

Dementia in rural Wales

The three challenges



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Dementia in rural Wales: the three challenges

At Alzheimer's Society, we understand the difficulties people with dementia can face living in remote and rural areas. Support services are less likely to be commissioned. Poor transport links make it harder to access help. And we know that carers are more likely to feel isolated and unsupported.

Yet it isn't just our own experiences of supporting people affected by dementia that has brought the problem into focus. Demographics shifts suggest that this is a growing challenge for Wales. We are a much more rural nation than our counterparts in mainland Britain, and our population is older. Age is the biggest risk factor for developing dementia, and there is also growing evidence that loneliness and social isolation may increase risk as well.

What does this mean for our communities in rural Wales? In short, there is a huge research gap that needs to be filled so we can better understand the problem affecting our communities and identify solutions.

Back in February 2016, over 30 people from a wide range of organisations – from across the public, private and voluntary sectors – met in Builth Wells to spend a day discussing the issue of dementia in rural Wales. Representatives of farming communities, faith groups, state services, emergency services, voluntary and community groups shared compelling and heart-breaking tales of how rurality had intensified already significant strains placed on families and individuals affected by dementia. The group had no formal status and no predetermined objectives, but by the end of the day it was abundantly clear that all of those in attendance felt that 'something needed to be done'. The first, tentative, steps towards establishing a Rural Dementia Taskforce had been taken.

In publishing this challenge, Alzheimer's Society does not pretend to have all of the solutions. Instead, this is the start of a much longer and more detailed focus on the issue of dementia in rural areas of Wales. With a new Assembly just elected in May, and plans¹ for the Welsh Government to deliver a National Dementia Strategy in the months ahead, we are highlighting the urgent need for progress on the issue.

¹ Welsh Government (2016) [Together for Mental Health Delivery Plan, 2016–19: consultation document](#), Wales: Welsh Government.

Our aim is to start to diagnose the problem, assess the impact of its symptoms, and draw the attention of policy-makers and researchers to the challenges faced in rural Wales by people affected by dementia. We have set out a series of recommendations which – if acted upon – will allow us to learn more about the extent, impact and potential growth of dementia in rural areas, and to see how Wales can lead the way in supporting people affected by it. Alongside this work, the Rural Dementia Taskforce will be a critical friend to Welsh Government in the months ahead to ensure that rural issues are adequately reflected in any future dementia strategy.

For too long, people affected by dementia in rural Wales have not had a voice. Let this be the first step towards putting that right.

Sue Phelps

Director, Alzheimer's Society in Wales

Summary and recommendations

- Based on an analysis of existing data, Alzheimer's Society estimate that approximately 17,000 people in Wales live in rural areas and have dementia.
- Wales has a proportionately larger older population than any other nation in the UK.
- Wales has a more rural population than both Scotland and England.
- The older population is growing faster in Wales' rural areas than in urban ones.
- These factors combined have led the Welsh Government to suggest that there will be a disproportionately large increase in the number of people with dementia in rural areas.

Recommendations:

- 1) The Welsh Government to invest in research to understand the extent of the problem**

Academic and research bodies in Wales should be encouraged (and, if necessary, commissioned) to develop a robust, evidence base and statistical data so that we can better understand the extent, impact and potential growth of dementia in rural Wales. As a bare minimum, the Welsh Government should commit to working with the Wales Rural Observatory to establish reliable baseline figures.
- 2) Identify good practice examples from across the UK and Europe**

A detailed review of research and other literature that already exists around the impact of dementia in rural areas should be commissioned to inform future policy decisions. This should either be from Wales specifically, or identify good practice from other nations which could be applied to a Welsh context.
- 3) Seek the lived experiences of people with dementia and their families**

Alzheimer's Society to commit to further engagement with people affected by dementia in rural areas in order to identify the human impact of rural dementia.

- 4) Address the challenges of dementia in rural areas in a Dementia Strategy**
The Welsh Government should include in their proposed national Dementia Strategy a specific component on tackling dementia in rural areas, to be developed in consultation with the Rural Dementia Taskforce.
- 5) Address dementia in a new Rural Health Plan**
Welsh Government should, when updating the Rural Health Plan, include a specific dementia component, as well as examining the wider health and wellbeing implications of rurality on people affected by dementia.
- 6) Identify links between dementia and Welsh language**
As part of the development of statistical data on rural dementia highlighted above, there is also a need for a comparison with data on Welsh language communities in Wales, so there can be a better understanding of the relationship between rural dementia and Welsh language.

Alzheimer's Society, in collaboration with the Rural Dementia Taskforce, is committed to playing our part in taking on these challenges. The Rural Dementia Taskforce aspires to be a credible and effective alliance which can bring together stakeholders from across all sectors to be a voice for people in rural Wales affected by dementia. Together, we will work with the Welsh Government and other partners in the months ahead to take these recommendations forward.

