

# Carers UK's written evidence to Public Bill Committee on the Health and Care Bill

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## 1. Submission details:

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## 2. About Carers UK:

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2.1. Carers UK is a charity which works to help the millions of people who care unpaid for family or friends in the UK. 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 work to make life better for carers by undertaking research and using carers' insights and lived experiences to help policy makers, employers, and service providers understand the challenges carers face, to help them improve carers' lives.

## 3. Introduction:

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3.1. Carers UK believes the Health and Care Bill presents a real opportunity to now recognise carers' in legislation and ensure they are not overlooked by our health and care systems. In the passing of the Bill, carers' rights need to be maintained and enhanced, and their existing rights must be safeguarded. For many years Carers UK has called for the NHS to be given new legal responsibilities towards unpaid carers, to recognise the vital role they play and ensure they get the support they need.

3.2. The NHS depends heavily on the role and input of people who care unpaid – usually family and friends, but also neighbours – in supporting people with long term conditions and disabilities in the community. 1.4 million people in the UK provide over 50 hours of unpaid care per week.<sup>1</sup> During the pandemic, the number of carers rose dramatically to 13.6 million across the UK, or one in four of the population<sup>2</sup>, and the value of the care they have provided to be £193 billion per annum.<sup>3</sup>

3.3. Carers often play numerous roles simultaneously in supporting those they care for and are often experts in providing care: administering medication, supporting daily activities of life such as eating, drinking, dressing, moving, supervision and cognitive support, through to more complex specialised nursing care. Their own health is often impacted by their caring role and they are twice as likely to have ill-health because of caring as non-carers.<sup>4</sup>

3.4. Despite the invaluable contribution they make, carers often say they feel invisible to health services, and overlooked by healthcare professionals when advocating on behalf of the person/people they care for. This can lead to poor outcomes such as delayed discharges and have a severe impact on both the patient and those caring for them.

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<sup>1</sup> Census 2011, figures for UK, published in Facts About Carers. Increased figures from Understanding Society suggests that this has increased since 2011 in Carers, Social Market Foundation, 2018

<sup>2</sup> Carers Week (2020) Carers Week Research 2020

<sup>3</sup> Carers UK (2020) Unseen and Undervalued: the value of unpaid care during the COVID-19 pandemic

<sup>4</sup> Carers UK (2019) Facts about Carers 2019

3.5. The lack of integration between health and care services is also a challenge many carers face; as well as being inefficient and negatively impacting care quality, it adds to carers' caring responsibilities and causes untold stress for families. Therefore, greater integration of health and care services is something that carers do support, as their lives are often made much harder when services are not joined up and when data is not shared effectively and efficiently.

3.6. The Bill offers a real opportunity to recognise the support carers provide, and in turn give them the support they need to care. Not only is this the right thing to do, but the aims for integration outlined in this Bill by Government can only work if unpaid carers are visible, recognised, and counted throughout the NHS. Doing so would also ensure carers' health and wellbeing is promoted across the NHS and leave a positive legacy for carers following the pandemic that sees their role acknowledged.

## **4. Summary of Carers UK's views on the Bill:**

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### **4.1. We welcome certain Clauses in the Bill, including:**

- New duty on NHS England to consult carers (Clause 5).
- New duty on Integrated Care Boards to consult carers around planning and commissioning and around services relating to the patient for prevention, treatment, and diagnosis (Clause 19).
- New powers for the Care Quality Commission to assess local authorities (Clause 121).

### **4.2. The Bill will undermine carers' rights particularly regarding hospital discharge. We are particularly concerned about the following clauses:**

- We are very concerned the Bill undermines carers' rights in relation to hospital discharge (Clause 78) removing a key element of their rights by enabling Care Act assessments to take place after an individual has been discharged from acute care. This is complex and is explained further below.
- The Committee should also consider amendments that ensure Integrated Care Boards (ICBs) are given a responsibility to monitor the extent to which follow-up visits and assessments are taking place after someone leaves hospital, and work with local partners to identify and address ongoing barriers.

### **4.3. The Bill should go much further to support carers and should be amended:**

- To place a duty on the NHS to have regard to carers and to promote their health and wellbeing – this would go beyond a duty to consult and involve but makes carers a specific group who must be considered in terms of their own needs, mirroring existing legislation that exists in social care through the Care Act 2014.
- To introduce a requirement on health and social care to ensure the sufficiency of supply of carers breaks, and to give every carer a right to a break.
- To require carers or carers' representatives to sit on either the Integrated Care Board or the Integrated Care Partnership (Clause 13).
- To ensure that there is real clarity that the Integrated Care Board also has responsibility for unpaid carers by clearly referencing carers (Clause 14).
- To consistently reference carers in the Bill e.g., in the promotion of the NHS Constitution (Clause 19).

### **4.4. We also seek clarification regarding:**

- Whether the definition of 'carers' in the Bill includes young carers and parent carers.

