

Health Bill Committee Stage Briefing: Put unpaid carers at the heart of the NHS

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This briefing outlines key ways in which the Health Bill (NHS Modernisation Bill) could be improved to better support unpaid carers. It summarises Carers UK's proposed amendments, as well as information on how you can get involved in our campaign, 'Put unpaid carers at the heart of the NHS.'

The briefing contains the following sections:

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2. Provisions in the Bill that will impact on unpaid carers
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 - Making it clear that unpaid carers will have access to the Single Patient Record, once the right permissions have been established
 - Duty on health bodies to provide information and advice to unpaid carers
 - Duty on Integrated Care Boards (ICBs) to identify and record unpaid carers
 - Duty on ICBs to promote the health and wellbeing of unpaid carers
 - A right to a break for unpaid carers via the National Respite Care Scheme
 - Responsibility on health bodies and local authorities to act on feedback from patients and unpaid carers
4. Information on how you can get involved in our campaign, 'Put unpaid carers at the heart of the NHS'

Executive Summary

Why is supporting carers in the Bill important?

There are 4.7 million unpaid carers in England¹ and the value of carers' support is worth £152bn in England alone, a 30% increase since 2011 – due to carers providing more care. This is the same as the budget of the NHS.² Unpaid carers outnumber health staff by around 3:1³ and yet they often feel invisible and unsupported. Furthermore, 1 in 3 NHS staff are themselves unpaid carers.⁴ Supporting unpaid carers is therefore essential to ensuring the long-term sustainability of the NHS.

What does the Bill do for carers?

Carers UK welcomes the introduction of the Health Bill, which includes provisions to ensure that unpaid carers continue to be involved and consulted following the abolition of NHS England and Healthwatches.

¹ Carers UK (2025) [Facts about carers](#)

² Carers UK (2024) [Valuing Carers 2021/22: the value of unpaid care in the UK](#)

³ House of Commons Library (2026) [NHS workforce: Size, characteristics and staffing levels](#)

⁴ NHS England (2025) NHS Staff Survey

The Single Patient Record could also have benefits for unpaid carers, allowing them to coordinate the care of the person they look after more easily and potentially reducing administration time when dealing with the NHS.

What amendments are we proposing and why are they needed?

The Bill presents an important opportunity to improve the interaction between the NHS and unpaid carers, aligning duties on the NHS with existing duties on local authorities. The Health Bill could therefore benefit from the following amendments:

- a) Making it clear that unpaid carers will have access to the Single Patient Record, once the right permissions have been established
- b) Duty on ICBs to promote the health and wellbeing of carers
- c) Duty on Integrated Care Boards (ICBs) to identify and record unpaid carers
- d) Provision of information and advice to unpaid carers
- e) Giving unpaid carers the right to a break via a National Respite Care Scheme
- f) Responsibility on health bodies and local authorities to act on feedback gathered by carers and people using services

A new duty on health bodies to provide information and advice is essential to supporting carers and improving patient safety. Carers often complete tasks, which relate directly to the healthcare of the person they look after, including administering medication, safely moving and handling someone to prevent injury, safe use of healthcare equipment, among others. 29% of carers said they need more information and advice about caring such as support with clinical tasks or managing someone's condition.⁵ While local authorities have direct duties to provide information and advice to unpaid carers, this does not extend to advice on healthcare matters.

A new duty on ICBs to proactively identify unpaid carers could be a huge step forward to ensuring carers are getting the support they need. While local authorities already have duties under the Care Act 2014 relating to identifying carers, there is currently no equivalent statutory duty on ICBs or NHS bodies. This is a significant gap given that unpaid carers are often far more likely to come into contact with NHS services than local authorities, particularly in the early stages of their caring journey. Carers are significantly under-identified in primary care: for every one carer identified by GP practices, approximately four are not identified, meaning that around one million unpaid carers are not currently recorded by GP practices.⁶

