

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.](#)

UC13 : Ymateb gan: Cyfarwyddwr Canolfan Ymchwil (CDGD Cymru) | Response from: Dementia Services Development Centre (DSDC Wales)

Senedd Cymru consultation: Improving access to support for unpaid carers

Submitter: Professor Gill Windle, Director of Dementia Services Development Centre (DSDC Wales), School of Health Sciences, Bangor University. [REDACTED] *I confirm that this submission does not need treating as confidential and that my name/the name of my team members/DSDC Wales can be referred to alongside the evidence.*

Submission represents: Research undertaken by DSDC Wales (Prof. Gill Windle, Drs Diane Seddon*, Gill Toms*, Jennifer Roberts, Patricia Masterson Algar). Established in 1999, DSDC Wales works closely with older people, people living with dementia and their carers, together with health and social care professionals to ensure the research we undertake will make a difference, improve the quality of care and inform policy and practice development.

Background: Dementia is a global public health priority with no cure and limited medical treatment. Supporting the unpaid carers of people living with dementia to live as well as possible is a national and global policy action area. Bangor University has led research that aims to improve post-diagnostic support by generating new, co-produced innovations for people living with dementia and their unpaid carers, including young carers. We believe they can contribute to improving the current health and care situation for unpaid carers.

Addressing unmet needs to enable carers to sustain a life beyond caring : In our research and discussions with people living with dementia and unpaid carers, a major problem was highlighted at the point of diagnosis where an overwhelming amount of information, often irrelevant, is often provided (1) and how that point of diagnosis can be hugely detrimental to their resilience (2). The research heard people use the phrase “Knowledge is Power” to describe how learning about living with dementia was important for their resilience. This led to the professional production of the first [‘Knowledge is Power’](#) a practical, freely available bilingual advice booklet in order to support the resilience of others following a diagnosis. In contrast to much of the generic information currently provided, this is a unique compilation of practical information on how to access services generated from the direct experiences of those living with dementia and their unpaid carers, so it has excellent applicability for others living with the condition. As of June 2025, over 13,000 copies of the booklet have been provided to professionals, people living with dementia and carers across Wales, including commissions from service providers. It has been adapted for use in England and Scotland, and Ireland are currently producing a version.

“Knowledge is Power is a very useful resource to hand out to people when they are struggling and we’re having those conversations with those people. The key information has all been put into one place and this is all we hand out to people. I have total faith and confidence in these resources because they were written by people with lived experience. We feel we have something definite to hand out to people.” (Service provider).

We recently worked with 44 carers and 8 people with dementia to develop [Knowledge is Power for Carers in Wales](#), which is already proving popular with over 4000 copies distributed.

Actions for consideration: We have reduced the provision of overwhelming amounts of information given at diagnosis into one resource 'Knowledge is Power' (KiP) designed by, and for people with dementia and unpaid carers. Given that many people find accessing health and social care services difficult to navigate, these are useful, low-cost resources when families are faced with a dementia diagnosis and could be implemented as part of core service provision.

Barriers faced accessing support due to age – young dementia carers: Our research found that young people who live in families affected by dementia struggle with anxiety, stress, and isolation, are often not recognised as carers, rarely receive bespoke support to help them understand dementia and cope with their caring role, and there are a lack of resources tailored to their needs (3). We worked with young people and Dementia UK (a charity that provides information, support and Admiral Nurses to families affected by dementia) to undertake major adaptations of iSupport for dementia carers, an online resource developed by the World Health Organisation to support the mental health and skills development of unpaid carers. This led to the production of a new resource for young carers, iSupport for Young People. This is the only online interactive support tool for young dementia carers in the world (4). We are working with colleagues globally and for the first time this has also brought a focus to young dementia carers in Spain, Brazil and Italy. We have just had funding to undertake further research (start date 1st October 2025) to develop a peer support programme for service providers to deliver to young carers. This will include iSupport for Young People as part of the programme.

