care Committee inquiry into cost of inaction on adult social care reform

#### Introduction

Carers Trust is the UK infrastructure organisation for local carer organisations. We reach over one million unpaid carers through our network of 131 local carer organisations. We cover about 90% of local authority areas, collectively employ 4,000 staff and work with 4,000 volunteers. Our work covers grant-making, programme delivery, policy and research, all whilst supporting our local partners to deliver much needed services to unpaid carers.

**A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction, cannot cope without their support. As part of this role, carers may also play vital roles in delivering virtual wards, hospital discharge and supporting people to be looked after at home and on NHS waiting lists.**

#### Reason for submitting evidence

Carers Trust believes that carers are integral to the sustainability of health and social care systems. Despite their essential role, currently, not enough carers get the support they need for their own needs. Without action to reform adult social care, carers will continue to bear the brunt of unmet need in the system, exacerbating the crisis in care provision.

Carers are vital to both the NHS and social care. Carers enable people to live at home for longer, facilitate hospital discharge and care for millions of people with support needs up and down the country. However, without targeted reforms, the strain on carers will intensify, leading to greater costs for the NHS and social care as carers themselves become unable to continue in their role due to burnout or financial hardship.

We are submitting evidence to highlight the critical need for investment in social care to support carers, ensure equitable access to local services, and mitigate the long-term societal and economic impacts of inaction. We would welcome the opportunity to provide oral evidence to the Committee on behalf of both the local services we work with and the million carers they reach.

## Summary

Carers play a vital role in supporting the NHS in meeting its objectives around waiting lists, virtual wards and hospital discharge, allowing people with care and support needs to return—and stay—at home. Carers also provide the vast majority of care in the country, and need support if they are to continue to do so.

We know that local carer organisations are crucial to ensuring that individuals can access the support they need to continue in their caring role sustainably, whilst maintaining their own needs. However, inaction of social care reform poses a significant risk to the sustainability of these services. This is exacerbated by the proposed changes on National Insurance Contributions and National Living Wage which we believe will cost the Network £7.5million a year. Reform must ensure that services are sufficiently funded to provide tailored and effective support to carers.

### 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?

- Inaction on adult social care reform is creating an increased reliance on unpaid carers to fill the gaps in social care, with many caring for more than 50 hours per week. Without reform, carers will more be vulnerable to burnout and experiencing adverse effects to their health due to excessive and inappropriate caring situations.
- The lack of sufficient social care also has an impact on the delivery of NHS services including delays to hospital discharge and long waiting lists. There are 7.5 million people on waiting lists for treatment, with many of them relying on support from unpaid carers in the interim.
- The lack of social care reform has led to a huge level of unmet need across the country. NHS leaders have also raised concerns that the lack of capacity in social care is placing patient's safety at risk.
- With a growing need for social care and an increase in reliance on carers undertaking unsustainable caring roles, the NHS and local authorities risk becoming unfit for the future.

### What NHS and local authority service reforms are not happening because of adult social care pressures, and what benefits are patients and the public missing out on?

The three shifts recommended by the Darzi Review will not materialise without reforms to social care and direct support for unpaid carers.

- There is an increasing need for crisis support which places pressures on acute services and hinders progress towards shifting care from hospital into the community. There must be sufficient funding to ensure that existing services can be maintained whilst making the transition to community based health care.
- A lack of funding in social care makes it challenging for local services to make the shift from treatment to prevention in alignment with the NHS. Currently local carer organisations are forced to focus resources on carers with the most acute needs due to funding and capacity limitations.
- The current inaction on social care reform prevents services, including those provided by local carer organisations from evolving and expanding to be able to offer digital support alongside their existing contracts, hindering the shift from analogue to digital within social care.

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

- Caring can have a significant impact on the health and wellbeing of carers. Without support, carers are more vulnerable to developing burnout or their own health conditions. Reform on social care will help to

ensure caring is recognised as a social determinant of health and carers can access support for their own needs.

- Lack of sufficient social care also affects a carer's ability to work. Many carers have left employment or reduced their hours to provide care. With more social care available, many individuals will be able to return to or remain in work if they choose.
- There are over 1 million young carers in the UK, many of whom experience disadvantages compared to their peers. Young carers need their health and wellbeing to be protected to ensure caring does not affect their life outcomes.

#### **Where in the system is the cost of inaction on adult social care reform being borne the most?**

- Local support services are stretched to their limit but despite this, they continue to be seen as the 'cloth to be cut'. Without action on adult social care reform many local carer services will close, with more reducing the number of carers they can support or the services they provide.
- The increase in pressures and lack of investment in social care reform means that individuals, such as unpaid carers are unable to access tailored support, relevant to their needs and circumstances.
- With no contract uplifts, local carer organisations face ongoing workforce challenges, such as difficulty retaining staff, especially due to the increases in employer contributions to National Insurance following the Autumn Budget 2024.

