Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Gwella mynediad at gymorth i ofalwyr di-dâl

This response was submitted to the Health and Social Care Committee consultation on Improving access to support for unpaid carers.

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Alzheimer's Society response to the Health and Social Care Select Committee's inquiry into improving access to support for unpaid carers.

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Nb: We are content for our name to be published with this response and do not require any of it to be treated as confidential.

Executive Summary

This response is submitted on behalf of Alzheimer's Society, the largest dementia charity in England, Wales and Northern Ireland. We are a leading voice on the issues that matter most to people living with dementia, from working with academics and commissioning robust, evidence-based research to influencing decision makers locally and nationally through our campaigns.

Dementia is the biggest health and social care challenge of our time. There are currently around 1 million people with dementia in the UK, and this is expected to rise to 1.4million by 2040[1]. In Wales there are around 51,000 people with dementia, projected to reach almost 70,000 by 2040 (an increase of 37%)[2]. There will be many more people impacted as family members and friends. Its reach extends into every corner of our society.

The associated economic cost of dementia in the UK today is £42bn, rising sharply to £90bn by 2040 - the largest cost associated being the cost of unpaid care, accounting for 50% of the total in 2024 in the UK[3]. In Wales, dementia currently costs £2.3bn, which will rise to £4.6bn in the next 15 years[4] - that's almost half the entire health and social care budget for the Welsh Government today. Regarding unpaid care costs, this translates to just under £1.1 million in 2024 in Wales, compared to £1.9 million in 2040[5].

Despite the scale of dementia, the day-to-day realities of living with and caring for someone with dementia often remains hidden or misunderstood. We recently undertook a survey of 3,487 people in England, Wales, and Northern Ireland affected by dementia[6] (including 405 in Wales).[7] identified that:

- 46% don't know who to contact for social care support. This rises to 56% among unpaid carers.
- A quarter of people who know or care for someone with dementia are dissatisfied with the health (24%) and social care (24%) support that is available to those who care for people living with dementia.
- Many unpaid carers also don't feel respected in their role by social care professionals. When unpaid carers were asked if they feel respected as a carer by social care professionals, nearly half (46%) disagreed, and only one in six (16%) agree that they feel respected as a carer. Those from an ethnically diverse

[1] Alzheimer's Society and Carnall Farrar (2024), The economic impact of dementia.
[2] Ibid
[3] Ibid
[4] Ibid
[5] Ibid
[6] Alzheimer's Society and Walnut Unlimited (2025), The Lived Experiences of Dementia
[7] Where we have Wales-specific data from this survey, we have made this clear in our response. Where not specified, data from our survey covers England, Wales and Northern Ireland.

background (7%) were even less likely to agree that they feel respected as a carer by social care professionals.

- 72% of unpaid carers in Wales said that caring has negatively impacted their lives, with 41% reporting a negative impact in their mental health and 28% reported feeling socially isolated. Just under half (48%) say that they spend less time doing the activities that they enjoy.[8]

In light of the significant impact that unpaid caring has on those caring for people living with dementia, it is clear that better access to dementia-specific support services is much needed.

We welcome the opportunity to respond to this important inquiry, emphasising that improving access to support services for people living with dementia and their carers must be a priority. Our vision is for people living with dementia to be able to easily access high-quality, affordable social care that meets their specialist needs, delivered by a well-trained workforce and for unpaid carers to receive the statutory support to which they are entitled and to be able to take breaks through access to dementia-specific respite care.

To achieve this, Alzheimer's Society is calling for Welsh Government to evaluate progress against the priorities in the National Carers' Strategy 2021, making any adjustments necessary in a refreshed strategy to ensure progress against the priorities is achieved.

Consultation questions

Question 1: The main barriers faced by unpaid carers in accessing the support they need, including any specific challenges for carers based on factors such as age, ethnicity or where they live.

1. Unpaid carers are the backbone of the social care support that people living with dementia receive in every nation in the UK, but over half of those who know someone with dementia in Wales say that friends and family are the only points of support.[9] An unpaid carer who contributed to our recent survey of lived experience told us: *"I have no time to spend on myself or see friends and family. It has dominated my life. It also had an impact on my mental health due to the constant worrying and lack of time to look after myself."*[10]

1.1 Despite the vital role they play, evidence shows that unpaid carers of people living with dementia too often encounter a multitude of challenges when it comes to accessing the support they need. This includes:

a) Limited awareness of available services (including dementia-specific respite care) and support:

- Of those who know or care for someone living with dementia, just 3 in 10 (31%) agree that social care support for dementia is easy to access. There was even lower agreement amongst those with experience of the early stages of dementia (18%), people from an ethnically diverse background (18%) and those who live in urban areas (22%).[11]

[8] Ibid
[9] Ibid
[10] Ibid
[11] Ibid

- Nearly half (46%) don't know who to contact if they need social care support for the person they know or care for[12].
- Only 23% of unpaid carers for people with dementia we recently surveyed reported to know about dementia specific respite breaks, and only 7% have used them[13].
- Of unpaid carers who are aware of the support available to them, many do not actually receive any support. Just under half (45%) do not receive any support that is available to them[14]. Only one in five (19%) receive attendance allowance, and a similar proportion (18%) receive carer's allowance. Even fewer unpaid carers have received a carer's assessment (12%) or any community support (11%)[15].
- Around a quarter (23%) of unpaid carers are aware of community support, dementia specific respite breaks and carer's assessment. The least known forms of support are direct payments (15%) and carer's credit (13%)[16].

b) Variations and inequality:

- There is a lack of consistency in the support available for people living with dementia. One in five people (23%) in Wales said that they have not received any healthcare, social care or financial support for the person living with dementia[17].
- There are even higher levels of dissatisfaction with health care support available among people living in a rural area (27%), those experiencing late-stage dementia (30%), and people with a disability (32%). Likewise, dissatisfaction for social care support available is greater among those with a disability (35%), in late stages of dementia (33%) and those living in a rural area (29%)[18].
- Dissatisfaction with the social care support available to unpaid carers is also higher amongst those with a disability (32%), those caring for someone experiencing late-stage dementia (30%) and people living in a rural area (27%)[19].
- 38% of the unpaid carers we surveyed said they don't feel respected by social care professionals; the percentage of dissatisfied carers rises to 60% for those from ethnically diverse backgrounds[20]. During our recent survey, we spoke to Jackie, who cares for her mother, and she urged decision makers to *"listen to patient's families because they know their relative best."*[21]
- Those from an ethnically diverse background (7%), those caring for someone in the early stages of dementia (7%) and those living in an urban area (8%) were even less likely to agree that they feel respected as a carer by social care professionals[22].

Impact on unpaid carers of people living with dementia:

1.2 For many unpaid carers, the current experience of social care support available to them is not satisfactory. Just 41% of the people in Wales we surveyed were satisfied with the

[12] Alzheimer's Society and Walnut Unlimited (2025), The Lived Experiences of Dementia
[13] Ibid
[14] Ibid
[15] Ibid
[16] Ibid
[17] Ibid
[18] Ibid
[19] Ibid
[20] Ibid
[21] Ibid
[22] Ibid

social care support available to people living with dementia. The above challenges can leave unpaid carers feeling isolated and overwhelmed, making it difficult for them to sustain their vital caregiving roles. Nearly two thirds of people we surveyed report they are struggling with their own health conditions while providing care, and one in five say that they are neglecting their own health[23].

Suggested actions:

1.3 As our population continues to age, ensuring effective support for unpaid carers has become increasingly crucial. By focusing investment and prioritising key areas, we have the opportunity to overcome existing challenges and enhance the resources available to unpaid carers in Wales. It is essential that decisive action is taken to improve the quality of life for unpaid carers of individuals living with dementia. Tangible steps could include:

a) In our survey, 58% of unpaid carers said that easier processes to access support from care workers who are skilled in delivering dementia care would best help improve the lives of people living with dementia[24]. More than half of people affected by dementia in Wales believe professional carers who are more skilled in caring for those with dementia would best help to improve the lives of those living with dementia[25]. Furthermore, people with dementia require more support as their dementia progresses. When considering accessing support services such as respite care, people living with dementia and their unpaid carers, need reassurance that their needs will be met before they access support services like respite care. Better training can help address this: for example, training can improve the ability of care workers to manage behaviours that challenge and agitation, improving relationships.[26] **We recommend that Welsh government introduce a statutory duty requiring all care staff to undertake dementia training, mapped to the Good Work Framework.**

b) **More support from professionals and a single named contact for advice or support.** Support from healthcare professionals is the top action identified by unpaid carers to improve carer support, with more than half (57%) reporting this as a need[27]. A similar proportion (55%) believe having one named person to support or advise them could improve the support available to carers. Half (49%) would generally like more support from professional carers[28].

c) Over half (54%) of the people we surveyed also believe that **better access to dementia specific respite care** would improve the support available to unpaid carers, and a similar proportion (52%) think additional financial support could help[29].

d) Unpaid carers would like **earlier support and greater training, practical support and guidance** to help reduce stress and to support them in their caring role. Some also want spaces within communities to share their experiences[30].

