

## Rare dementia support in rural and remote areas

Windle, Gill; Roberts, Jen; Sullivan, Mary Pat

### Journal of Dementia Care

Published: 01/01/2021

Peer reviewed version

[Cyswllt i'r cyhoeddiad / Link to publication](#)

*Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):*

Windle, G., Roberts, J., & Sullivan, M. P. (2021). Rare dementia support in rural and remote areas. *Journal of Dementia Care*, 29(1), 22-24.

#### Hawliau Cyffredinol / General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal ?

#### Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

## **Glancing at rare dementia support in rural and remote regions**

Gill Windle, Bangor University, Wales

Jennifer Roberts, Bangor University, Wales

Mary Pat Sullivan, Nipissing University, Canada

The majority of the 850,000+ people diagnosed with dementia in the UK are older and retired, however rare dementias are more common in individuals with a younger age at onset (<65 years), creating additional problems in relation to work, income, retirement planning and family life (Svanberg, Spector and Stott, 2011; Allen, Oyeboode and Allen, 2009). In a previous article from the team of the Rare Dementia Impact project, our colleagues described the importance of support for people affected by a rarer dementia (Brotherhood et al., 2020), noting the considerable difficulties many face in obtaining help from services. In this article, we consider how this may particularly manifest for those affected by a dementia who living in a rural or remote area. We draw on examples from international research, but also situate this in two rural contexts where the RDS Impact Project is running – Wales and Canada.

### **What is the challenge for rural areas?**

The environment and places we live may support or exacerbate the experience of living with dementia, and rurality is intimately linked to remoteness. Compared to a density of 406.8 people per km<sup>2</sup> in England, population density is much lower in Wales (144.7), Northeastern Ontario (1.8) and Northern Ontario (0.97). Sixty-three percent of the Welsh population live in rural areas (<10,000 people; ONS, 2013). Estimates suggest the increases in the number of people living with a dementia in Wales between 2011-2021 are higher for rural areas (44%) than the rest of Wales (31%; WG, 2011).

National dementia strategies put an emphasis on those facing inequalities in care, including those who live in rural and remote places. The dementia strategy for Canada recognises the challenges faced by people living in rural and remote locations as well as those providing services and support, and the need for solutions and interventions to be specific to their unique needs (Public Health Agency of Canada, 2019). In the UK, the Dementia Action Plan for Wales (2018) acknowledges that living with dementia in rural and remote areas is a core area of consideration across the dementia care pathway.

However there are challenges to policy implementation in rural areas. The lower population density and the geography of rural areas pose additional barriers and costs relating to service and support provision, travel costs and time, and discrepancies in resource allocation (Palmer, Appleby & Spencer, 2019; Szymczynska, Innes, Mason & Stark, 2011). This may leave people affected by a dementia in rural places at a significant disadvantage compared to their urban counterparts, leading to a heavy reliance on unpaid sources of support from family and friends. For example forty percent of the \$818 billion estimate of the

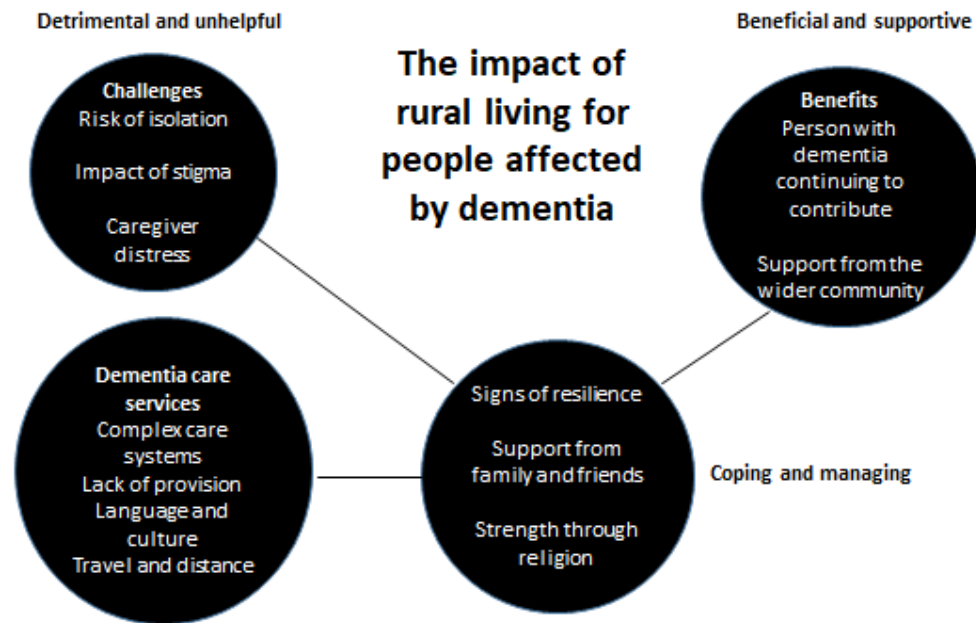
international economic impact of dementia is attributable to family caregiving (Wimo et al., 2017).

