

Westminster Hall Debate on Unpaid Carers and Carers Week – 22 July 2021

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1. Summary

- **There are approximately 700,000 informal carers of people with dementia in the UK, many of whom are themselves older people with their own physical/mental health issues.**¹
- During the first wave of the Covid-19 pandemic, family and friends have spent an additional **92 million hours** caring for loved ones with dementia.²
- Since the pandemic began, **unpaid carers have provided £135bn worth of care – a significant contribution to our economy.**³ But we know that without reasonable support, informal care relationships are at risk of breaking down.
- Existing difficulties in **accessing appropriate support services, carers assessments and respite care** have been exacerbated by the pandemic. **The Government must require public health bodies to gather data on the number of carers' assessments being offered and taken up, and on the number of short breaks provided to carers.**
- Forthcoming proposals on **social care must ensure carers are recognised as an integral part of the care ecosystem.**

2. Dementia and Informal Carers – the Context

The 700,000 informal carers of people with dementia in the UK play an invaluable role in the social care system and in society as a whole. Many carers are themselves older people with their own physical and/or mental health issues. **Unpaid carers for people with dementia do a superb job in sometimes trying circumstances** and are often keen to provide the support they do. Their role needs far greater acknowledgement, and the state needs to help them fulfil this role, ensuring safeguards are in place if they are no longer able to do so.

Caring for someone with dementia can be both rewarding and challenging, meaning it's all the more important that effective support is available. Due to the complex nature of both dementia and the health and social care system, unpaid carers are often expected to be proactive in seeking an assessment of their needs and appropriate support services. **This need to actively seek support and identify oneself as a carer is a significant barrier to local areas fully supporting their carer populations.**

3. Support for Unpaid Carers

It is vital that the Government equips local authorities with all they need to provide the support they want to offer to unpaid carers. Innovation at a local level has also been hampered by inconsistent data collection. This is **why Alzheimer's Society is calling on the Government to require public health bodies to collect local authority and health authority-level data on a) the number of carers assessments offered and the number taken up,** with the reason for their caring responsibility (e.g.

¹ Alzheimer's Society. The Fog of Support: An inquiry into the provision of respite care and carers assessments for people affected by dementia. 2020. https://www.alzheimers.org.uk/sites/default/files/2020-09/as_new_the-fog-of-support_carers-report_final-compressed.pdf.

² Alzheimer's Society. Worst Hit: Dementia During Coronavirus. 2020. <https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf>.

³ Carers UK. Unseen and undervalued: The value of unpaid care provided to date during the COVID-19 pandemic. 2020.

the condition(s) of the person they care for) also recorded, **and b) the number and type of short breaks for carers provided.**

In recognition of the progressive nature of dementia and thus of caring responsibilities, too, we must ensure that carers' assessments of carers for people with dementia are provided at least annually. More regular reviews should also be implemented if appropriate to circumstances, and assessments should cover emergency planning in the event a carer were unexpectedly no longer able to provide care.

More broadly, it's vital that a strengths-based approach is adopted for carers assessments, which focusses on the positive aspects of carers' practice while also acknowledging areas where they may need extra support and advice. Simple language changes are also very important and can have powerful implications for carers: Alzheimer's Society's [Fog of Support](#) report found that guilt was a significant barrier to people accessing support. 'Carers' assessments' can sound to some carers like they're being inspected, so using phrases like 'check in' instead can have a hugely positive impact; similarly, instead of asking 'if' someone needs a break from their caring responsibilities, talk about 'when', which will help address the feelings of guilt many carers experience.

A strengths-based approach can also be encouraged; **rather than focussing on the areas where a carer might be struggling, emphasise and celebrate the areas they are doing well,** while also identifying others where extra support could be offered. **Low-cost initiatives such as peer support groups for carers of people with dementia, led by a facilitator** have repeatedly been found to improve mental wellbeing, allowing carers to feel heard and be reassured.⁴

4. Covid-19 Context & Social Care Reform

During the first stages of the Covid-19 pandemic, **family and friends spent an additional 92 million hours caring for their loved ones with dementia.**⁵ Months in lockdown, **spent without assessments of their needs or respite care and with limited social contact,** has meant that **95% of carers reported a negative impact on their mental or physical health.**⁶ These issues were present prior to the pandemic but have now been exacerbated.

Since the pandemic began, **unpaid carers across the UK have provided £135bn of care to people with all kinds of health conditions – a hugely significant contribution to our economy.**⁷ For too long, this contribution has been taken for granted – particularly now, when the pandemic has left many unpaid carers feeling isolated and struggling to cope. Without reasonable support, informal care relationships are at risk of breaking down.

Alzheimer's Society's #CureTheCareSystem campaign highlights the need to ensure that social care reform is attentive to quality of care, not just its cost. **The needs and abilities of carers must also be considered as part of this reform, with carers recognised as an integral part of the care ecosystem.**

The following lines from the Secretary of State for Health and Social Care's recent speech to the Local Government Association are especially welcome: **'now we all want to see high-quality personalised care. We all want to see fairer ways of paying for that care. We all want people to have the choice of housing that works for them. We all want carers to be better recognised for the work they do.'**

⁴ Thompson, Spilsbury, Hall et al. Systematic review of information and support interventions for caregivers of people with dementia. 2007. BMC Geriatrics 7, article 18.

⁵ Alzheimer's Society. Worst Hit. Dementia During Coronavirus. 2020.

⁶ Ibid.

⁷ Carers UK. Unseen and undervalued: The value of unpaid care provided to date during the COVID-19 pandemic. 2020. https://www.carersuk.org/images/News_and_campaigns/Unseen_and_undervalued.pdf.