A clear statutory duty on ICBs to improve and maintain the health and wellbeing of unpaid carers would mean that unpaid carers, who are much more likely to experience poorer health than non-carers, can be targeted and prioritised as a group by the health service. Unpaid carers consistently experience poorer physical and mental health outcomes than non-carers, with 72% of carers reporting a long-term condition or disability compared with 60% of non-carers.⁷ Carers often develop both physical and mental health conditions or even injury during their caring journey. As many as 40% of current carers postpone or cancel their own medical appointments because of caring – an estimated 4.8m people.⁸

⁵ Carers UK (2025) [A fresh approach to supporting unpaid carers](#)

⁶ Nuffield Trust (2025) [How good are general practices in England at recording who is an unpaid carer?](#)

⁷ Carers UK analysis of [GP Patient Survey data](#) (2025)

⁸ Carers UK (2025) [Caring about equality](#)

A new right to a break for unpaid carers would secure carers' entitlement to breaks in legislation. Although carers in England are entitled to a Carer's Assessment under the Care Act 2014, around 70% of assessments do not result in meaningful breaks including replacement care support.⁹ Many carers describe severe exhaustion, burnout, isolation and worsening mental health resulting from being unable to step away from caring responsibilities.

Provisions in the Bill that will impact on unpaid carers

Involvement of carers in relation to services (Clauses 5 and 15)

Carers UK welcomes the fact that carer involvement and consultation with carers has been preserved and is on the face of the Bill. With the abolition of NHS England, the relevant duty to involve carers has been transferred to the Secretary of State and to Integrated Care Boards.

Abolition of Healthwatches (Schedule 10)

The NHS Act 2006 which established local Healthwatch included responsibilities in relation to unpaid carers' views of health and local authority services. These are now transferred to Integrated Care Boards and local authorities directly. These cover:

- What services are needed
- Experience of health services
- The standard of the provision of health services
- How health services could be improved
- How health services ought to be improved

Similar provisions and requirements exist for public health services and social care services, the latter placing duties on local authorities and amending the Care Act 2014. Carers UK welcomes the fact that the involvement duties explicitly reference carers. This protects and keeps clear the responsibilities of service providers and commissioners to unpaid carers.

However, we are concerned about whether carers' views will be taken into account and acted on without an independent body in place to lead on this. Further assurances and details of protections would be useful to ensure that complaints and feedback from carers is acted on by the relevant bodies.

Single Patient Record

The establishment of a Single Patient Record could have many benefits for carers, including reducing the administration time they spend dealing with the NHS.

However, carers are not explicitly mentioned in primary legislation or in the explanatory notes, although Clause 47 includes provisions for the sharing of patient information (2) *2C(i) making it available to people other than a patient on the patient's behalf.*'

⁹ NHS England (2024) [Adult Social Care Activity and Finance Report, England, 2023-24](#)

Amendments needed to support unpaid carers

The Health Bill presents a key opportunity to provide a step change in the interaction between and support offered by the NHS to unpaid carers, who often feel overlooked and unsupported by the health service. In this section, we have brought together information on amendments which could transform carers' interaction with the NHS:

- Making it clear that unpaid carers will have access to the Single Patient Record, once the right permissions have been established
- Provision of information and advice to unpaid carers
- Duty to identify and record unpaid carers
- Duty to promote the health and wellbeing of unpaid carers
- Giving unpaid carers the right to a break via a National Respite Care Scheme
- Responsibility on Health Bodies and Local Authorities to act on feedback gathered by carers and people using services

Single Patient Record: enabling appropriate access for unpaid carers

The Single Patient Record (SPR) offers an opportunity to make a real difference and the majority of carers are in favour of it. Carers tell us that they are tired and exhausted by having to repeat information time and again, chasing test results and appointments on behalf of the person they care for, having to coordinate care when the NHS fails to do so and rights errors and mishaps when information is not shared properly. 13% of carers spend 40 hours a month on NHS admin.¹⁰

The establishment of a Single Patient Record could have many benefits for carers, including reducing the administration time they spend dealing with the NHS. Carers would also not need to repeat their story multiple times and do less joining up between different services, ensuring that all important information about the person they look after has been recorded in different settings

This is why it is vital that unpaid carers are given access to the SPR for the person they care for. The Bill suggests that the Single Patient Record would be accessed, in part, with different permissions, by someone on behalf of the patient. However, unpaid carers are not explicitly mentioned in primary legislation or in the explanatory notes. We therefore support an amendment to clarify that the SPR would be made available to unpaid carers – once the right patient permissions have been granted and in the right circumstances.