#### **What contribution does adult social care make to the economy and HM Treasury and how might this change with action on reform?**

- Adult Social Care contributes £68.1 billion to the economy each year. The ONS estimates unpaid carers provide care worth an additional £57 billion per year.
- Social care also provides socioeconomic benefits amounting to £265 million.
- The number of people employed within the social care sector suggests that social care should be seen as an "anchor" institution alongside the NHS.
- Reform would improve the lives of carers and those they support but would also benefit HM Treasury by increasing tax revenues, reducing welfare needs, and creating a more sustainable approach to meeting the UK's growing care demands.

### **Full Consultation Response**

#### **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?**

It was recognised in Lord Darzi's review of the NHS in England that "too many people end up in hospital, because too little is spent in the community"<sup>1</sup>

#### **Increased reliance on unpaid carers**

According to the Census, there are at least 5 million carers in England.<sup>2</sup> This is already 9% of the entire population but is likely to be underestimated as people often struggle to self-identify as carers. The ONS

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<sup>1</sup><https://www.gov.uk/government/publications/independent-investigation-of-the-nhs-in-england>

<sup>2</sup><https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/articles/unpaidcarebyagesexanddeprivationenglandandwales/census2021>

estimates unpaid carers provide care worth £57 billion per year.<sup>3</sup> Without unpaid carers, both the NHS and social care would collapse. Carers provide the vast majority of care in the country, and need support if they are to continue to do so.

The London School of Economics suggest that by 2035 there will be demand for 8 million unpaid carers but only 6 million will be available. This is because the number of people in late old age is set to increase much faster than the number in the age groups most likely to offer care. The need to plan ahead and ensure appropriate workforce and provision are in place is therefore an urgent requirement.<sup>4</sup>

The evidence is clear that carers play a crucial role in providing care for the people they care for, in helping the NHS and social care function and achieve its aims. Despite this, a 2023 Carers Trust survey revealed that over a third of carers 'disagreed' or 'strongly disagreed' that the NHS understands their caring responsibilities or received appropriate support.<sup>5</sup>

There has been a huge rise in the number of people providing 50 and 100hrs of care per week, and the result is many carers reaching breaking point. The University of Birmingham recently found 41% of parent carers of disabled children had thought about suicide, while the mental health of carers as a whole is at an all-time low. For every carer that reaches and passes breaking point, the state has at least two people it has to give more support to - the carer and the cared for.

Unpaid carers are already recognised as key to virtual wards<sup>6</sup> and an important part of enabling hospital discharge or keeping those on waiting lists out of hospital in the first place.

Lord Darzi recognised the role of carers in his report this year, stating *"A fresh approach is needed which regards unpaid carers both as people with their own needs where caring is a significant factor in their lives, but also as a provider of care who should be treated as an equal partner. The current paradigm leads to poorer outcomes for people needing care, for carers, and for the health service. A different approach is needed."*<sup>7</sup>

This is not new - commenting on the results of the Confederation survey of NHS leaders Lord Victor Adebowale, (chair of the NHS Confederation) said *"Decades of delay and inertia have left social care services chronically underfunded and in desperate need of more support."*<sup>8</sup>

There is an undisputable interconnected relationship between the NHS and social care. NHS reforms will not succeed without reform of social care. Without reform of social care, there will continue to be extra pressure placed on the NHS. The cost of not reforming social care is felt within the NHS through delayed discharge, lower productivity, increased waiting times, poor health across the population and an increased reliance on carers to prop up social care.

## **Hospital Discharge**

The NHS delivery plan for urgent and emergency services acknowledges the need to improve hospital discharge processes and increase capacity in short term /intermediate and social care.<sup>9</sup> According to the

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<sup>3</sup><https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/articles/unpaidcarersprovidesocialcareworth57billion/2017-07-10>

<sup>4</sup> Saloniki, E et al. The Impact of Formal Care on Informal Care for People Over 75 in England, Personal Social Services Research Unit, University of Kent, 2019.

<sup>5</sup> [https://carers.org/downloads/adult-carer-survey-report-2023--full-uk-report-\(english\).pdf](https://carers.org/downloads/adult-carer-survey-report-2023--full-uk-report-(english).pdf)

<sup>6</sup> [https://www.england.nhs.uk/wp-content/uploads/2022/04/B1382\\_supporting-information-for-integrated-care-system-leads\\_enablers-for-success\\_virtual-wards-including-hos.pdf](https://www.england.nhs.uk/wp-content/uploads/2022/04/B1382_supporting-information-for-integrated-care-system-leads_enablers-for-success_virtual-wards-including-hos.pdf)

<sup>7</sup> See footnote 1

<sup>8</sup> <https://www.nhsconfed.org/news/nhs-leaders-warn-social-care-workforce-crisis-risks-patient-safety>

<sup>9</sup> <https://www.england.nhs.uk/wp-content/uploads/2023/01/B2034-delivery-plan-for-recovering-urgent-and-emergency->