## **5. Specific clauses relating to unpaid carers that we welcome:**

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## **5.1. Consultation duties to include an explicit reference to carers: Public involvement (Clause 5)**

5.1.1. Carers and people who use care services bring particular experience and having a non-specific consultation duty misses out the very specific contribution and experience of carers to the NHS.

5.1.2. The Bill introduces a new duty on NHS England to involve and consult carers as part of public involvement (Clause 5). This is long overdue and where NHS England must involve and consult patients, they must now also include carers where services are being or will be provided. Taking carers' views on board also ensures that they will be included for commissioning highly specialised services and the other commissioning functions of NHS England. Carers UK hopes that this will prevent situations where NHS England has failed to include carers properly in consultations or guidance e.g., Discharge to Assess guidance, where carers were not included in two versions of published guidance.

## **5.2. General Duties for ICB's (Clause 19)**

5.2.1. There are new duties on Integrated Care Boards (ICBs) to consult and involve carers (Clause 19). This includes two provisions to ensure that ICBs consult and involve carers in the planning of commissioning arrangements, and secondly, in relation to any services related to diagnosis, treatment, or prevention in terms of the patient. These are vital measures to ensure that carers' views are taken on board, since they provide the bulk of care in the UK – equivalent to that of the NHS. This moves closer towards carers being considered equal partners in care.

5.2.2. Given that carers are part of and often responsible for the care of millions of patients and people who use care services in England, these measures help ensure that the system pays the appropriate level of attention to carers and their experiences. The experience of carers and people who use care services are essential to good integrated services.

## **6. Areas where the Bill needs to be amended:**

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### **6.1. Membership and constitution of ICBs (Clause 13)**

6.1.1. The Bill stipulates that ICBs must have a Chair and at least 3 ordinary members; one jointly nominated by NHS Trusts and NHS Foundation Trusts, one jointly nominated by persons who provide primary medical services, and one jointly nominated by local authorities. We are disappointed that including the experience of the voluntary and community sector, patients, people who use social services and carers will not be required for all ICBs.

6.1.2. In designing and delivering health services it is vital that the experiences of the people using the services and their carers are included. We believe it is fundamental to ensure that carers or carers representatives, alongside the voluntary and community sector are members of all ICB's.

### **6.2. Hospital Discharge, (Clause 78)**

6.2.1. The Bill proposes changing the approach to hospital discharge by amending the legislative framework to enable a 'discharge to assess' model. This model includes enabling Care Act assessments to take place after an individual has been discharged from acute care. It removes the need to assess a patient at the point of hospital discharge by repealing the Community Care (Delayed Discharges, etc.) Act 2003 and Section 74 and Schedule 3 of the Care Act 2014 which has the same provisions. Under the CC (Delayed Discharges, etc.) Act 2003 a carer's assessment can be requested and if so, a decision must be made about what

services need to be provided to the carer, whether by social services or a consideration by the NHS, to ensure that the “patient is safe to discharge”. Whilst the main provisions around the Care Act and a carer’s assessment remains in place, the changes in legislation remove this important test and removes the requirement to consider what support might be provided to the carer to ensure that the patient is “safe to discharge”. We are concerned that the Care Act 2014 will also not be applied until the patient is discharged, compromising carers’ rights and putting their health and wellbeing at risk.

6.2.2. Discharge from hospital following treatment can be a critical time for families, with many people finding they become unpaid carers overnight when their loved one comes home from hospital (or other healthcare settings). Prior research shows that carers are often not consulted before discharge of the person they care for: 26% of carers were not consulted about discharge and a third (33%) were only consulted at the last minute.<sup>5</sup> Even those who have been caring for a long time can face new and difficult challenges looking after someone who is recovering from an operation, as their needs for support may increase. It is crucial that families are prepared for this and that the right support is in place to help them cope. Carers UK is currently undertaking further research on carers’ recent experiences of hospital discharge, which we will share with the Committee in due course.

6.2.3. To enact this ‘discharge to assess’ model, the Government plans to repeal existing requirements to assess for care needs prior to hospital discharge, and the accompanying process of assessment and discharge notices.

6.2.4. Carers UK previously raised the important issue that the two previous versions of the NHS guidance in March and in August did not include carers’ rights during the process, despite this being the law and despite raising this when consulted. We are pleased that the update guidance published on the 5 July now includes carers’ rights. While the updated guidance has addressed carers by the inclusion of two paragraphs referring to the Care Act 2014 Part 1 provisions, it does not replace the fact that other important rights of carers are being removed. Carers UK wants to see carers’ rights maintained and not reduced. We are also concerned that this practice not including carers has now been operational for nearly 18 months.

6.2.5. We believe to remove this provision to ensure safe discharge would undermine carers’ rights at a time when social care is extremely stretched and underfunded. The current rights also confer a level of responsibility on the NHS to ensure that the patient is safe to discharge which are lessened in relation to carers by the Bill’s proposal to remove these provisions.