Challenge one: the continuing rise of dementia in rural areas

Wales has a higher level of rurality, and a higher proportion of the population living in rural areas, than other parts of mainland Great Britain.^{2,3}

Nation	Populous areas (over 10,000 people)	Unpopulous areas (up to 10,000 people)
Wales ⁴	63.3 %	36.7 %
Scotland ⁵	70.2 %	29.8 %
Northern Ireland ⁶	56.0 %	43.9 %
England ⁷	81.4 %	18.6 %

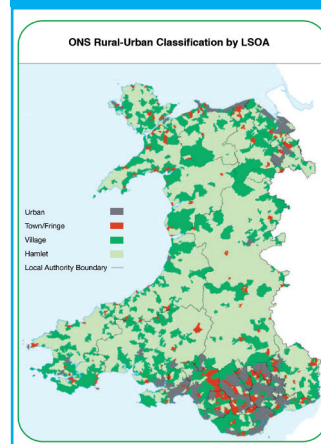
The Office for National Statistics rural-urban classification⁸ defines populations of fewer than 10,000 people as being rural, while those above a population of 10,000 are defined as urban. This definition, although somewhat arbitrary, does allow for an easy breakdown of the number of people in Wales living in 'rural' areas, with 63.3 % of the Welsh population falling into the rural category, demonstrated by the map (right⁹):

- 2 Welsh Assembly Government (2009) [Rural Health Plan: improving integrated service delivery across Wales](#), Wales: Welsh Assembly Government: p5.
- 3 Welsh Assembly Government (2008) [A Statistical Focus on Rural Wales](#), Wales: Welsh Assembly Government.
- 4 Welsh Government (2015) [Wales Rural Development Programme 2014–2020 document](#), Wales: Welsh Government: p13/14.
- 5 Scottish Household Survey (2011) [Scottish Household Survey: update note – Scottish Government Urban Rural Classification 2011–2012 Analysis](#), Scotland SHS: p7.
- 6 Based on figures from Northern Ireland Statistics & Research Agency (2015) [Review of the Statistical Classification and Delineation of Settlements](#), Northern Ireland: NISRA: p18.
- 7 Pateman, T. (2011) [Rural and urban areas: comparing lives using rural/urban classifications](#), Newport: ONS: p8.
- 8 Office for National Statistics (2013) [Urban and Rural Area Definitions for Policy Purposes in England and Wales: methodology, v1.0](#), Newport: ONS / Welsh Government / Department for Environment, Food & Rural Affairs / Department for Communities & Local Government.

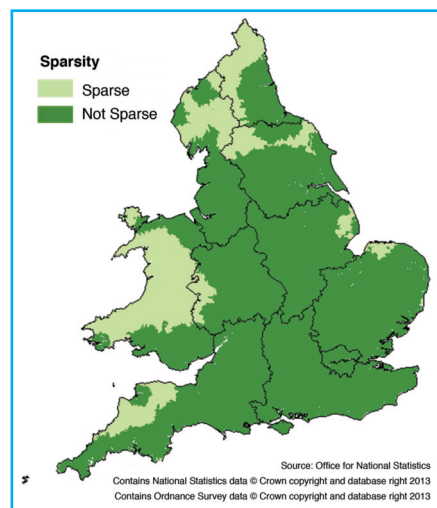
We estimate that approximately 17,000 people in Wales live in rural areas and have dementia.

This is based on the fact that 38% of the overall population live in rural areas (settlements of fewer than 10,000 people). If the same proportion of people with dementia live in rural areas, that would give a figure in the region of 17,000.

If anything, this figure probably underestimates the scale of rural dementia, given that dementia rates are increasing more quickly in rural areas.



A more sophisticated way to identify the proportion of Wales' population in rural areas is to adopt the ONS definition of 'sparseness'.¹⁰ Whilst comparisons for this are not available in Scotland and Northern Ireland because of definitional differences, we know that 14.5 % of the population in Wales live in the sparsest rural areas¹¹ – compared to 1.8 % for Wales and England as a whole.¹² The map (right¹³) further underlines the sparse nature of Mid & West Wales in particular when compared to England and to urban South Wales.



Within these rural/sparse areas of Wales, we know from existing data that the population is generally older and that dementia rates are higher than for Wales as a whole. Figures from the 2011 Census¹⁴ revealed that 29 % of the rural population in Wales is aged 60 or over, with the ONS stating:¹⁵ *“Every unitary authority except Cardiff and Swansea saw increases in the proportion of the population aged 65 and over... The majority of increases have been seen in rural areas. The Isle of Anglesey has seen the largest increase of 4 percentage points, those aged 65 and over now constitute 22% of the population”*.