Nuffield Trust, the most common reason for delay for patients who had been in hospital for seven days or more was waiting for further support provided at home (23%).<sup>10</sup>

The findings of the NHS Confederation survey highlight that more than four in five NHS leaders warn that the absence of care packages for people to be able to return home or be moved into a care home is the main reason why medically fit patients are stuck in hospital longer than they should be.<sup>11</sup>

The Lord Darzi review highlighted that whilst there has been a focus on shifting treatment from hospital to community for several years, out of hospital components which enable this shift, including social care, have declined.<sup>12</sup> The Nuffield Trust research supports this, showing that delays in discharge from the hospital arise when the process is slow or when capacity is constrained in out-of-hospital care.<sup>13</sup> As a result of the delays to hospital discharge, there has been a fall in productivity within the NHS, affecting the flow of patients including those waiting to be discharged from hospital and those on waiting lists.

### Waiting lists

The cost of inaction on social care reform is directly linked to the reduction of outpatient appointments and longer waiting lists. According to analysis by NHS, there are 7.5 million people on an NHS waiting list. 26% of those people are unpaid carers, while many more of them rely on unpaid carers to manage their health in the interim.

According to the Lord Darzi review, “the dire state of social care” means 13% of NHS beds are occupied by people waiting for social care support or care in more appropriate settings.<sup>14</sup> The consequence of this is that:

- There are 7% fewer outpatient appointments for each consultant per day
- There is an 18% decrease in activity for each clinician working in emergency medicine

### Cost of negative health outcomes for carers

Carers must be recognised as patients too. According to the NHS Long Term Plan: Stronger NHS action on health inequalities, “carers are twice as likely to suffer from poor health compared to the general population, primarily due to a lack of information and support, finance concerns, stress and social isolation”.<sup>15</sup> The Census data<sup>16</sup> reinforces this by highlighting that

- A higher percentage of unpaid carers reported having a disability as defined by the Equality Act (27.9%) compared to non-carers (17.5%).
- A higher percentage of unpaid carers reported having very bad and bad health (7.2%) compared to non-carers (5.4%) and a lower percentage of unpaid carers reported having good and very good health (71.9%) compared to non-carers (82.0%).
- Almost half (48.6%) of unpaid carers reported at least one adverse health effect of providing care.

The National Institute for Health and Care Research found that caring also has a negative impact on the physical and mental health of Young Adult Carers. It is estimated that each Young Adult Carer costs an additional £289 to the health service than their non-caring peers per year.<sup>17</sup>

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[care-services.pdf](#)

<sup>10</sup> <https://www.nuffieldtrust.org.uk/resource/delayed-discharges-from-hospital>

<sup>11</sup> <https://www.nhsconfed.org/news/nhs-leaders-warn-social-care-workforce-crisis-risks-patient-safety>

<sup>12</sup> See footnote 1

<sup>13</sup> See footnote 10

<sup>14</sup> See footnote 1

<sup>15</sup> <https://www.longtermplan.nhs.uk/online-version/chapter-2-more-nhs-action-on-prevention-and-health-inequalities/stronger-nhs-action-on-health-inequalities/#:~:text=Carers%20are%20twice%20as%20likely%20to%20suffer%20from,and%20support%2C%20finance%20concerns%2C%20stress%20and%20social%20isolation>

<sup>16</sup> See footnote 2

<sup>17</sup> [https://www.sscr.nihr.ac.uk/wp-content/uploads/SSCR-research-findings\\_RF108.pdf](https://www.sscr.nihr.ac.uk/wp-content/uploads/SSCR-research-findings_RF108.pdf)

Without support, carers health and wellbeing will continue to deteriorate. This has a negative impact on the carer and may lead to carer burn out which will mean expensive, unplanned social care or NHS interventions for the carer and the person with support needs.

If carers are to continue to play a vital role in helping people to live well for longer, without risk of carer burnout or significant declines in their health, the UK Government must invest in social care including increasing carer support within the community to ensure they are able to continue their caring role without being pushed to the limit and look after their own health needs. The government needs to act to prevent carers' health from deteriorating by identifying carers of all ages early and supporting them in their caring role through social care.

### **Access to social care**

The lack of social care reform has led to massive unmet need across the country. The Care and Support Alliance say that at least 2.6 million people have to go without the care they need.<sup>18</sup> This adds to the demands and pressures on carers, who continue to provide the majority of care across the country.

The Nuffield Trust's report on the decline of publicly funded social care estimates that fewer than half of older people with care needs were receiving publicly funded support.<sup>19</sup>

Their report also highlighted the role of unpaid carers in supporting older adults, with over half of people aged 65 and over who were being cared for only accessing informal care in the period 2016–2022 whilst only under a fifth exclusively accessed formal care. (Around a quarter accessed both formal and informal care.)

