

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

CC17: Ymateb gan: | Response from: Ian Davies-Abbot



Evidence submitted by Dr Ian Davies-Abbott [REDACTED]

This evidence is related to the inquiry ‘*Supporting people with chronic conditions*’ with a further focus on:

The readiness of local NHS and social care services to treat people with chronic conditions within the community.

Access to essential services and ongoing treatment, and any barriers faced by certain groups, including women, people from ethnic minority backgrounds and disabled people.

The ability of NHS and social care providers to respond to individuals with multimorbidity rather than focusing on single conditions in isolation

The evidence is related to dementia as a chronic condition, focussing on rare forms of dementia

Key points:

Issues to address

- Rare dementia is poorly understood in Welsh health services resulting in delayed diagnosis and higher diagnostic costs compared to more common types of dementia.

Findings from research

- Alongside heightened costs to the NHS, people affected by rare dementia in Wales often pay for private healthcare to accelerate the pathway to receiving a diagnosis.
- People affected by rare dementia in Wales rarely feel that they are involved in their own diagnosis. It is something that happens to them, rather than with them.
- The diagnostic journey for people living with rare dementia in Wales can be beset by disputes between themselves and service providers or between different service providers.
- Positive experiences of the diagnostic journey are often due to luck (meeting a knowledgeable clinician) rather than a sound diagnostic pathway.

Recommendations based on research findings

- A timely diagnosis of rare dementia in Wales should be available across all areas of the country and should not be dependent on luck.
- Clinicians working in primary care and memory assessment services must be aware of rare dementia symptoms to ensure that people can be referred to the appropriate services and receive essential support.

These issues and findings are drawn from a study exploring the referral pathways for people living with rare dementia in Wales. This study is one part of the larger Rare Dementia Support Impact Study (Brotherhood et al, 2020). The Rare Dementia Support website is available here: <https://pubmed.ncbi.nlm.nih.gov/31876030/>

The term 'rare dementia' describes atypical and inherited types of dementia which are usually characterised by a younger onset and other cognitive symptoms besides memory loss (Rare Dementia Support, 2023). Younger people living with dementia are more likely to experience additional challenges compared to older people with more common forms of dementia, typically regarding issues such as family, work and finances (Gelman & Rhames, 2020; Svanberg, Spector & Stott, 2011). There are also fewer services for people within this younger age group living with dementia compared to people with more typical dementia types (Sullivan et al, 2022).

The dementia diagnosis rate in Wales is 53% (Alzheimer's Research UK, 2020). Delayed diagnosis and misdiagnosis are not uncommon for people living with rare dementia (Woolley et al., 2011). Although Welsh policy has already acknowledged the problem of living with undiagnosed dementia (Welsh Government, 2018), there are currently no agreed pathways for a rare dementia diagnosis like those available for the diagnosis of Alzheimer's, vascular, Lewy body and frontotemporal dementia (National Institute for Health and Care Excellence, 2018).

The annual UK cost of dementia healthcare in the UK is £1.7 billion (Alzheimer's Research UK, 2023). However, there is little research about the economic cost of diagnosing dementia in Wales. Findings from Michalowsky et al's (2017) study were used to provide a baseline of dementia diagnosis costs in memory assessment services. The cost of the diagnostic pathway depended on whether the outcome was mild cognitive impairment (376€/£331.41 at the current exchange rate), Alzheimer's disease (649€/£572.03) or vascular/mixed dementia (662€/£583.49). However, the

highest costs were observed in the diagnosis of unspecified dementia types (705€/£621.39). In Wales, people with undiagnosed dementia have suggested that the emotional and physical cost of pursuing a diagnosis outweighs the benefits of receiving a diagnosis of dementia (Henley et al, 2021)

Following interviews with 10 people affected by rare dementia across Wales (one person living with rare dementia, nine family members), the full economic cost of an individual diagnosis ranged from £489 to £8,234. The cost to the NHS for an individual diagnosis ranged from £171.98 to £7,755.16. The cost of privately funded care paid for by participants ranged from £0 to £895. Whilst the diagnosis of different forms of rare dementia will have influenced the overall economic costs of individual diagnoses, the disparity between the costs is indicative of the lack of structured diagnostic pathways for people living with rare dementia in Wales.

Alongside these economic costs are the emotional and psychological costs of the journey. Family carers describe having to 'fight' for the support they need and having to 'chase' clinicians for appointments ('I always have to be ringing up, and asking, and pushing for things). They often do not feel listened to ('I have had to fight to get what I wanted') and lack confidence in clinicians ('I'm always double-checking things now'). They have also expressed concern that people who do not 'fight' will be missed ('Those who do not push hard enough will just drop into an abyss') and are distressed when they are excluded from the diagnostic process ('I can't understand when you go into a consultant and you've got someone who's got memory problems and speech problems, and yet the partner, the wife, isn't allowed (in)').

The diagnostic pathway is described as a series of challenging disputes, which makes the emotional journey even harder. Some disputes are between family members and the person undergoing the diagnostic assessment ('My wife wouldn't co-operate. She wasn't being bolshy or difficult, but she could not see why we wanted her to see a doctor'). Family members also felt that clinicians often lacked insight into the difficulties of getting their relative to attend an appointment, with an expectation that they should fit with the service rather than the service adjusting their approach to the person ('You've got to get him there'). When family members felt that the diagnosis was inaccurate, they often felt ignored ('Whenever I questioned it, I was just fobbed off. Then we had a pseudo dementia diagnosis. This went on for

quite a few years'). Family members and people living with rare dementia could also feel excluded and trapped due to diagnostic disagreements between clinicians ('But then I had a fight on my hand, then to get through to him, because the one doctor had said, the psychologist had said I'm going to pass him over as an urgent patient. And I heard nothing and when I rang to speak to the secretary to find out where he was on the list, they said, oh, the doctor said it's not an emergency').

