

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.](#)

UC36: Ymateb gan: Dr Josie Henley and Dr Edith England| Response from: Dr Josie Henley and Dr Edith England

Improving access to support for unpaid carers call for evidence 19/09/2025

Dr Josie Henley, Lecturer in Social Psychology, School of Social Sciences, Cardiff University

Dr Edith England, Senior Lecturer in Social Policy, School of Education and Social Policy, Cardiff Metropolitan University

We base this response primarily on our evaluation study of the Dial project, a buddying scheme for people with dementia and support for their family carers. This study was commissioned in 2021 by Platfform, who ran the service. We interviewed ten informal family carers in total, from Cardiff and the surrounding area. All were adult aged, mainly spouses and daughters, and were recruited via the scheme. In addition to these interviews, we also interviewed four more daughters of a parent with dementia as part of a wider project looking at experiences of dementia and home.

Additionally, Dr Josie Henley has conducted previous research with people with dementia and suspected undiagnosed dementia and their family carers, including in 2016-2017 the REACT project (an investigation of the active components of a specialist home treatment intervention to prevent hospital admission of people with dementia in crisis in the community; Cardiff University) and in 2018-2019 the IDEAL study (Improving the Experience of Dementia and Enhancing Active Life; University of Exeter). Josie's work on the REACT project was to interview family carers as well as staff in community and hospital settings in Cardiff and the surrounding area. On the IDEAL study, Josie interviewed people with suspected undiagnosed dementia, and their family carers, in their homes in North and South Wales. These two studies add an additional approximately twenty informal family carers' experiences to this consultation response.

As part of the IDEAL study, a paper was published outlining potential reasons why people with suspected undiagnosed dementia and their families might not seek a diagnosis. This included an expectation that there would be barriers to accessing

services even with a diagnosis, and that the effort involved in seeking a diagnosis would outweigh any benefit such as respite schemes, should they be available. These barriers therefore contribute to the underdiagnosis of dementia in Wales, meaning that any estimation of the number of informal family carers may also be compromised.

Henley, J., Hillman, A., Jones, I. R., Woods, B., MacLeod, C. A., Pentecost, C. and Clare, L. 2023. 'We're happy as we are': the experience of living with undiagnosed dementia. *Ageing and Society* 43(9), pp. 2041-2066.
([10.1017/S0144686X21001495](https://doi.org/10.1017/S0144686X21001495))

An accessible non-academic summary of this paper is available here:

https://www.idealproject.org.uk/v8media/universityofexeter/schoolofpsychology/ideal/laysummaries/IDEAL_happy_as_we_are_undiagnosed_accessible_summary.pdf

Ethical approval was gained for all three of these projects, from Cardiff Metropolitan University (Dial), and from NHS ethics (IDEAL and REACT). All participants consented to be part of the projects, their data were anonymised prior to analysis, and no identifying information is included in this response. Instead, it is based on a summary of experiences discussed within interviews.

This response is specifically based on experiences of informal family carers of people with dementia or suspected dementia in Wales. The response will focus on the first point that is noted in the consultation.

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.

In our evaluation of the Dial project (2021) we found that the carers we interviewed valued the scheme and the flexibility in the approach. The Dial project is funded provision where a regular worker comes to the house to spend time with the person with dementia, building a relationship with the individual and their family. This might involve sitting with them at home for an activity or taking them out, enabling the carer to spend time in their home.

Another part of the Dial project is a carers' group, run as a course, that they could attend to discuss aspects of their experiences and to gain mutual support. Some, but not all, carers also found this useful. Although not all interviewees made use of it, they acknowledged that having the option of a support group is essential for carers' wellbeing.

One key aspect of the Dial project that was praised by carers was the fact that a relationship was built with the worker over time. The flexibility in terms of

arrangements for when the worker would visit and what activities they would do, including whether in the house or out, and the fact that this could be adapted week by week dependent on circumstances, was very much valued by carers.

Characteristics of spousal carers for people with dementia and suspected dementia include that they are often of or close to retirement age and/or with health problems themselves, and that their own needs go unmet due to the overwhelming nature of the care they provide. Other family carers, while not necessarily older, also find that their own health and needs are compromised, for example that their career may be compromised in order to provide care, impacting the financial situation of the family as a whole. Therefore the need for flexibility and understanding from service providers is crucial.

In the course of the interviews in the Dial evaluation, and in both the IDEAL and REACT projects, carers discussed other provision and services that they had experienced, or that they would like to have access to, noting challenges and barriers to access. The following outline three of these kinds of services and specific challenges related to them.

Schemes where a paid worker comes to the house to provide physical care (e.g. washing, feeding, or medication) for their relative, supplied by an agency and/or paid for by the local authority.

There is no guarantee that this person will be the same worker each time; the time of day that they attend might not be flexible to fit the routine of the person with dementia or their family; the worker might not have been given enough time and/or information that they need to provide adequate care for the person; and communication between the agency and family is not always efficient. Family carers told us that they had experienced having to do more work prior to the visit of the paid worker to prepare their relative for this visit, thus negating any benefit of the provided care. Additionally, when professionals are not able to build a relationship with the person with dementia, either due to a lack of time at each visit or to regular staffing changes, additional work is needed from the family carer to provide information on the individual's needs. Family carers also reported having to clean up after a professional carer's visit, and sometimes felt disrespected and invaded in their home. Opportunities to take a person out for activities or events, such as family parties, were curtailed due to the inflexibility of the timings of professional carer visits. Although these schemes are essential for those who need them, in some cases they do not adequately provide respite for family carers due to the visits causing more stress than had they not been in place.

Family carers were keen to point out that they did not blame the professional carers for these issues, but the system itself in terms of the low pay and high pressure to complete tasks and move on to the next client. In several cases, we found that people who would be entitled to this support made other arrangements, such as paying for private care or managing within the family, due to their negative

experiences. When these experiences cause families to disengage from a scheme, the impression is given that fewer people need the service.

Schemes where an activity is provided for people with dementia in a location outside of the home.

These schemes might involve an exercise class or craft activity and are praised by family carers as positive and rewarding for their relative as well as providing respite for themselves. However, in some cases no transport is in place, meaning that the responsibility is on the family carer to take the person to the activity and to collect them, which does not provide adequate respite. For people living in rural areas or reliant on public transport, this can be a very long journey. People with dementia often have a fluctuation of their ability to engage in activities. Family carers worry about signing up to a regular activity for this reason. Explicitly offering transport and flexibility is crucial to engagement.

Schemes where the carer and their relative are invited to a group where activities are in place for the people with dementia in one room and a support group available for carers in another room.

These schemes are again praised by family carers as positive for. However, the transport and fluctuating abilities issues noted above are also relevant here. In addition, not all carers want to socialise with other carers, so the support group should be an option.

The key message from our research is that informal family carers value having a choice of options and the flexibility to take part in schemes as and when they are able to.