However, the inability to access social care does not only apply to older adults. Healthwatch found that up to 1.5 million working age disabled people in England could need social care support but are not accessing it.<sup>20</sup>

In England, there was a higher percentage of unpaid carers in the most deprived areas ( 10%) compared with the least deprived areas (8.%). People living in the most deprived areas also showed a higher percentage of 50 or more hours per week of unpaid care (4.0%) compared with those living in the least deprived areas (1.9%).

The lack of social care reform both exacerbates and cements in wider socio-economic inequalities. Carers are more likely to live in deprived areas. Carers are often financially disadvantaged because of their caring role, and have poorer health outcomes further because of both their caring role and their socio-economic status.

### **Delivery of safe patient care**

Nearly all of the 250 NHS leaders who responded to the NHS Confederation Survey say that the lack of capacity in social care is putting the care and safety of patients at risk.<sup>21</sup>

The findings suggest that it places additional pressure on frontline NHS services and is causing delays to hospital discharge, higher demands on A&E departments and longer ambulance response times. These will all have a negative impact on the quality of care given.

The respondents of the survey shared that the most impactful solution would be to invest in the social care workforce.

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<sup>18</sup> <https://careandsupportalliance.com/budget-2024/>

<sup>19</sup> <https://www.nuffieldtrust.org.uk/resource/the-decline-of-publicly-funded-social-care-for-older-adults>

<sup>20</sup> <https://www.healthwatch.co.uk/blog/2024-07-23/exposing-unmet-need-social-care-your-stories#:~:text=Ten%20years%20since%20the%20Care, and%20going%20to%20the%20shops.>

<sup>21</sup> See footnote 8

### **Inaction risk NHS and local authorities becoming unfit for the future:**

Research from the Joseph Rowntree Foundation projects the number of carers is expected to rise over the next 10 years due to demographic changes with the population getting older and people with long term health conditions living longer with their illnesses. By 2035, there will be 400,000 additional individuals providing 10 or more hours of unpaid care per week, a rise of 11.3% compared to today.<sup>22</sup>

If adult social care remains unreformed, the already high level of unmet need will continue to increase, and informal carers will be expected to shoulder even more responsibilities. An LSE study indicates that the increasing number of unpaid carers will still not be enough to provide care for an ageing population, and the country will have a shortfall in 2035 of 2.3 million unpaid carers.<sup>23</sup>

### **What NHS and local authority service reforms are not happening because of adult social care pressures, and what benefits are patients and the public missing out on?**

The three shifts recommended by the Darzi Review and that the upcoming 10-Year Health Plan is looking to deliver will not materialise without reforms to social care and direct support for unpaid carers.

### **NHS Shift from hospital to community**

The Lord Darzi report highlights how there has been a commitment to moving care away from hospitals and into the community since 2006.<sup>24</sup> However the findings of his review of the NHS in England, it is evident that there is a clear need for existing crisis services, with hospital expenditure and staffing numbers increasing.

There is an argument that currently, individuals are reaching crisis point before being able to access support for their physical or mental health, which is placing pressure on services in acute settings. In the CQC State of Care 2022/2023, 24% of people attended an emergency or urgent setting as they did not think their GP would be able to help with their condition and more attended because they couldn't get a GP appointment quickly enough or their condition had got worse.<sup>25</sup>

### **To shift care from hospitals to communities, reforms must also ensure joined-up services between health and care providers, including voluntary organisations, through Integrated Care Systems (ICSs).**

As a result of the Health and Care Act 2022, Integrated Care Boards have a legal duty to consult carers of all ages, including young carers, in the planning of commissioning arrangements. However, local carer support organisations struggle to participate in their ICS in many areas.

That being said, there are some examples where they have contributed to improving outcomes in population health and healthcare and tackling inequalities in experience and access.

Examples include:

- Suffolk Family Carers is part of the REACT (Reactive Emergency Assessment Community Team) and EIT (Early Intervention Team West) partnerships. These are prevention teams in Ipswich and West Suffolk hospitals, where family carer advisers work alongside other professionals to enable people to stay in their homes rather than have an unnecessary hospital admission.
- Caring Together improved awareness of the ICSs' legal duty to consult carers and improve the identification and support of carers. Cambridgeshire and Peterborough were invited to feed into the development of the joint Health and Wellbeing and Integrated Care strategy, and the ICB is working with

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<sup>22</sup> <https://www.jrf.org.uk/care/the-future-of-care-needs-a-whole-systems-approach>

<sup>23</sup> <https://www.lse.ac.uk/cpec/assets/documents/Economics-of-caring-2018.pdf>

<sup>24</sup> See footnote 1

<sup>25</sup> <https://www.cqc.org.uk/publications/major-report/state-care/2022-2023>

Caring Together to explore how to encourage organisations to sign up for the local Carer Friendly Tick accreditation.

**Local carer organisations are well placed to work within their systems to upskill frontline workers and embed carers as a priority at a strategic level across the ICS.**

Given the size of the carer population and the expected rise in numbers, Carers Trust wants to see each ICS footprint working with local authorities to produce local needs assessments of unpaid carers. Unpaid carers are vital to the fabric of the local health and care system, so local areas should have an established plan for how they will support unpaid carers – both in their caring role and for their own health.