**What is known from the literature about the personal experiences of people affected by dementia (carers and those living with the condition) who live in a rural area?**

The specific issues facing people affected by dementia in rural areas were examined by Innes, Morgan and Kostineuk (2011), who reviewed international published scientific literature on dementia care and service provision in rural and remote settings in relation to informal/family caregiving. Twenty-six papers were included in their synthesis. The majority of the studies focussed on the experience, use and barriers to formal service provision (15 papers) with limited attention given to the education and support needs of caregivers (6 papers) or personal, caregiver experiences (5 papers). The authors draw attention to the need for more research about the impact of rurality on caregiving, and the education and support needs of rural informal family caregivers, and conclude:

“Rural areas globally have aging populations that will require adaptable solutions to their local context. However, to date there is insufficient information available to develop rural dementia care services that support the person with dementia and their family caregivers” (p. 45).

Now a decade later from this work of Innes and colleagues, part of our ongoing work programme is examining the international published research to establish if there are any changes or further knowledge regarding informal caregivers’ experiences (Roberts et al., forthcoming). As no review of published research has focussed on the individual perspective of the person with dementia in rural settings, nor the potential beneficial aspects of living with a dementia in a rural location, our work also explores these aspects. Specifically, we undertook a systematic scoping review of peer-reviewed journal articles of primary research (e.g. not commentaries or opinion pieces). After sifting through 1831 summaries of research papers, we focussed our synthesis on the work of 49 studies that were relevant to the research question. Here we present a short overview of the main findings, and Figure 1 visualises the themes derived from the analysis.



Two themes suggested possible benefits of living in a rural community; ‘the person living with dementia continuing to contribute’ reflecting the opportunities for ongoing activity and learning, and ‘support from the wider community’, reflecting the potential cohesion within and across rural communities. Detrimental aspects of rural living are particularly prominent in relation to difficulties with dementia care services, which included four sub-themes. ‘Complex care systems’, reflecting a lack of awareness of any available services, difficulties obtaining a diagnosis and challenges providing long-term care and alternative housing options. ‘Lack of provision affecting continuity of care’, reflecting poor service provision; ‘transport and travelling’ reflecting the difficulties faced in getting to any service centres and receiving daily home care; and ‘language and cultural sensitivity’, reflecting the challenges faced by Indigenous or minority language groups in securing appropriate services. Other detrimental aspects of living in a rural community included ‘the risk of isolation’, ‘the impact of stigma’ and ‘caregiver distress’. All of these are likely to be problematic in urban areas, but are exacerbated by the pressures from difficulties with dementia care services. Inevitably, people have to cope and manage despite difficulties. ‘Support from family and friends’ is important regardless of location, but especially crucial when service provision is limited. Some of the studies suggested that ‘religion’ is a frequently used coping mechanism for rural caregivers. Others note how some carers, despite being distressed and feeling overwhelmed also managed to find positive aspects of their role, suggesting ‘signs of resilience’.

On the whole our findings suggest support in rural areas for people affected by a dementia in rural areas is difficult to obtain, with people having to draw on their own personal sources of strength. How might this manifest for those living with rarer forms of dementia? Many of the research papers included in our work (full list available from the authors) did not provide details about the type of dementia. Where reported, only four studies

appeared to include people living with a rarer form (fronto-temporal dementia). Similarly, there appears to be a gap in the research literature regarding the experiences of people living with dementia alone (i.e. without also studying caregivers, or other individuals), with only two studies doing so in the present review. A tentative conclusion is there is a lack of knowledge about the experience of dementia in rural areas, especially how it may affect those living with rarer forms of the condition. As part of our ongoing research programme, the Rare Dementia Impact project team have work underway that will provide some new insights around the support needs and care preferences of people living with rarer forms of dementia. In Canada and Wales we are working to establish regional groups of rare dementia support, finding people who are currently ‘hidden’ from the mainstream and who could benefit from the [Rare Dementia Support Network](#).