Provision of information and advice to unpaid carers

Local authorities have duties to provide information and advice to unpaid carers under Section 4 of the Carer Act 2014. Whilst the local authority's duties extend to social care and other local services that they either commission or deliver in the local area, their duties do not extend to the NHS. An amendment to introduce a new duty on health bodies to provide information and advice to unpaid carers would ensure that carers are

¹⁰ Carers UK (2025) [A fresh approach to supporting unpaid carers](#)

equipped with appropriate information more consistently to enable them to care safely and well.

Carers often complete tasks which relate directly to the healthcare of the person they look after, including administering medication, safely moving and handling someone to prevent injury, safe use of healthcare equipment, among others. Moreover, around a fifth (22%) of unpaid carers sustain injuries as a result of their caring role.¹¹

The provision of advice from the NHS is therefore a matter of safety for the patient as well as the carer feeling supported to provide certain types of care, which requires specialist knowledge.

Advice from the NHS to enable carers to care safely and well is therefore essential but often not provided in practice. Carers often say that there is an assumption from the health service that a family member will automatically take-on care, without first checking that this is possible. Only 14% of carers were asked about their ability and willingness to provide care at hospital discharge.¹²

Carers often find it difficult to find information and advice about how to manage the condition(s) of the person they care for: 29% of carers said they need more information and advice about caring such as support with clinical tasks or managing someone's condition.¹³

Carers can perform a range of healthcare tasks as part of their caring role:¹⁴

- 72% of carers were providing support with medication, with 48% directly administering the medication
- A quarter (25%) of carers said they monitored blood pressure or blood sugar
- 23% made decisions about whether to give emergency or specialist medication
- 20% dressed a wound
- 11% are using equipment such as a hoist to lift someone
- 7% gave injections

Many carers – particularly those who are new to caring – felt that they lacked the training and advice to perform clinical tasks and were anxious about whether they were performing these tasks correctly. Currently, many carers are relying on their own research to support the person they care for: our State of Caring 2023 survey found that when carers need advice about caring, doing an internet search is the most common way they obtain information (45%), followed by a local carers' organisation (36%) and a national carers charity (25%). Just a quarter (24%) of carers say they get information and advice from a GP or health professional.¹⁵

When the person they care for had to receive care in hospital, only 1 in 5 (19%) of unpaid carers agreed that they were “given the relevant information and support by NHS staff to care safely and well”. Nearly half (47%) disagreed with this statement,

¹¹ Carers UK (2023) [State of Caring 2023: The impact of caring on health](#)

¹² Carers UK (2025) [A fresh approach to supporting unpaid carers](#)

¹³ Ibid.

¹⁴ Carers UK (2023) [State of Caring 2023: The impact of caring on health](#)

¹⁵ Ibid.

thereby showing the need for more specialist information and advice from the NHS to carers.¹⁶

64% of carers said they were involved in monitoring mental health and wellbeing of the person they care for. Some carers highlighted a lack of support for this.¹⁷

Being given the right information and advice at the right time is therefore not just about the safety of the person being cared for but the health and wellbeing of the carer themselves. 54% of carers said their physical health had suffered since they started providing unpaid care, and 22% said that caring had caused them injuries.¹⁸

Caring can become stressful when carers are not getting enough support to care safely and well. Our State of Caring 2024 survey found that over half of carers (57%) feel overwhelmed often or always.¹⁹

Duty on ICBs to identify and record unpaid carers

The Care Act 2014 already places duties on local authorities relating to the identification of unpaid carers. No equivalent duty exists for Integrated Care Boards (ICBs), which commission the vast majority to health services. Yet unpaid carers are more likely to come into contact with health services earlier than with local authorities.