Reform of social care which alleviates the persistent pressures on adult social care will enable the NHS, local authorities, and other organisations to support carers, ensuring that carers are empowered, well-informed, and prepared to provide care, reduce emergency incidents, and look after their own needs.

**NHS Shift from treatment to prevention**

Due to the existing financial pressures on adult social care, many services including those provided by local carer organisations, are unable to make the transition from treatment to prevention in alignment with the NHS.

The Adult Social Care Activity and Finance Report, England, 2022-23 found that there has been a 13% reduction in direct support provided to carers over the time period 2018-23.<sup>26</sup> This is a false economy for local authorities, local carer organisations and the wider health and care system.

The impact of the increasing pressures within adult social care is that organisations are forced to reduce their services and focus resources on carers with the most complex challenges or who are in crisis - sometimes at the expense of preventative support for those who have lower needs. According to the ADASS Spring Survey 2024, over half of Directors (51%) are concerned about the sufficiency of their budgets to meet their legal duties relating to prevention and wellbeing in 2024/25<sup>27</sup>

The Hewitt review (April 2023) raised the concern that the opportunity to focus on prevention may be delayed until the pressures upon the NHS had been addressed, considering prevention measures as ‘nice to have’. The review urges that must change that prevention must be prioritised.

When speaking to the local carer organisations in our network, they told us

- 80% of the local carer services in Carers Trust’s network agree that unmet need of carers is growing
- Statutory funding per carer across the Carers Trust network of local services has fallen 13% in real terms since 2021/22
- In 2023/24 Local authorities paid local carer services in Carers Trust’s network £78 per each registered carer – equivalent to 1 day’s work at National Living Wage.
- The NHS paid local carer services in Carers Trust’s network £12 per carer registered for 2023/24, with minimal change since 2020/21

**Without reform to social care, carers will inevitably miss out on the benefit of support to help them live well with a caring role.**

We want to see carers' own health needs prioritised across the NHS and Social Care. Action on social care, including measures to support carers’ health would help to ensure carers needs are prioritised. For example,

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<sup>26</sup> <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2022-23>

<sup>27</sup> <https://www.adass.org.uk/wp-content/uploads/2024/07/ADASS-Spring-Survey-2024-FINAL.pdf>



carers should be eligible for an Annual Health Check where they have the opportunity to speak about the impact of their caring role and talk about support for their health and wellbeing.

### **NHS Shift from analogue to digital**

Research and insights from the Carers Trust network indicates that awareness, personalisation (caring for different support needs will require different digital solutions), accessibility (digital skills and infrastructure) and integration with existing health and care services to ensure take up and impact for carers, are all barriers to take up for unpaid carers. The current inaction on social care reform prevents services, including those provided by local carer organisations from evolving and expanding to be able to offer digital support alongside their existing contracts.

There is also a perceived fear that digital solutions might substitute other forms of support that carers are already receiving which makes carers hesitant to engage unless assured these solutions will not affect their rights in other statutory support such as respite care, access to training and work-life balance measures. Without sufficient funding, local carer organisations are often required to focus their resources, so it is not unlikely that, to offer digital solutions other forms of support must be cut.

Worryingly, the risks are that digital may exacerbate existing inequalities- those who are likely to need services most, who are more likely to be digitally excluded, may find themselves prevented from accessing them. For example, older people with protected characteristics – such as Black, Asian and Minority Ethnic older people or older people with disabilities- often face additional barriers in terms of language and accessibility. Currently research shows that health inequalities persist (or even increase) when digital technologies are employed.

To enable action on reform of social care in alignment with the NHS's shift from analogue to digital, local health and care commissioners and providers should:

- Ensure there any future digital element of support will connect carers into the local ecosystem of support, such as their local carer centre.
- Support carers to access digital support. Some carers may need support to have the hardware (laptop, tablet, etc) needed to access digital support, whilst others may need support with the cost of data.
- Ensure that 'data poverty' and low broadband are not an additional barrier for carers to access digital support
- Provide digital literacy sessions to enable unpaid carers to gain confidence

### **What is the cost of inaction to individuals and how might people's lives change with action on adult social care reform?**

#### **Impact on carers health**

Unpaid carers are a population group with their own specific health needs, experience inequalities, and are a vital part of delivering the health and social care system. Despite this, in Carers Trust's Adult Carer Survey (2023), only around half (55%) of unpaid carers told us they get the support they need to be an unpaid carer.<sup>28</sup>

**Carers face increased health risks due to the physical, mental, and emotional demands of caring. Carers who are in intense caring situations are more likely to experience an adverse impact on their health, life outcomes and ability to provide care.**

The ONS report on understanding health outcomes of unpaid carers<sup>29</sup> found that:

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<sup>28</sup> See footnote 5

<sup>29</sup> <https://www.ons.gov.uk/releases/unpaidcareexpectancyinenglandandwales>

- Almost half (49%) of unpaid carers reported at least one adverse health effect of providing care.
- Carers are 1.4 times more likely to report 'not good health' than non-carers, which increases to 1.7 times when caring for 50+ hours per week.

