

## **Alzheimer's Society briefing – Social Care Provision and the Role of Carers – 24 June**

Full motion: that this House takes note of social care provision in the United Kingdom, and the role of carers in that provision. **For more information contact Laura Mullaney at [laura.mullaney@alzheimers.org.uk](mailto:laura.mullaney@alzheimers.org.uk)**

This briefing includes:

1. **Summary**
2. **Background and forthcoming Dementia Strategy**
3. **The role of carers**
4. **The case for social care reform in England, Wales and NI**

### **1. Summary**

- National Government must provide dementia carers with the support they need to provide care and meet their own physical and emotional needs.
- Better national data on respite and carers' assessments would enable the Government to better understand existing provision and identify gaps that need filling.
- Social care reform must support people with dementia to live with choice and control, and move beyond a focus on personal care to strengthen relationships with families and communities.

### **2. Background and Dementia Strategy**

There are an estimated 850,000 people living with dementia in England<sup>1</sup>. It is estimated that 14% live with mild dementia, 28% live with moderate dementia and 58% have a severe form of the condition<sup>2</sup>. By 2025, 1 million people will be living with dementia and by 2040, 1.6 million people will live with the condition<sup>3</sup>.

#### Dementia Strategy

**The Department for Health and Social Care is currently developing a Dementia Strategy, designed to “boost dementia awareness, diagnosis, care, support and research in England”<sup>4</sup>. This is an opportunity to draw together all strands of the Government's dementia activity to form a strategy with a clear timeline, which **must recognise the substantial impact that the pandemic has had on people affected by dementia, and ensure that people with dementia can be supported to recover from the effects of the pandemic.****

Alzheimer's Society welcomes the opportunity to feed into the Strategy. However, we are concerned by a lack of concrete ambitions in the latest draft we have seen. **It must urgently address the impact of Covid-19 on people affected by dementia with a clear, timetabled strategy supported with sufficient resource to succeed.**

### **3. The role of carers**

There are currently 700,000 informal carers of people with dementia in the UK.<sup>5</sup> Carers of people living with dementia are often older people who may have their own mental or physical health issues. While they are often hugely dedicated, providing care can take a huge emotional and physical toll.

#### The impact of Covid-19 on carers

**We know carers are exhausted, as a group which has provided millions of hours more care than usual during the pandemic in the absence of respite provision.** 40% of carers have spent over 100 hours a week caring for people with dementia<sup>6</sup>. Because of Covid-19 restrictions, wider family support has also been far less available to carers.

#### Challenges in providing carer support

**The lack of integration between our health and social care system means that the onus is too often on dementia carers to seek out support,** which is particularly challenging given the pressures carers are under. There is a reported lack of available services that enable carers of people living with dementia to take a break from caring. National data on carers and specific conditions are limited and cannot be disaggregated to provide a clear view of publicly funded

<sup>1</sup> Wittenberg et al. Projections of Older People with Dementia and Costs of Dementia Care in the United Kingdom, 2019-2040 (2019)

<sup>2</sup> Ibid

<sup>3</sup> Ibid

<sup>4</sup> HC Deb 27<sup>th</sup> May 2021 Vol 696 Col 583

<sup>5</sup> Lewis et al 2014 'Trajectory of dementia in the UK – making a difference <https://www.ohe.org/publications/trajectory-dementia-uk-making-difference>

<sup>6</sup> Alzheimer's Society. 'Exhausted' family and friends spent 92 million extra hours caring for loved ones with dementia since lockdown. 2020. <https://www.alzheimers.org.uk/news/2020-10-05/exhausted-family-and-friends-spent-92-million-extra-hours-caring-loved-ones>.

support for carers of people living with dementia. Furthermore, national data sets do not contain good quality information related to short breaks for carers.

#### How we can better support carers

Carers can find providing care very rewarding but need effective support to enable them to continue caring. Alzheimer's Society recommends:

National governments in England and Wales should require public health bodies to collect local authority and health authority-level data on:

- a. *The number of carers assessments offered and number taken up, with the reason for their caring responsibility (e.g. the condition(s) of the person they care for) also recorded, and;*
- b. *The number of short breaks for carers provided recorded, including the type of break. Parallel codes should be used for financial spend and the volume of support provided to enable comparisons of unit prices for support.*

#### 4. The case for social care reform in England

##### The impact of Covid-19 on people with dementia

**People with dementia have been worst-hit by the pandemic, accounting for over a quarter of all Covid-19 deaths.**

<sup>7</sup> Tens of thousands more have seen their condition deteriorate at an increased pace than would otherwise be the case over the last 12 months due to limited support and social isolation brought on by repeated lockdowns.

##### Social care reform

**During his first speech as Prime Minister, Boris Johnson committed to 'fix the crisis in social care once and for all'.**

As we approach two years since the Prime Minister took office, Alzheimer's Society was concerned to hear this week that a ministerial meeting to discuss the forthcoming proposal was postponed. We hope to see a proposal at the earliest opportunity.

**The central principle of social care must be that it focuses on what matters to people while acknowledging the importance of care that offers people choice and control;** that supports the individual with choosing and setting their own goals; that recognises the importance of relationships to health and wellbeing; and that improves people's experiences of 'living well,' grounded in research.

**The right care and support services can make a huge difference for people with dementia and their families.**

Personal care can help with washing, dressing, laundry and meals; extra support helps people with dementia carry on doing activities they love and spend more quality time with the people who matter most in their lives. Respite breaks for family carers give them time to recharge and look after their own wellbeing.

##### Social care in Wales

As services and day centres slowly begin to re-open in Wales, and with the Welsh Government announcing £3 million of funding towards respite care, there is a sense that things are beginning to return to 'normal' for our unpaid carers. What the pandemic has shown though, is that 'normal' isn't good enough. Prior to COVID-19, our carers were stretched, struggling and strained. **The fact that all four parties elected to the Senedd in early May talked about social care reform in their manifestoes is a sign of a step change in how Members of the Senedd see the issue of social care. This change needs to happen at pace** if we are to truly recognise the contribution of our unpaid carers through the pandemic.

##### Social care in NI

**Carers NI indicate that 79% of carers said they had not had any breaks during the pandemic<sup>8</sup> so the need to restore short respite breaks for carers is a central issue currently.** During the vaccination roll out, which was specifically widened to include carers, it became clear that there was a lack of detail in Northern Ireland as to the definition of a 'carer' and there is no formal register of those people providing care which urgently needs addressing.

<sup>7</sup> González, Livingston et al. Impact and mortality of COVID-19 on people living with dementia: cross-country report. 2020. International Long Term Care Policy Network, Care Policy and Evaluation Centre, London School of Economics. <https://lccovid.org/wp-content/uploads/2020/08/International-report-on-the-impact-of-COVID-19-on-people-living-with-dementia-19-August-2020.pdf>.

<sup>8</sup> Carers NI 2021 <https://www.carersuk.org/northernireland/news-ni/worn-out-unpaid-carers-in-northern-ireland-uncertain-the-services-they-rely-on-will-continue-post-pandemic>