Question 2: The current availability of respite care across Wales, including levels of variation across regions.

2. Clearly, unpaid carers are fundamental to the social care system, yet their contributions often go unnoticed and unsupported. With the challenges carers can face, dementia

[23] Alzheimer's Society and Walnut Unlimited (2025), The Lived Experiences of Dementia
[24] Ibid
[25] Ibid
[26] Alzheimer's Society (2024) Because We're Human Too, p19
[27] Alzheimer's Society and Walnut Unlimited (2025), The Lived Experiences of Dementia
[28] Ibid
[29] Ibid
[30] Ibid

specific respite care (short-term residential care for people living with dementia) should enable carers to take breaks and manage their own wellbeing. Ensuring easily and timely access can be crucial for helping carers to feel less overwhelmed in their caring role, maintaining their relationship with the person cared for and other relationships, preventing burnout and maintaining caring arrangements for longer.

2.1. Yet, concerningly, our research suggests take-up of respite services amongst those who are caring for someone with dementia is low: just 7% of those we surveyed have been able to access appropriate dementia-specific respite care[31].

2.2. With over half (54%) of people we surveyed believing that better access to dementia specific respite care would improve the support available to unpaid carers[32], it's important that uptake is increased.

2.3. This is further supported by Dementia Carers Count data, which indicates that 85% of unpaid carers of people living with dementia have reached crisis point, with 52% stating they receive no support at all[33].

Suggested actions:

2.4. Alzheimer's Society believes that the main priorities for Welsh Government's updated National Strategy for Unpaid Carers should include:

a) Ensuring unpaid carers receive the statutory support to which they are entitled.
b) Ensuring unpaid carers can access dementia-specific respite care.
c) Ensuring that all social care workers, including those delivering respite care, have received high-quality dementia training, mapped to the Good Work Framework.
d) Providing long-term sustainable investment into social care, with a shift from short-term thinking to multi-year funding settlements. The certainty this will provide will enable long-term planning, improvement and innovation, which can help to ensure that dependable services exist to support unpaid carers.

Question 3: The extent to which the demand for carers support services is being assessed and addressed, and current levels of unmet needs.

3. As outlined in our response to question 1, our recent survey identified that 1 in 7 carers were not aware of any sources of support, while 46% don't know who to contact to find out how to access social care support[34]. Furthermore, our evidence found that a fifth are not aware of any areas of support that are available for carers, and over half have not received any help[12].

Question 4: The role of Regional Partnership Boards in the provision of support for unpaid carers, and the effectiveness of current commissioning practices for services.

4. Not answered

Question 5: The actions required to improve the implementation of the Social Services and Well-being (Wales) Act 2014 provisions for unpaid carers (including Carers Assessments and support plans).

[31] Alzheimer's Society and Walnut Unlimited (2025), The Lived Experiences of Dementia
[32] Ibid
[33] Dementia Carers Count (2024), What if... i'm not there to care?
[34] Alzheimer's Society and Walnut Unlimited (2025), The Lived Experiences of Dementia

5. Our latest research reveals significant gaps in the awareness and uptake of carer's assessments among those caring for people with dementia in Wales, England, and Northern Ireland. Specifically:
   - Only 23% of carers are aware of their entitlement to carer's assessments.
   - Only 12% of carers have received an assessment[35].

5.1. Furthermore, in Wales, a Carers Wales report outlines delays to assessments, while only 17% carers surveyed had received a Carer's Needs Assessment in the last 12 months[36]. This is despite a legal right to one under the Charter for Unpaid Carers.[37]

5.2. These findings highlight a concerning picture of the delivery on the statutory rights of carers and demonstrates a need for urgent, effective and sustainable action.

5.3. In terms of improvements and actions that can be taken, our survey shows that 52% of respondents identified having one central contact as a way to improve the support available to carers of people living with dementia[17]. We encourage the prioritisation of effective and sustainable actions to uphold carers' statutory entitlements and improve outcomes for carers and people living with dementia. Failure to address these issues risks leaving carers unsupported, which in turn can negatively impact the wellbeing of both carers and those they care for.

[35] Alzheimer's Society and Walnut Unlimited (2025), The Lived Experiences of Dementia
[36] Carers Wales (2025), State of Caring in Wales 2024 The impact of caring on: Carers' health and wellbeing, and support with caring
[37] Carers Wales (2024) Track the Act 2024