In the analysis of the most recent GP Patient Survey (2023), it showed that almost 1 in 10 (9%) carers rated their experience as 'poor' or 'very poor', compared to 6% of those who aren't caring, and increase from previous years. It also showed that this number was higher, reaching up to 13% for particular groups of carers such as carers aged 25 and under, carers from the LGBTQIA+ communities, and carers who are Asian.<sup>30</sup>

Carers Trust therefore agree with the Public Health England's review and analysis of the GP Patient Survey which made clear that caring should be considered a social determinant of health. The report found that carers are at increased risk of illness, specifically musculoskeletal conditions, cardiovascular disease, generalised cognitive deterioration and function, and poor sleep.<sup>31</sup> The GP Patient Survey 2024 also shows that "after adjusting for age, sex, ethnicity and deprivation, carers were 16% more likely to be living with two or more long term health conditions than non-carers."<sup>32</sup>

Long term, unsustainable caring roles, and lack of preventative support leaves carers more vulnerable to developing their own health conditions or experiencing carer burnout. In the GP Patient Survey 2024, 70% of carers reported having a physical or mental health condition lasting, or expected to last, 12 months or more.<sup>33</sup> This supports the findings of Carers Trust's Adult Carer Survey 2023<sup>34</sup>

- 60% of adult carers who responded reported having a physical or mental health condition.
- A further 27% of carers who responded were awaiting treatment or support.

Findings from the 2024 ADASS Spring Survey also revealed that 88% of directors reported an increased level of need among carers, identifying carer burnout as the leading contributor to carer breakdown.<sup>35</sup>

### **The need for preventative support**

We also know that financial constraints meant 5% fewer carers were directly supported by local carer organisations last year, despite 88% of people saying the services had improved their quality of life.

Carers Trust's analysis of the Social Care Activity and Finance Short and Long Term (SALT) data shows that in 2023-24, 70% of carers who underwent assessments or reviews (252,875 carers) received only information, advice, or signposting rather than direct support.<sup>36</sup>

Many carers are reaching breaking point which is having a significant impact on their mental health. As previously mentioned, the University of Birmingham recently found 41% of parent carers of disabled children had thought about suicide. The Sutton Trust COMSO study found that Young people with caring responsibilities have a higher prevalence of self harm (25% compared to 17% of non-caring young people) and of those that have experienced self-harm, young carers are twice as likely to attempt to take their own life.<sup>37</sup>

Social care reform would ensure that carers do not miss out on the benefit of help to manage health needs proactively and support to avoid crisis which would reduce reliance on health and social care services long

<sup>30</sup> [https://gp-patient.co.uk/downloads/2023/GPPS\\_2023\\_National\\_report\\_PUBLIC.pdf](https://gp-patient.co.uk/downloads/2023/GPPS_2023_National_report_PUBLIC.pdf)

<sup>31</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/971115/Caring\\_as\\_a\\_social\\_determinant\\_report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/971115/Caring_as_a_social_determinant_report.pdf)

<sup>32</sup> <https://gp-patient.co.uk/surveysandreports>

<sup>33</sup> See footnote 3

<sup>34</sup> See footnote 5

<sup>35</sup> <https://www.adass.org.uk/documents/adass-spring-survey-2024/>

<sup>36</sup> <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2023-24/carers>

<sup>37</sup> <https://www.suttontrust.com/cosmo-the-covid-social-mobility-and-opportunities-study/>

term. For every carer that reaches and passes breaking point, the state has at least two people it has to give more support to - the carer and the cared for. Investment in carers therefore has a huge return on investment.

### **Carers in employment**

Good jobs and productivity growth are essential for the country's economic prosperity. However, many carers are locked out of the jobs market, and 25% of carers are economically inactive, often because they cannot access the replacement care they need.<sup>38</sup> This exclusion limits their personal and professional development and undermines the nation's broader economic potential.

There are over 2.8 million carers are juggling work and care across the UK. Yet huge numbers of carers end up leaving the labour market because the right support for them, or the person they care for is not in place – it is estimated that around 600 carers give up paid work every single day.<sup>39</sup>

According to Carers Trust's Adult Carer survey, 48% of carers had to give up work or study, and an additional 15% had to reduce their working hours to meet their caregiving responsibilities.<sup>40</sup>

Reforming adult social care will support carers to stay in or return to work. As a result, carers will be able to be 'better off,' both economically and in terms of their overall wellbeing as well as contributing to the economy through increased taxes and a lesser reliance on welfare assistance.