Actions for consideration: young dementia carers have many challenges, are often 'hard to reach and hidden' and so can miss out on support. iSupport for Young People is specifically designed with and for their needs and could be implemented as part of core service provision and the profile raised with schools. It is freely available <https://www.isupportdementiacarers.co.uk/>

Addressing the 'postcode lottery' of accessing support by unpaid carers: We explored the aims of the Dementia Action Plan around the two themes of assessment and diagnosis, and post-diagnostic support across Wales, and assessed whether these are being realized. Further, we gained insight and recommendations around how the experiences may be improved across Wales, according to those with lived experience. Some key recommendations made by respondents, including 61 carers (5).

Only 27% of carers had received an assessment of their own needs. Several carers described having to do their own research and 'fighting' to access suitable support. Respondents made several recommendations for improving diagnosis and post-diagnosis support. Some suggested improvements that would require changes in how services operate, whereas others made suggestions that would be attainable without restructuring or a high financial impact. For example, a need was described in acknowledging the value of carer/family input, and there were calls for professionals to listen to the insight and knowledge of close family members, as well as include them in the process and support team from the beginning.

- People described a need for education and advice around how to prepare and what to expect, such as the opportunity to ask questions, to receive information about signposting, lasting power of attorney, plans for future care, training on how to communicate well with someone living with dementia, and how to respond to behavioural psychological symptoms of dementia. People also said that they would benefit from counselling or someone to talk to.

- Professional staff training on dementia and how to communicate with people living with dementia and their families were recommended, particularly around empathy, sympathy, and compassion. People affected by rarer forms of dementia called for increased education for health professionals about rare dementias to raise awareness and understanding, which should in turn assist with recognizing and identifying dementia, as well as in providing the most suitable support.
- There is a need for more integrated services and continued information/support from a variety of sources. Many respondents suggested that people should have a named person that they can contact, who stays in touch and helps coordinate all support. The findings also revealed the need for better provision of services in Welsh and more Admiral Nurses in Wales.

Short breaks for carers: *Dr. Diane Seddon and Dr. Gill Toms have submitted a separate response. This reflects their research, demonstrating that personalised break options can contribute towards positive outcomes for unpaid carers, which informed the Welsh Government's £12.5 million investment in a National Short Break Scheme, reaching over 21,000 unpaid carers in Wales and increasing access to short breaks. Dr. Seddon is currently leading a national evaluation of the short break scheme and preliminary findings indicate that recipient unpaid carers reported feeling socially connected, less isolated, optimistic about the future, supported, and able to take care of themselves.

Sources

1. **Roberts, J. R., Jones, C. H., Windle, G., & The Caban Group (2023).** Knowledge Is Power: Utilizing Human-Centered Design Principles with People Living with Dementia to Co-Design a Resource and Share Knowledge with Peers. *International journal of environmental research and public health*, 20(20), 6937. <https://doi.org/10.3390/i>
2. **Windle, G., Roberts, J., MacLeod, C., Algar-Skaife, K., Sullivan, M. P., Brotherhood, E., Jones, C. H., & Stott, J. (2023).** 'I have never bounced back': resilience and living with dementia. *Aging & mental health*, 27(12), 2355–2367. <https://doi.org/10.1080/13607863.2023.2196248>
3. **Masterson-Algar P, Egan K, Flynn G, Hughes G, Spector A, Stott J and Windle G. (2023).** Hard to reach and hidden: improving identification of young dementia carers. *International Journal of Environmental Research and Public Health*, <https://doi.org/10.3390/ijerph20237103>
4. **Masterson-Algar, P., Egan, K., Flynn, G., Hughes, G., Spector, A., Stott, J., & Windle, G. (2022).** iSupport for Young Carers: An Adaptation of an e-Health Intervention for Young Dementia Carers. *International journal of environmental research and public health*, 20(1), 127. <https://doi.org/10.3390/ijerph20010127>
5. **Roberts, J. R., Windle, G., MacLeod, C. A., Sullivan, M. P., Camic, P. M., Stott, J., Brotherhood, E.V., Jackson, K., & Crutch, S. (2024).** "It's a postcode lottery": how do people affected by dementia in Wales experience their diagnosis and post-diagnostic support, and how may these be improved?. *International Journal of Environmental Research and Public Health*, 21(6), 709. <https://doi.org/10.3390/ijerph21060709>