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About Carers UK:

[Carers UK](#) is a charity set up to help the millions of people who care unpaid for family or friends. We are a membership organisation of carers, run by carers, for carers. We provide information and advice about caring alongside practical and emotional support for carers. We also campaign to make life better for carers and work to influence – using carers’ insights and lived experiences – policy makers, employers, and service providers, to help them improve carers' lives.

In responding to this inquiry, we raise the need for greater support and recognition to be given to unpaid carers, many of whom face negative consequences because of their caring responsibilities – including worse health and wellbeing outcomes than the general population.

Introduction and summary of our views:

Carers play an essential role in supporting the NHS and social care systems. The pandemic has clearly underlined the essential role that unpaid carers play. Without their support, our health and care systems would have not been able to cope with the increased demand they have seen in the past year.

Greater integration of health and care services is something that unpaid carers want to see more of; carers’ lives are often made much harder when services are not joined up and when data is not shared effectively and efficiently.

We welcome the aims of the Bill, however we are very disappointed that there was no explicit mention of unpaid carers in the White Paper proposals for the Bill.

Not only do carers deserve to be recognised for the important support they provide, but the aims for integration as outlined in the White Paper can only work if unpaid carers are visible, recognised, and counted as part of the NHS.

This Bill presents an excellent opportunity to acknowledge the role of carers in supporting our health and social care systems and provide support for them to look after themselves and the person they care for.

As such, we are calling for carers to be a clear part of the reforms.

Our main calls for the forthcoming Bill are for:

- A duty on the NHS to have regard to carers and to promote their health and wellbeing.
- Clear and explicit references to carers where there are duties for new or existing bodies to consult with patients and communities.
- A carer representative on key decision-making bodies.
- Clear inclusion of carers in the proposed new responsibilities for the Care Quality Commission around the Care Act 2014.
- Explicit safeguards for carers’ rights under the Care Act 2014, if the requirements for assessment and discharge notices are removed.

There are also a number of measures within the Bill that we believe have the potential to improve the experiences of carers. We welcome:

- The aim of greater intergration across health and care systems.
- Measures to share data across systems and within the health system. These will be enhanced if carers are clearly flagged within data systems and their experience tracked across different parts of the health and care system.
- The proposal for the Care Quality Commission to review commissioning by local authorities under the Care Act 2014.

We provide additional detail below.

Improving carers' health and wellbeing as well as outcomes for people who need health and care – introducing a duty to have regard to carers:

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.¹ During the pandemic, the number of carers rose dramatically at one point as many as 13.6 million carers across the UK, or one in four of the whole population.²

Carers health is often impacted by their caring role and they are twice as likely to have ill-health because of caring.³ Carers often play numerous roles simultaneously; administering medication, supporting daily activities of life such as eating, drinking, dressing, moving, supervision and cognitive support, through to more complex specialised nursing care.

Whilst unpaid carers provide the bulk of all care, 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.

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. For effective integration across systems to be achieved, it is essential that both the NHS and social care have a clear, direct and common statutory duty to have regard to carers specifically and to promote their wellbeing. Our work has shown that general wellbeing duties do not result in the outcomes that are desired.

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 the relative's/friend's 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.

¹ 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

² Carers Week (2020) Carers Week Research 2020

³Carers UK (2019) Facts about Carers 2019

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.

Carers and people who use care services bring particular experience; we are concerned that currently, in both existing legislation and in these proposals, carers are not explicitly included. This often leads to consultation missing out the very vital contribution of unpaid carers.

Given that carers are part of, and responsible for, the care of millions of patients and people who use care services in England, including a specific requirement to consult them beyond 'patients and citizens' would ensure that the system paid 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.

We recommend both:

- **A requirement for representation of a carer and a person who uses care services on any decision-making committee or body.**
- **Clear and explicit references to consulting carers where there are duties for new or existing bodies to consult with patients and communities.**

Hospital Discharge:

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). 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 put in place to help them cope.

We are very concerned about the 'discharge to assess' model. To enact this 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.

We are also deeply concerned that the Discharge to Assess guidance published by the NHS did not include any reference to carers' rights under the Care Act 2014. The only reference to carers in the main body of the guidance was to be contacted to collect the person they cared for from hospital. **If this process were to be followed it would fail to meet the statutory requirement in the Care Act 2014 of an assessment of the carers' willingness and ability to care.**

Carers should expect to be involved in decisions about care and to receive support that meets their own needs following discharge. They must also be informed of their rights.

We are concerned that the proposals erode carers' rights and do not allow for effective decision making on whether the amount of care provided by individual carers or families is sustainable. A core element and intention of the Care Act 2014 is to determine if carers are able and willing to continue caring at the same or increased levels.

During the pandemic, 78% of carers have reported an increase in the needs of the person they care for.⁴ This will result in any documentation that the council holds in relation to the carers' needs, willingness, and ability to care being out of date, since the majority of carers have increased care, alongside decreased mental and physical wellbeing.

