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.

UC03 : Ymateb gan: Parkinson's UK Cymru | Response from: Parkinson's UK Cymru

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Response to the Senedd Health and Social Care Committee consultation on: Improving access to support for unpaid carers.

Summary

This is Parkinson's UK Cymru's response to the Senedd Health and Social Care Committee consultation. It is informed by our conversations with unpaid carers across Wales at a series of engagement events (in Abergavenny, Carmarthen, Wrexham and Bangor) during June 2025 where we provided a short presentation on the rights of unpaid carers to a total of 103 people (both unpaid carers and people living with Parkinson's) and invited discussion on the issues important to unpaid carers of people living with Parkinson's informally throughout the event.

The response is also informed by data collected via an online survey circulated via our Campaigns Network in Wales specifically to inform the inquiry of 'live issues' around support for unpaid carers. There were 15 responses to the online survey and, although we acknowledge this is not a large number, and therefore isn't statistically robust in any way, the data reflects the direct experiences and concerns of those currently providing unpaid care for people living with Parkinson's in Wales and is reflective of the conversations we had with participants at our engagement events. We therefore felt it important to highlight the key issues raised through our work with the Parkinson's community over the past few months.

The overwhelming sentiment among those we spoke to at our engagement events

and those who responded to our survey is one of ongoing challenge and isolation in navigating support both for themselves and the person they care for. These are not new themes and the ongoing confusion and disparity in information about, paying for and access to respite care suitable for those caring for someone living with Parkinson's is causing distress to those affected.

Main barriers faced by unpaid carers in accessing the support they need. Specific challenges for carers based on factors such as age, ethnicity or where they live:

- **Difficulty in accessing information and contacts:** Respondents highlighted the challenge of knowing what support is available, who to contact, and where to turn for useful information.
  "Not knowing who or where to turn to." (survey participant)
- **Issues with social services and DWP:** Respondents faced slow responses, lack of staff availability, and difficulties in getting help from social services, with one individual experiencing a "total nightmare" with the DWP carers allowance team.
- **Lack of available care and respite:** Several unpaid carers reported that carers and respite care were not available when needed, not frequent enough, or not available after certain hours, making it difficult to get uninterrupted sleep.
  "Slow response from social services; carers and respite care not available when needed, then not frequent enough; support for my caring role at home seems grudging because "why don't you try residential care" (I guess this would be easier for them to provide!); no care available after 7pm; very hard to get help so I can have one or two nights uninterrupted sleep: I get very tired. Continuity of care from GP no longer available." (survey participant)
- **Poor communication and continuity of care:** Issues included having to repeatedly provide information, professionals not reading notes, and a lack of continuity of care from GPs.
- **Geographical location:** Living in a rural area or areas with limited health facilities, such as Powys, makes accessing support difficult. Distance from

coastal towns was also cited as a barrier and people told us of there being no help nearby. *Social services say that if we lived in a more populous area that they would be able to provide some help. (survey participant)*

- **Personal barriers:** A personal reluctance to burden the NHS support systems. *"My main challenge is me! I realise how much pressure the NHS is under and I don't want to burden the support systems with my problems unless it is absolutely necessary." (survey participant)*
- **Local health service failings:** Local hospitals and GP services being in special measures (in some locations), leading to long ambulance wait times and extended waits in A&E, significantly adds to stress for carers and compromises patient safety.
- **Assumptions and employment:** There's an assumption that professional jobs can be set aside for caregiving, impacting access to support. *"My age was a factor because I was still working in a professional job but the assumption seemed to be that I could put this aside in order to care." (survey participant)*
- **Transportation issues:** Poor transport options in rural areas are a barrier when long-distance travel to hospitals is required.

Unpaid carers told us about some of the things that they need but which they feel are not currently available to them:

- **Respite care:** More frequent and accessible respite care, including night-time care and day centres, as current options are often insufficient or difficult to plan. *"Respite care more frequently (once in 12-16 weeks is not enough). Night time care perhaps once or twice a week so I can sleep sometimes." (survey participant)*
- **Financial support:** There is a need for an increase in carer's allowance, as the current amount is considered inadequate to live on, and private care costs are prohibitive.
- **Practical help:** Assistance with daily tasks like morning routines (washing, dressing, medication) and support for the person they care for, including someone to visit them.

- **Information and guidance:** A need for better communication about available support, advice, pointers, and training, as they often feel unprepared for their role.
- **Social interaction:** Some unpaid carers feel very lonely and desire more social interaction. "*Social interaction (can feel very lonely)" (survey participant)*

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

Nine out of 13 respondents who answered our online questions told us that it was not easy to find suitable options for respite care. Only one respondent felt it was easy to find suitable options with the other 3 respondents telling us respite care wasn't applicable to their circumstances. Other issues raised relating to the availability of respite care include:

- **Lack of awareness and guidance:** Respondents were unaware of respite care options or didn't know where to begin looking for them. "*Didn't realise we had respite care and when we did , we had to do the work checking and looking at respite homes." (survey participant)*
- **Unsuitable and inadequate options:** Existing local daycare centers were described as outdated and unsuitable for complex needs, and overnight stays were often in nursing homes or old people's homes, which were also considered unsuitable.
- **Care quality concerns:** There were issues with care providers not understanding the importance of timely Parkinson's medication, leading to the person with Parkinson's becoming unwell. *"Not all care providers understand the importance of giving Parkinson's medication at the correct time even when that doesn't fit with "medication rounds". Makes person with PD very unwell if they get it wrong and don't listen when she's trying to tell them why she is not good." (survey participant)*
- **Financial and logistical barriers:** Social services were unwilling to pay for respite care, and arranging additional care was perceived as potentially difficult.

- **Limited provision:** One respondent reported receiving only four hours of care per week at a cost of £100.

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

There were 15 responses to our question asking people *'have you had a carers assessment?'* Of these 4 stated yes, 8 stated no, 1 was unsure, 1 had asked for an assessment and was placed on a waiting list and another had undergone an assessment.

- **Respite and overnight care:** Difficulty accessing respite care, overnight care, sitters, and befrienders, as well as day centers and morning/afternoon care for the cared-for individual. The high cost of private care and lack of family support contribute to this difficulty. *"Additional help to give me a break. Private care is prohibitively expensive. Family don't appear to have the time or inclination to help." (survey participant)*
- **In-home social care:** Challenges in accessing in-home social care at relevant times. *"Help with day to day living. Just not available" (survey participant)*
- **Social interaction and advice:** Difficulties in finding social interaction due to distance and unavailability of medical and social service advice.
- **Help with daily living:** General unavailability of help with day-to-day living.
- **Feeling of isolation:** Some carers expressed feeling alone and unsure of what to do. *"I feel alone and I don't know what to do about it" (survey participant)*

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

Parkinson's UK Cymru is unclear on the role of RPBs in providing support for unpaid carers and believe this in itself this is part of the challenge. As a UK wide organisation, with a dedicated team of 'on the ground' staff based across Wales who provide client facing work to unpaid carers of people living with Parkinson's, there is minimal interaction with RPBs - we're unclear on how we could support the work of RPBs, how the RPB can recognise and benefit from the support work we offer and how we can

feed in to decision makers, at an RPB level, the challenges unpaid carers at a local level tell us they face.

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).

There undoubtedly remains much work to be done to ensure that the implementation of the Act is as effective as possible. In particular:

- Identification of unpaid carers
- Training for social services staff around carers assessments, reviews.
- Resources and capacity.
- Recording of information around unpaid carer needs.