**‘The person living with dementia continuing to contribute’**

Maintaining a social life, continuing long-term friendships and activities and connecting people affected by dementia via peer-to-peer opportunities can all enable opportunities for continued involvement. At Bangor University in Wales we support ‘The Caban’, a group of people living with primarily younger onset dementia and their carers who regularly work with researchers and students, contributing to research, undergraduate and post-graduate study about what is important to people affected by dementia. The group have contributed to some of the work of the RDS impact project, inspired by discussions on the topic of resilience to develop videos sharing their ‘top tips’ following a dementia diagnosis. As one member notes:

*“I joined a group and I felt useful again. I wasn’t waiting to die. I feel good about it because I am doing something. I feel empowered”.*

At Nipissing University in Northern Ontario, we are documenting what support groups, if any, people with a rare dementia or their care partner are accessing. We anticipate this work will begin to identify how best to connect people with a rare dementia living in large and culturally diverse geographical areas and build on existing or new support opportunities to address their needs.

**Funding:**

Economic and Social Research Council, Grant/Award Number: ES/S010467/1; National Institute for Health Research; Nipissing University; Bangor University; University College London



## Acknowledgements:

We are indebted to the current and former members of Rare Dementia Support we have the privilege of working with, without whom this study would not be possible.

We would like to thank the research and support teams for their invaluable work at Rare Dementia Support (Suzie Barker, Paul Camic, Ian Davies Abbott, Rhiannon T Edwards, Victory Ezeofor, Nick Fox, Adetola Grillo, Chris Hardy, Emma Harding, Charles Harrison, Zoe Hoare, Roberta McKee-Jackson, Jennifer Roberts, Jonathan Rohrer, Rebecca Sharp, Joshua Stott, Aida Suárez-González, Mary Pat Sullivan, Eva Tait, Millie van der Byl Williams, Claire Waddington, Jason Warren, Rimona Weil, Veronika Williams, Gill Windle, Eira Winrow, Olivia Wood, Keir Yong, and Nikki Zimmermann).

Rare Dementia Support is generously supported by the National Brain Appeal (<https://www.nationalbrainappeal.org/>). We are grateful to Wellcome for their ongoing support in hosting RDS meetings. Community partners for this study involve the Alzheimer's Society (UK), Alzheimer's Research UK UCL Network, Alzheimer Society Sudbury-Manitoulin North Bay and Districts (Canada), Ageing Well in Wales, Royal Society for Public Health, and the British Psychological Society Faculty of the Psychology of Older People. The RDS Impact study was funded by the ESRC/NIHR Dementia Research Initiative (ES/S010467/1) as "The impact of multicomponent support groups for those living with rare dementias." Lead investigator S. Crutch (University College London); co-investigators J. Stott, P. M. Camic (University College London); G. Windle, R. T. Edwards, Z. Hoare (Bangor University); M.P. Sullivan (Nipissing University); R. McKee-Jackson (National Brain Appeal).

## References

- Allen J, Oyebode JR, Allen J. (2009). Having a father with young onset dementia: the impact on well-being of young people. *Dementia*, 8, 455-480.
- Brotherhood, E., Walton, J. and Crutch, S. (2020) Why Do We Need Rare Dementia Support? *Journal of Dementia Care*, 28 (6), 20-23.
- Innes, A., Morgan, D., & Kostineuk, J. (2011). Dementia care in rural and remote settings: a systematic review of informal/family caregiving. *Maturitas*, 68(1), 34-46.
- Office for National Statistics (ONS). Report on language breakdown in England and Wales. <https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/language/articles/languageinenglandandwales/2013-03-04>
- Palmer, B., Appleby, J., & Spencer, J. (2019). Rural health care: A rapid review of the impact of rurality on the costs of delivering health care. <https://www.nuffieldtrust.org.uk/research/rural-health-care>
- Public Health Agency Canada (2019). A Dementia Strategy for Canada: Together We Aspire. <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy.html>

Roberts, J. R., Windle, G., Brotherhood, E. V., Camic, P. M., Crutch, S., J., Stott, J., Sullivan, M.P. (Forthcoming). Dementia in rural settings: A scoping review exploring the personal experiences of people with dementia and their caregivers.

Svanberg E, Spector A, Stott J. The impact of young onset dementia on the family: A literature review. *International Psychogeriatrics*. 2011; 23: 356-371.

Szymczynska, P., Innes, A., Mason, A., & Stark, C. (2011). A review of diagnostic process and post-diagnostic support for people with dementia in rural areas. *Journal of primary care & community health*, 2(4), 262-276

Welsh Government (2018). Dementia Action Plan for Wales 2018-2022.

<https://gov.wales/sites/default/files/publications/2019-04/dementia-action-plan-for-wales.pdf>

Welsh Government. (2011). National Dementia Vision for Wales: dementia supportive communities. Wales: Welsh Assembly Government/Alzheimer's Society.

Wimo, A., Guerchet, M., Ali, G. C., Wu, Y. T., Prina, A. M., Winblad, B., ... & Prince, M. (2017). The worldwide costs of dementia 2015 and comparisons with 2010. *Alzheimer's & Dementia*, 13(1), 1-7.