Identification of carers in the NHS is important to ensure:

- Public health measures are well targeted at unpaid carers, for example with free flu vaccination, assessments for common health problems (carers are more likely to have higher blood pressure, musculoskeletal issues, etc.)
- Inclusion of unpaid carers in risk and prevention strategies.
- Access to local initiatives to better support unpaid carers such as flexible appointments.
- Inclusion of unpaid carers in hospital discharge planning.
- Referral to support services and Carer's Assessments by the local authority.
- A contact list ready to deploy in the right way during a pandemic – this is an essential part of pandemic preparedness.

There is evidence of significant under-identification of unpaid carers within the NHS. Analysis by the Nuffield Trust of 13 million GP records found only 1.4% of patients were coded as unpaid carers in GP systems, compared with Census estimates suggesting a true prevalence of approximately 8.8%. For every one carer identified by GP practices, roughly four are not identified nearly, meaning that around one million carers were effectively “missing” from GP records.²⁰

The analysis also found substantial inequalities in identification rates. Around 28% of carers were identified in the most affluent areas compared with approximately 14% in

¹⁶ Carers UK (2025) [A fresh approach to supporting unpaid carers](#)

¹⁷ Carers UK (2023) [State of Caring 2023: The impact of caring on health](#)

¹⁸ Ibid.

¹⁹ Carers UK (2025) [State of Caring 2025: The impact of caring on carers' mental health and the need for support from social care](#)

²⁰ Nuffield Trust (2025) [How good are general practices in England at recording who is an unpaid carer?](#)

the most deprived areas, meaning that unpaid carers were twice as likely to be identified in the most affluent areas compared with the most deprived.²¹

Unpaid carers can also take a long time to identify themselves. Carers UK's State of Caring Survey 2022 found that 51% of carers took more than one year to recognise their caring role and 36% took more than three years.²² These findings reinforce the need for proactive identification by NHS services rather than relying on self-identification alone.

A critical issue that arose during the COVID-19 pandemic and key learning was that carers needed to be identified quickly to ensure that they had key information and advice, and that public health measures could be deployed quickly. This provision would ensure ongoing measures to identify carers.

Duty on ICBs to promote the health and wellbeing of carers

Unpaid carers are essential to the sustainability of the NHS and social care system, yet carers consistently experience poorer physical and mental health outcomes than non-carers and frequently struggle to access support for their own health needs.

Although ICBs have broad duties relating to population health and inequalities, there is currently no explicit statutory duty requiring ICBs to improve the health and wellbeing of unpaid carers specifically. An amendment to introduce a duty for ICBs to promote the health and wellbeing of unpaid carers would therefore ensure that carers are prioritised and targeted with support as a group.

Caring is recognised as a social determinant of health²³, impacting both physical and mental health:

- The GP Patient Survey 2025 found that 72% of carers report a long-term condition or disability compared with 60% of non-carers.²⁴
- The Office of National Statistics found that low mental well-being was more common among unpaid carers (20%) than those not providing unpaid care (15%).²⁵
- Carers Week 2025 research also found that 48% of carers said a physical or mental health condition had developed or worsened since taking on caring responsibilities.²⁶

Caring intensity is related to how likely it is a carer will experience ill health.²⁷ More than 1.4 million people in England provide over 50 hours of unpaid care each week - a figure that has grown steadily over the past decade.²⁸

²¹ Ibid.

²² Carers UK (2022) [State of Caring 2022: A snapshot of unpaid care in the UK](#)

²³ Public Health England (2021) [Caring as a social determinant of health: review of evidence](#)

²⁴ Carers UK analysis of [GP Patient Survey data](#) (2025)

²⁵ ONS (2024) [Unpaid care expectancy and health outcomes of unpaid carers, England](#)

²⁶ Carers UK (2025) [Caring about equality](#)

²⁷ ONS (2024) [Unpaid care expectancy and health outcomes of unpaid carers, England](#)

²⁸ ONS (2023) [Unpaid care, England and Wales: Census 2021](#)

Many carers report being unable to prioritise their own health due to the demands of caring and because NHS services are not designed around carers' needs.