### **Cost to young carers and their life outcomes**

There are approximately one million carers aged under 18 in the UK.<sup>41</sup> According to the Census, between 40% to 60% of young carers care for an adult with care and support needs. This amounts to between 400,000 to 600,000 children across the UK including 15,000 of children across England and Wales caring for 50+ hours a week - of which 3000 are 5 to 9 year olds.<sup>42</sup>

Carers Trust want to see the health and wellbeing of young carers and young adult carers protected. Young carers and young adult carers face a number of challenges and disadvantages compared to their peers who are not in a caring role. The Young Carers Covenant<sup>43</sup> outcomes should be at the centre of any plans relating to young carers or young adult carers and health organisations should be encouraged to sign up to the Covenant. Young carers should have access to specialist carer support both within the NHS for their caring role and in the community. Action should be taken to reduce the impact of caring on a young person's health, wellbeing and life chances. Integrated care boards and other health providers should also be encouraged to sign up to No Wrong Doors for Young Carers Memorandum of Understanding<sup>44</sup>,

Research by The Sutton Trust shows the significant impact caring can have on young people's mental health.<sup>45</sup> It found that young carers are significantly more likely to report severe psychological distress (56%) than their peers without a caring role (43%). For those caring for at least two years, the figure was even higher, at 60%. Young carers were also more likely to self-harm and make attempts on their own lives.

We know that identification, assessment of needs and provision of support for young carers is often lacking due to a breakdown in communication between children and adult's services. As a result we encourage all

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<sup>38</sup> <https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2022-to-2023/family-resources-survey-financial-year-2022-to-2023>

<sup>39</sup> <https://www.carersuk.org/media/no2lwyl/juggling-work-and-unpaid-care-report-final-web.pdf>

<sup>40</sup> <https://carers.org/downloads/resources-pdfs/pushed-to-the-edge.pdf>

<sup>41</sup> <https://carers.org/downloads/guide-to-the-young-carers-covenant-final120324.pdf>

<sup>42</sup> <https://carers.org/downloads/no-wrong-doors-briefing-note.pdf>

<sup>43</sup> [The Young Carers Covenant - Carers Trust](https://www.carersuk.org/the-young-carers-covenant)

<sup>44</sup> [https://carers.org/downloads/no-wrong-doors---insights-briefing-\(final\).pdf](https://carers.org/downloads/no-wrong-doors---insights-briefing-(final).pdf)

<sup>45</sup> <https://www.suttontrust.com/cosmo-the-covid-social-mobility-and-opportunities-study/>

areas to adopt the No Wrong Doors<sup>46</sup> approach, which we believe would stop so many young people falling through the cracks.

**Caring as a child can have a significant impact, not only on their health but their education, employment and life outcomes.**

Findings from the inquiry by the All-Party Parliamentary Group on Young and Young Adult Carers show that young carers miss 23 school days per year on average, and young adult carers are substantially (38%) less likely to achieve a university degree than their peers without a caring role.<sup>47</sup>

Young adult carers are also four times more likely to drop out of college or university than students without caring responsibilities, and 24% of young adult carers in school say they cannot afford to go to college or university.<sup>48</sup> Long term, these challenges are likely to affect their employment, financial health and career opportunities.

Reform in adult social care, with increased awareness of how to identify and support carers, could help to reduce the delays in being identified and linked into support. For young carers, a Young Carers Alliance snapshot survey found that it took on average three years for young carers to be identified. Some were caring for over ten years before being linked into support.

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

Local carer organisations in the Carers Trust network tell us that shrinking local authority budgets and poor commissioning practices have stretched these support services to their limit. The demand for services has gone up, and carers in accessing support for increasingly complex caring situations such supporting people with more complicated conditions or are caring for more than one person.

**This means that resources are being stretched to support fewer people.**

Our own annual survey of local carer organisations shows a picture of hugely stressed local organisations, with over 50% having had no uplift in contract value in recent years and a pattern of being asked to do more for less. This has left carer organisations in an increasingly vulnerable financial position, not only unable to meet growing demand, but concerned about their future viability.

**Local care organisations need to be protected. Over recent years, they have been seen as ‘the cloth to be cut’ when making savings.**

The SALT data shows reduction in spending on carer support has fallen by 6.1% from 2022-23, dropping from £195 million to £183 million per year.<sup>49</sup> According to our most recent data from the Carers Trust network, only £91 of statutory funding is spent per year per identified carer.<sup>50</sup>

In Carers Trust’s 2023 Adult Carer Survey,<sup>51</sup> carers told us that:

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<sup>46</sup> <https://carers.org/campaigning-for-change/no-wrong-doors-for-young-carers-a-review-and-refresh>

<sup>47</sup> <https://carers.org/all-party-parliamentary-group-appg-for-young-carers-and-young-adult-carers/appg-on-young-carers-and-young-adult-carers-inquiry-into-life-opportunities>

<sup>48</sup> <https://learningandwork.org.uk/news-and-policy/open-letter-young-adult-carers-and-the-21-hour-rule/>

<sup>49</sup> See footnote 36

<sup>50</sup> [2024-carers-trust-network-data-exchange-external-report.pdf](https://carers-trust-network-data-exchange-external-report.pdf)

<sup>51</sup> See footnote 5

- 21% they were not receiving support from their local authority anymore or that the amount of support they were getting from their local authority was less than before.
- More than two thirds (68%) of carers were unable to get a respite break from their caring role when they needed it.

