This briefing sets out a series of recommendations to support Local Authorities to improve their support for carers of people living with dementia.

The importance of supporting carers

Supporting and caring for someone living with dementia can be positive and rewarding, but it can also be very challenging. Currently, there are around 700,000 informal carers of people living with dementia in the UK. It is likely that the true number is larger due to the high number of family and friends who do not see themselves as a carer in the formal sense, but nonetheless play a significant role supporting their loved one to live well with the condition.

While caring for someone with dementia can be incredibly rewarding, it can also take its toll. Carers of people with dementia are often older people who may have their own health challenges to deal with, or people who are juggling work and family life alongside their caring responsibilities.

Due to the progressive nature of dementia and the many forms it can take, symptoms vary and change over time. Aggressive behaviour, walking with a purpose and memory challenges can be very distressing. It can be hard to know how to manage these behaviours, leading to feelings of guilt, anger and stress. Carers often become isolated as they feel unable to safely leave the cared-for person alone, and struggle to know where to turn for support.

We believe councils have a significant role to play in improving the lives of those caring for people with dementia. Adult Social Care teams alongside local health and social care partners can provide information about dementia, how to manage symptoms, and where to go for practical advice and support. They can also provide respite care, support carers to look after their own mental health and wellbeing and help families to feel less isolated.

Informal carers of people living with dementia account for a significant proportion of adult carers in many areas of England. As such, Alzheimer’s Society believes that:

- All councils should have a Carers Strategy with a specific focus on carers of people with dementia. This should detail the support available, including access to psychological support and practical training for informal carers.
- Current and former carers of people living with dementia should be actively consulted as part of the development and regular review of the Carers Strategy.

The importance of breaks for carers

Around 40% of family carers have clinically significant depression or anxiety. Respite care enables carers of people living with dementia to take a break, offering them time to look after their own physical and mental health. It also gives them a chance to catch up on activities they may have missed due to their caring responsibilities, or time to do something just for themselves.

Without the carer, there can be a significant reduction in the level of care provided for the person living with dementia. By providing a range of respite options – from one hour to one week - Local Authorities can support the carer which in turn may help the person with dementia to stay in their home for longer.

However, we have heard from professionals and family carers that there is a shortage of respite care places that are suitable for the needs of people living with dementia. This includes people with young onset dementia, those requiring in-home support and pre-planned residential care. The result is that short-term care or last-minute residential places that enable carers to have a break are limited. In addition, many Carers report challenges in booking care in advance and cited these as specific barriers to taking much needed breaks away from caring.

---


3 Ibid
To support carers to access respite care, Councils should:

- Provide carers with accessible information about quality local respite care options that meet the needs of both the person living with dementia and the carer, including those with young onset dementia.
- Provide carers with straightforward methods of booking overnight care in advance to allow them to properly manage when they have a break from their caring responsibilities.

The importance of Carers Assessments

Anyone who cares for a person living with dementia is entitled to a Carers Assessment. This assessment helps to determine what support the carer might need to enable them to care for their loved one while maintaining their own health.

Although councils have a statutory duty to identify and consider the needs of carers, Alzheimer’s Society research highlighted that only a minority of carers across England had received an assessment of their needs. In many instances, carers seem to be missing out because councils expected carers to approach them for an assessment, rather than automatically offering one. This has led to large gaps in care and support.

Of those who had received an assessment, many carers told us they felt there was a lack of understanding about dementia and how it would impact on their personal circumstances. Telephone assessments were also felt to be very impersonal, whilst assessments provided in person at the location were felt to be more positive for the person with dementia and the carer.

To ensure every carer receives an assessment Councils should:

- Proactively offer a Carers Assessment to all identified carers and ensure they are provided in person. Where a telephone assessment is unavoidable, follow up face-to-face meetings should be offered.
- Ensure that Carers Assessments are provided at least annually by people trained to Tier 2 of the NHS-backed Dementia Training Standards Framework.

The impact of the Covid-19 pandemic on carers of people living with dementia

Across England, the pandemic has brought intense additional pressures on those caring for people living with dementia. Family carers lost formal respite opportunities, and the burden of care was increased by successive lockdowns and Government shielding advice for the over 70s.

Alzheimer’s Society estimates that between March and August 2020, family and friends spent an extra 92 million hours caring for loved ones with dementia. This additional burden has taken its toll. 95% of carers of people living at home with dementia reported a negative impact on their mental or physical health, including exhaustion, anxiety, depression, physical injury and insomnia.

Informal carers have experienced increased pressures during the Covid-19 pandemic and need emotional and practical support. As a matter of urgency Councils should:

- Ensure those who took on a caring role during the pandemic are identified and given the opportunity to access the information and support they require.
- Proactively offer all existing dementia carers a new Carers Assessment to identify how support needs may have changed during the pandemic.
- Ensure respite services are reopened at the earliest opportunity and when safe to do so.

For more information, please contact Alzheimer’s Society’s Regional Public Affairs and Campaigns team at local@alzheimers.org.uk.

---

7 Ibid