6.2.6. The Bill should also be amended to ensure Integrated Care Boards (ICBs) are given a responsibility to monitor the extent to which follow-up visits and assessments are taking place after someone leaves hospital, and work with local partners to identify and address ongoing barriers.

### **6.3. Care Quality Commission, regulation of adult social care (Clause 121)**

6.3.1. The Bill introduces a new duty for the Care Quality Commission (CQC) to review and assess the performance of English local authorities in their delivery of their adult social care functions under Part 1 of the Care Act 2014.

6.3.2. Carers UK welcomes the newly proposed powers for the CQC. However, we believe that the founding regulations of CQC need to be amended to explicitly reference carers, to ensure they do not just refer to people to who use services. This is especially important as Part 1 of the Care Act 2014 includes duties on local authorities to promote carers wellbeing, and to carry out an assessment of their needs.

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<sup>5</sup> Carers UK (2016) ‘Pressure points: carers and the NHS’

6.3.3. It is therefore vital in the review and assessment of the performance of local authorities' delivery of adult social care functions includes a review of the support provided to and the assessment of the needs of carers in a local area.

6.3.4. It is also important that the regulatory powers conferred on the Care Quality Commission cross different organisation boundaries e.g., hospital discharge across acute, primary, and social care.

## **6.4. Introducing a duty to have regard to carers, to improve carers' health and wellbeing as well as outcomes for people who need health and care**

6.4.1. Whilst unpaid carers provide the bulk of care, and are often relied upon, they are not systematically identified, supported, or included throughout the NHS. Good practice exists in certain areas, but this is neither systematic nor systemic throughout the NHS. This lack of recognition and support for carers hinders evaluation and measurements of effectiveness. Carer experience surveys are highly valuable measures and demonstrate that carers' experiences of accessing health and care services are either static or worsening.

6.4.2. NHS legislation currently does not have to have regard to carers own wellbeing explicitly, nor does it have to identify carers. This is not the case for social care, which treats carers equally in legislation alongside people who use services. Closer integration between health and social care means that one system recognises carers legally as an equal part, the other does not. For effective integration across the system to be achieved we believe that both the NHS and social care need to have a statutory duty to have regard to carers and to promote their wellbeing.

6.4.3. The lack of systematic identification and support for carers across the NHS has significant risks, including:

- Negative impact on carers' mental and physical health
- Carers having to cope with more complex conditions at home/in another home
- For certain carers, significant risks to their ability to juggle work and care
- Increased direct health costs in the longer term
- Increased health inequalities
- Increased disparity in the social determinants of ill-health

6.4.4. We are therefore recommending that the Bill includes a duty on the NHS to have regard to carers and to promote their health and wellbeing.

## **6.5. Carers' breaks**

6.5.1. We are concerned that currently there is insufficient supply of services to provide breaks to carers, and that many carers are not able to access the breaks they need to look after their health and wellbeing. Even before the pandemic carers were struggling to access meaningful breaks, with 44% of carers saying they did not get the breaks they needed. This situation has worsened during the pandemic, during which 72% of carers have not had any breaks; of those carers who did get breaks two thirds (66%) said they had fewer breaks or insufficient breaks to look after their physical and mental health<sup>6</sup>. Carers reported that they had on average, 25 hours of support per month over the past 18 months<sup>7</sup>.

6.5.2. Carers are reporting high levels of fatigue and stress after caring during the pandemic, with almost three quarters (74%) reporting feeling exhausted and worn out because of caring

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<sup>6</sup> Carers Week (2021) 'Breaks or Breakdown'

<sup>7</sup> Ibid.

during the COVID-19 pandemic. Nearly two thirds (63%) are worried about continuing to care without a break.

6.5.3. Carers access to breaks are essential to manage their own health and wellbeing and prevent carer breakdown. We believe the bill should introduce a requirement on health and social care to ensure the sufficiency of supply of carers breaks, and to give every carer a right to a break.

## **6.6. Clarification about people for whom the ICB is responsible (Clause 14)**

6.6.1. The Bill is also unclear whether the ICB would have specific responsibilities towards carers. As several provisions are linked to this, it is important to include carers here.

## **7. Areas of the Bill that need to be clarified:**

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### **7.1. Definition of carers to include young carers and parent carers**

7.1.1. The Health and Care Bill does not define “carers”. We are therefore assuming that, since the NHS is an all-age service, “carers” would include the same definition as the Care Act 2014, “parent carers” under the Children and Families Act 2014 and the Carers (Recognition and Services) Act 1995 and “young carers” under the same legislation.

7.1.2. We ask for this to be clarified and clearly stated in statutory guidance, or on the face of the Bill.

## **8. Contact us:**

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9.1. For further information about this evidence submission, please contact John Perryman, Senior Policy and Public Affairs Officer, Carers UK ([john.perryman@carersuk.org](mailto:john.perryman@carersuk.org) / 07481038183).

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