Carers Week 2025 research from last year found that 40% of current carers said they had postponed or cancelled a medical appointment, test, scan, treatment or therapy because of caring – an estimated 4.8m people. Of those who had cancelled or postponed, 23% had done so in the last 12 months. The top reason for the cancellation was that the carer could not find appointments at a time when they could attend (39%).²⁹

Carers are also not being involved and having their needs considered at discharge, despite it being a statutory duty to involve them in the discharge process. Just 14% of carers felt they were asked about their ability and willingness to provide care.³⁰

A new duty on ICBs to exercise their functions with a view to improving carers' physical health, mental health and wellbeing, would help to:

- Reduce inequalities experienced by carers.
- Involve carers appropriately in care decisions.
- Embed carers within Joint Forward Plans and prevention strategies.

The NHS Staff Survey found that 1 in 3 NHS staff are themselves unpaid carers and carers working within the NHS were significantly more likely to report work-related stress than non-carers - 47% compared to 39%.³¹

Supporting carers' health is not only a matter of fairness — it is essential to NHS resilience. Without better support, there is a growing risk of carer burnout, breakdown in caring arrangements, avoidable admissions and greater pressure on health and care services.

Right to a break for unpaid carers via a National Respite Care Scheme

Although carers in England are entitled to a Carer's Assessment under the Care Act 2014, many assessments do not result in meaningful breaks or replacement care support. Many carers reported long delays, lack of follow-up support, and assessments that felt like "tick-box exercises".

Official data for 2023–24 shows only around 8% of all unpaid carers were assessed or supported by local authorities and 70% of carers approaching local authorities received only information, advice or signposting, or no direct support at all.³²

Nuffield Trust analysis has shown that the number of carers receiving direct support has fallen significantly. There were 13,000 fewer carers getting direct support in 2020/21 than there were six years previously in 2015/16.³³

²⁹ Carers UK (2025) [Caring about equality](#)

³⁰ Carers UK (2025) [A fresh approach to supporting unpaid carers](#)

³¹ NHS England (2025) NHS Staff Survey

³² NHS England (2024) [Adult Social Care Activity and Finance Report, England, 2023-24](#)

³³ Nuffield Trust (2022) [Falling short: How far have we come in improving support for unpaid carers in England?](#)

Carers UK's State of Caring 2024 survey found that 49% of carers said they needed more breaks from caring; 54% said being able to take regular breaks would be a challenge over the coming year; and 57% reported feeling overwhelmed often or always.³⁴

Many carers describe severe exhaustion, burnout, isolation and worsening mental health resulting from being unable to step away from caring responsibilities. Unpaid carers, who are unable to take regular or meaningful breaks from caring, can experience serious consequences for their health, wellbeing, employment and family life.

Carers UK's State of Caring 2023 survey found that 73% of carers with bad or very bad mental health continued caring despite feeling at breaking point.³⁵ Research for Carers Week 2025 found that 40% of carers had postponed or cancelled their own medical appointments, tests, scans, treatment or therapy because of caring responsibilities — equivalent to an estimated 4.8 million people. 39% of current and former carers who had a health condition develop or become worse said that being able to take regular breaks from caring would have helped to prevent this.³⁶

The Association of Directors of Adult Social Services (ADASS) Spring Survey 2025³⁷ reported a substantial increase in carer breakdown. Directors identified carer burnout as the single most important contributing factor.

600 unpaid carers leave paid employment every day in order to provide care.³⁸ The most commonly cited factor that would have helped carers stay in work was more affordable, accessible, or reliable replacement care services. 35% of carers who had given up employment said this would have prevented them from reaching a tipping point.³⁹

Breaks from caring are therefore not simply desirable: they are essential preventative support that helps carers maintain their own health and continue caring safely and sustainably.