The needs of people living with rare dementia and their families are not currently being addressed for all people affected in Wales. They remain a marginalised group, not due to any malicious intent but a lack of knowledge, services and an absence of established pathways to diagnosis. People living with rare dementia are often misdiagnosed due to their symptoms being related to other conditions, which inevitably impacts on their ability to access essential services.

This study is currently being written up for publication for a peer reviewed health journal.

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Evidence submitted by Dr Ian Davies-Abbott [REDACTED] .

This evidence is related to the inquiry ‘*Supporting people with chronic conditions*’ with a further focus on: ‘*The impact of the pandemic on quality of care across chronic conditions*’.

The evidence is related to dementia as a chronic condition.

Key points:

Issues to address

- To prevent infection people were required to wear masks and isolate from contact with others during the pandemic. It is believed that these measures reduced the quality of life and general well-being of people living with dementia in hospital or social care. This belief was not based on the testimony of people living with dementia in care settings, who were silenced due to pandemic restrictions.
- Whilst pre-pandemic initiatives including ‘John’s Campaign’ recognised the rights of people living with dementia to have unrestricted access to family visitors, this access was removed due to lockdown restrictions. The physical and psychological care provided by these visitors was therefore removed.
- Despite being the experts regarding living with dementia, people with this chronic condition were generally silenced due to lockdown restrictions during the pandemic.

Findings from research

- People with moderate to severe dementia receiving care on mental health hospital wards and subject to strict infection prevention measures can still achieve high levels of well-being if communication by staff is person centred.
- Nursing staff are able alter the focus of their care to deliberately overcome the challenges due to restrictions on family visiting to provide attachment and psychological support to people living with dementia.
- People living with dementia can share personal views of living with a chronic condition if given the right support and mechanisms.

Recommendations based on research findings

- People living with dementia should not be positioned as silent partners in their care. Whilst dementia is a chronic condition, its impact on the person’s

cognitive and physical health alongside its impact on families means that it is often more complex than other conditions. Listening to people living with dementia must be a key focus of any work regarding chronic conditions if care services are to be improved for this population.

- Positive practices during lockdown should be shared across health and care sectors to ensure that best practice is followed if lockdown restrictions are required in the future.

These issues and findings are drawn from three studies.

Study one explored the impact of restrictions on well-being for people living with moderate to severe dementia in acute mental health hospital care. 'Dementia Care Mapping' is highlighted in standard 16 of the national dementia standards for Wales (Improvement Cymru, 2022) and was used as the observational tool to determine the well or ill-being of people living with dementia during the study. Observations were undertaken in two mental health hospital wards during a period of lockdown restrictions when personal protective equipment was actively being used. The levels of well-being observed in the wards was higher than expected when compared to the anecdotal discussions of care otherwise reported. A further change was observed in the focus of psychological care delivered through mental health nursing interventions aimed at enhancing the well-being of the people living with dementia on the wards. It was evident that whilst the nursing staff were faced with an unprecedented challenge due to significant changes in their practice, they responded by mitigating the impact of infection prevention measures by adjusting their communication style to compensate for the absence of family visitors. The negative impact of restricting family visitors for people living with dementia is not disputed and it would be unacceptable to not recognise this as an issue to address in the event of lockdowns in the future. The approaches observed in this study could be replicated in other care settings, with the aim of improving well-being for people living with dementia.

The study was printed in the Journal of Psychiatric and Mental Health Nursing and can be accessed in full here: [Dementia care from behind the mask? Maintaining well-being during COVID-19 pandemic restrictions: Observations from Dementia Care Mapping on NHS mental health hospital wards in Wales - PubMed \(nih.gov\)](https://pubmed.ncbi.nlm.nih.gov/33893693/)
<https://pubmed.ncbi.nlm.nih.gov/33893693/>

Study two was conducted to understand the lived experience of a person living with dementia in a care home during the pandemic. It was conducted as a response to the absence of the voices of people with dementia living in care homes during the pandemic in research and other accounts of care during that period. This was a single case study to discover the experiences of one person living with dementia in a care home during a period of lockdown. The findings illustrated the participant's ability to adapt, accept and dispute lockdown restrictions whilst sharing considerable insight into their situation. Whilst the pandemic had restricted access to care homes, which informed the single case study approach, the findings allowed a small insight into life during lockdown for care home residents living with dementia, who were otherwise silenced. People living with dementia must be involved in decisions about their residence, with the offer of inclusion matching the insight, ability and interest of the individual. Whilst a pandemic virus is a source of anxiety, the everyday fears of people in care may be driven more by the psychosocial losses caused by restrictions. Services should ensure that people living with dementia are not further disempowered by supporting them to maintain control over appropriate aspects of their lives.

This study was printed in *Quality in Ageing and Older Adults* and can be accessed in full here: [Living in a care home during COVID-19: a case study of one person living with dementia | Emerald Insight](https://www.emerald.com/insight/content/doi/10.1108/QAOA-02-2021-0024/full/html)

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Study three explored how people living with dementia could use the change management approach of Appreciative Inquiry to reduce stigma towards dementia in other members of society. A group of people living with dementia explored their positive experiences and created a short film which was shared with groups of healthcare workers, family members and lay people. The results indicated that listening to people living with dementia led to positive language and behavioural changes in other societal groups, particularly in lay people (those with no direct caring experience with a person living with dementia). An adaptation of Appreciative Inquiry would be an appropriate tool to support people living with dementia to share their perspective of living with this and other chronic conditions.

This study was shared at international dementia conferences for Alzheimer Europe and Alzheimer's Disease International. It is currently being drafted for journal publication.

References

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