The funding from the NHS to local carer organisations is also often too small to fund short-term projects over one to two years. This does not allow projects to become fully embedded or realise their full potential. Local carer organisations need project funding over a longer period to allow for stability and give the project to realise its potential and increase its impact.

**The increase in pressures and lack of investment in social care reform also means that individuals, such as unpaid carers are unable to access tailored support, relevant to their needs and circumstances.**

Analysis of the Adult Social Care Finance and Short and Long Term (SALT) Data 2023-24<sup>52</sup> showed that 70% of carers assessed/ reviewed (252,875 carers) received only general information and signposting, rather than direct support.

We know that the demands for carers support will only continue to grow. Carers Trust's network of local carer organisations in England reaches 930,000 carers annually. This is a significant increase from 2021 – 22, when the Network reached 800,000 carers. Adult social care needs a significant uplift in expenditure to ensure it can continue to meet the increasing needs of carers long term.

With no contract uplifts, local carer organisations face ongoing workforce challenges, such as difficulty retaining staff, especially due to the increases in employer contributions to National Insurance following the Autumn Budget 2024<sup>53</sup>. Many organisations are now forced to diversify their funding streams to stay afloat, yet these efforts alone are insufficient to meet the rising demand.

The cost of inaction on adult social care reform is borne heavily by local carer organisations who are subsidising the health and social care system. With inadequate funding from local authorities and the NHS, these services struggle to meet demand, fulfil statutory duties, and provide essential support to unpaid carers. Addressing these funding gaps through reform could improve service capacity, workforce stability, and overall carer support, ultimately benefiting both carers and the people they care for.

### **What contribution does adult social care make to the economy and HM Treasury and how might this change with action on reform?**

The ONS estimates unpaid carers provide care worth £57 billion per year. According to Skills for Care the adult social care sector (excluding informal care) contributes £68.1 billion.<sup>54</sup>

Skills for Care also reports that the contribution of Adult Social Care can be seen in socioeconomic benefits amounting to £265 million including improved wellbeing and reduced NHS cost. Therefore, whilst adult social care costs around £110 million (according to 2023's figures), the return on the investment is around 240%.

In 2020, it was estimated that 1.48 million people were working in the social care sector. The NHS suggest that this number is likely to increase by another 500,000 by 2030.<sup>55</sup> The number of people employed within the social care sector suggests that the government should start to view social care as an "anchor"

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<sup>52</sup> See footnote 36

<sup>53</sup> <https://www.gov.uk/government/publications/autumn-budget-2024>

<sup>54</sup> <https://www.skillsforcare.org.uk/resources/documents/About-us/Infographic-2-Social-Care-England.pdf>

<sup>55</sup> <https://www.healthcareers.nhs.uk/working-health/working-social-care>

institution alongside the NHS which can drive local economic development. With sufficient and sustainable investment, social care could become a driver for economic growth with significant benefits to the local and national economy.

Reform could increase funding for local carer support services, allowing carers to access timely assessments, respite care, mental health support, and financial guidance. This would empower carers to manage their health without falling into crisis, reducing the need for costly emergency interventions and allowing carers to contribute more robustly to the economy.

The Family Resources Survey revealed that only 50% of carers are employed, with just 34% working full-time.<sup>56</sup> We know that carers often have to sacrifice their working hours to provide care because the social care system is absent.

Carers Trust's Adult Carer survey (2022)<sup>57</sup> shows that:

- 48% of carers had to give up work or study entirely, and
- 15% had to reduce their working hours.

Carers being forced out of the workforce due to their caring role costs the public purse approximately £6.2 billion according to the Centre for Social Justice.<sup>58</sup> Embedding a support system for working carers would allow more carers to remain in or return to work and enhance their financial independence whilst contributing to the economy.

With more robust social care in place, carers have the opportunity to improve their ability to maintain a balance in the caring role. Reform would therefore not only improve the lives of carers and those they support but would also benefit HM Treasury by increasing tax revenues, reducing welfare needs, and creating a more sustainable approach to meeting the UK's growing care demands.

***December 2024***

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<sup>56</sup> See footnote 38

<sup>57</sup> See footnote 40

<sup>58</sup> [https://www.centreforsocialjustice.org.uk/wp-content/uploads/2024/02/CSJ-Creating\\_a\\_Britain\\_that\\_Works\\_and\\_Cares.pdf](https://www.centreforsocialjustice.org.uk/wp-content/uploads/2024/02/CSJ-Creating_a_Britain_that_Works_and_Cares.pdf)