UK Nations

Scotland has introduced a new statutory right for unpaid carers to access breaks from caring responsibilities. England has no equivalent explicit right.

Funding

³⁴ Carers UK (2025) [State of Caring 2025: The impact of caring on carers' mental health and the need for support from social care](#)

³⁵ Carers UK (2023) [State of Caring 2023: The impact of caring on health](#)

³⁶ Carers UK (2025) [Caring about equality](#)

³⁷ ADASS (2025) [2025 Spring Survey](#)

³⁸ Carers UK (2019) [Juggling work and unpaid care: a growing issue](#)

³⁹ Carers UK (2026) [The tipping point: When unpaid carers can no longer combine caring with paid employment](#)

Funding for carers' support is primarily delivered through the Better Care Fund (BCF). While the BCF policy framework⁴⁰ recognises the importance of supporting unpaid carers, funding for carers' breaks is not ringfenced.⁴¹

In 2022/23, £291.7 million in BCF funding was earmarked for short breaks, advice and support for carers.⁴² However, local authority expenditure on support for carers fell from £195 million in 2022/23 to £183 million in 2023/24 – a drop of 6.1%.⁴³

To ensure effective implementation of a right to breaks:

- Funding for carers' breaks should be increased to allow local authorities to fulfil their duties - Carers UK has long called for an increase on spending on carers' breaks by at least £1.5bn per year.
- Dedicated funding should be ringfenced to ensure it does not get lost within local budgets and it is used for the intended purpose.
- Sufficient replacement care capacity must be available locally.

National Respite Care Scheme

The amendment to introduce a National Respite Care Scheme would be one way of delivering a right to a break for unpaid carers, ensuring that eligible needs identified in the Carer's Assessment are met and funding is allocated centrally to ensure breaks are delivered. This amendment would mean that within six months of legislation being passed, the Secretary of State must establish a National Respite Care Scheme and provide sufficient support to local authorities to ensure that all local authorities can deliver breaks and support to carers. Carers UK supports this amendment which provides for the right to a break for unpaid carers and sufficient funding for breaks to be delivered by local authorities.

Responsibility on health bodies and local authorities to act on feedback gathered by carers

Carers UK welcomes the fact that the involvement duties explicitly reference unpaid carers. This protects and keeps clear the responsibilities of service providers and commissioners to unpaid carers.

However, we would like to see assurances that patient and carer voice will be gathered, listened to and acted upon, including independent accountability and scrutiny to ensure this happens, once Healthwatches are abolished.

Our State of Caring 2025 survey found that only a fifth of carers (18%) said they were confident that any feedback or complaint they made about a health or social care service would be acted on. Similarly, only 14% of carers said that they felt listened to during hospital discharge about their willingness and ability to provide unpaid care.²

⁴⁰ Department of Health and Social Care and Ministry of Housing, Communities and Local government (2025) [Better Care Fund policy framework 2025 to 2026](#)

⁴¹ [PQ on the Better Care Fund](#) (2025)

⁴² [Ibid.](#)

⁴³ NHS England (2024) [Adult Social Care Activity and Finance Report, England, 2023-24](#)

Carers UK would also like to see data collection specifically related to carer experiences which is separate and distinct from patient experience so that health bodies can focus on carers as a group and their needs.

Carers UK is a member of National Voices and will be supporting amendments in order to strengthen the transparency, independence and accountability around patient and carer voice, to ensure that feedback is acted upon.

How you can support our campaign

We are asking organisations to demonstrate their support for these amendments by adding their name to our campaign. You can register their support by completing our [online sign-up form](#).

We are also encouraging individuals to contact their MP and urge them to support these amendments to build widespread parliamentary support. You can email your MP using our template letter [here](#).

About Carers UK

Carers UK is a charity set up to help the millions of people who care 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 policy makers, employers, and service providers, to help them improve carers' lives.

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