⁴ Carers UK (2020) 'Caring Behind Closed Doors – Six Months On'

We are concerned about the removal of the requirement for assessment and discharge notices without explicit safeguards in place for carers. Any new primary legislation for discharge to assess must ensure that, before someone is discharged from hospital, their carer is willing and able to care for that person. Under the Care Act 2014, this is an important right along with unpaid carers' right to a Carer's Assessment and this needs to be reflected in any future legislation.

Care Quality Commission – additional duties:

Carers UK welcomes the newly proposed powers for the Care Quality Commission. However, in redrawing the regulations regarding the Care Quality Commission to encompass the Care Act 2014, this needs to explicitly reference carers to reflect the Act.

The new duty for the Care Quality Commission to assess local authorities' delivery of their adult social care duties, must go alongside the regulations for the Care Quality Commission being updated to reflect the Care Act 2014. This is important because the founding regulations of the CQC's duties only refer to people to who use services and do not include carers.

Integration and the establishment of Integrated Care Systems:

We welcome the steps towards integration and a legal footing for Integrated Care Systems alongside objectives to ensure that there is integration within and between different NHS organisations as well as social care. Carers often say that the lack of integration causes additional stress and difficulty.

Increased data sharing:

Carers UK welcomes the proposal that there is increased data sharing. Carers become very frustrated when they have to continually repeat information to different agencies. This also has the potential to connect carers with support earlier in their caring journey. Data sharing has the power to improve carers' lives in this way if carried out appropriately. It would be vastly enhanced if carers were flagged on key records and their journey potentially tracked as well.

Long term plans for social care and health:

We welcome some measures and principles contained within the White Paper. If carers are included properly in NHS legislation, as we are advocating in this submission, then there are some foundations for some elements of long term planning/reform of adult social care.

However, the White Paper does not deliver the social care reform that has been widely promised by Government as necessary. Even before COVID-19 arrived, social care was widely recognised as being in urgent need of reform and refinancing following years of underfunding; between 2010/11 and 2018/19, when adjusted for the increase in population size by age, real terms spending on social care per head of the adult population is estimated to have fallen by a mammoth 12% over this eight-year period.⁵

To look at the longer term and not include carers is a serious oversight. Reform is urgently needed and the government needs to set out plans for a long term, sustainable solution to funding social care that has carers at its heart. A failure to do so will only see social care continue to be in crisis, with knock on effects on hospitals, the economy, families, carers and people who need access to care.

⁵ Care and Support Alliance (2021) A cry for hope: why 2021 must be the year for social care reform

A reformed system and funding solution must guarantee stability and sustainability, deliver improvements to care and be well funded, with sufficient resources to enable the delivery of consistent high-quality care. We want to see care free at the point of delivery under a system of pooled risk, ideally funded through taxation. The plans need to include working age disabled people and older people, as well as key specific measures to support carers.

Carers have also given the message loud and clear that social care reform must go hand in hand with specific measures to support carers. They must also be involved in the development and delivery of these plans. Anything less than these measures will be falling short of what carers want, need and deserve.

Workforce strategy:

We support others' calls for the Workforce Strategy and see this as both essential and urgent. So often carers' health and wellbeing is dependent on care workers good quality support. 2.6 million carers have had to give up work to care because of they could not find suitable alternative care.⁶ Short ages of care which lead to lower quality affects carers health and wellbeing and can impact upon their ability to work.

Testimony from carers:

The following quotes from carers show the impact that caring has on people, and why it is important for the NHS to have regard to carers, and to promote their health and wellbeing:

"I had been caring for my mother for years and my health was deteriorating and it got to the point when I had stress and could not cope"

"My GP surgery told me I wasn't recognised as a carer because I don't get Carer's Allowance. I feel totally helpless"

"Both people I care for have medical conditions that are not straightforward to manage. No one in the health services has an overview of either. Life gets very complex and I've found it difficult to maintain my own diet and exercise regime. And in a 10 minute GP appointment, there isn't time to explain everything."

"Looking after your own health is one of the most difficult aspects of caring which professionals don't seem to recognise or prepare for."

"I often feel under stress as my own mental/physical health and financial situation deteriorates, due to the fact that I am not sure where to access all possible avenues of support and those that I have enquired about have turned out to be mostly 'blind alleys' as I don't fit into any neat little pre-existing categories properly. If I am ill (other than seriously) or unable to cope for any reason, there is seemingly no help available whether practically or financially so I am looking at a very bleak old age."

"There is no doubt that my caring role has affected my physical and mental wellbeing. I have dealt with this by reducing my working hours to reduce stress, and hiring private care workers to supplement free care."

"I always put myself last. I often don't have time to seek medical support for my long term health condition. I know that this will have a long term effect on my health."

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⁶ Carers UK (2019) Juggling work and unpaid care: a growing issue