Furthermore, the Welsh Government has stated¹⁶ that rural Wales has a disproportionately high share of its population aged over 64. There is expected to be a disproportionately large increase in the number of people with dementia; whilst the number of people with dementia in Wales is likely to increase by 31 % between 2011 and 2021, this figure rises to 44 % in some rural areas.¹⁷ This disproportionately older population, with disproportionately high levels of dementia and some pockets

9 Taken from Welsh Assembly Government (2009) [Rural Health Plan: improving integrated service delivery across Wales](#), Wales: Welsh Assembly Government: p12.

10 Welsh Government (2015) [Wales Rural Development Programme 2014–2020 document](#), Wales: Welsh Government.

11 Welsh Government (2015) [Wales Rural Development Programme 2014–2020 document](#), Wales: Welsh Government: p13.

12 Office for National Statistics (2013) 2011 [Census Analysis: comparing rural and urban areas of England and Wales](#), Newport: ONS: p9.

13 Office for National Statistics (2013) 2011 [Census Analysis: comparing rural and urban areas of England and Wales](#), Newport: ONS: p4.

14 Wales Rural Observatory (2016) [Wales Rural Observatory website](#), accessed 31st March 2016.

15 Office for National Statistics (2012) [Statistical bulletin: 2011 Census: Population and Household Estimates for Wales](#), Newport: ONS.

16 Welsh Assembly Government (2008) [A Statistical Focus on Rural Wales](#), Wales: Welsh Assembly Government.

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

of deprivation (although generally lower levels of deprivation than the general population) fits with previous findings¹⁸ that rural central Wales in particular is less-well connected and less well-off than is normal for England and Wales as a whole.

The emerging picture is that dementia in rural Wales is a substantial and growing problem, but without better data it will be impossible to tackle. Alzheimer's Society is therefore calling for greater research so that policy solutions can be found.

18 Pateman, T. (2011) [Rural and urban areas: comparing lives using rural/urban classifications](#), Newport: ONS.

Challenge two: the human impact of dementia in rural areas

The statistical and demographic figures behind dementia in rural areas only tell one side of the story. Just as significant are the human voices affected by dementia and living in remote parts.

There is, at present, only limited qualitative data specifically harnessing the voices of people in Welsh rural areas affected by dementia – and this is a gap which must, as a priority, be addressed. Nevertheless, from our own work, we can identify some important key concerns which might help to guide future research.

A series of interviews (n=12) with people affected by dementia in rural areas, were carried out in spring 2016 with a self-selecting sample of people who replied to adverts on social media and requests to Alzheimer's Society's existing service user review groups from across Wales (including rural areas). This sample gave limited but indicative insights, and it is clear from the responses that the isolation felt by people with dementia and their carers was intensified by rurality. Unsurprisingly, transport in particular was a key concern:

It's not even about getting around, living in rural areas you know no different. So if you don't drive, you get used to taking the bus. I used to love going on the bus and with my dementia, it helps to keep me stimulated. But, there is only one bus a week now to one place – so even that's limited. It wasn't always like this, there used to be quite a few to different areas.

The local council did send out a questionnaire, they asked if we could travel 5–10 miles for respite. There is clearly no consideration in this question for a rural area. Yes, I would travel 5–10 miles, but respite is further for us living in rural areas. I had to travel 40 miles to find a home for my wife to stay and it was a disaster. The staff weren't trained to support people with dementia, or not as advanced as my wife's. They phoned my daughter and asked if they could sedate my wife otherwise we would have to take her home.

Even when services and support were available, distances and travel times often meant that their usefulness was limited:

There is no respite available here – no one comes this far or if they do, they have to leave after twenty minutes to make it to another visit. I'm stuck if I have appointments.

I know of someone who has social services visits during the day, but they want to put him to bed at 7.30pm each night because they have four more calls to do before 10.30pm. That isn't enabling.

Furthermore, the support services that existed were often too generic in their provision. One younger person with dementia described how this led to a referral to a service which was completely inappropriate to their needs:

You go there and there are older people – they're given socially stimulating games. But the picture cards they use have Nat King Cole on them – I mean I'm not that old. They also have music sessions where they play Vera Lynn – it's not age appropriate and I have said there needs to be more to socially stimulate people who are younger... I've also had to check that staff are dementia specific trained – following my concerns this has been addressed and all staff have to have a minimum standard of training now'

Respondents also noted different social attitudes towards dementia in rural areas – and mentioned both positive and negative aspects of how dementia was viewed and understood in rural communities:

Friends and neighbours are aware of dementia. People in rural communities talk to each other more than in bigger areas.

There isn't much of an awareness of dementia in rural areas because there's limited services and no presence... [T]he more rural communities need to come together and need more in terms of raising awareness.

These anecdotes and experiences indicate a wider set of policy challenges beneath the surface, and a mostly negative set of views around dementia support. Whilst the quotes are drawn from a small number of interviews, further work in this area would be helpful to identify common areas of concern. Some of the related issues which Alzheimer's Society might expect to be highlighted because of our own experiences and contact with people affected by dementia might include:

- The overlap between rurality and the challenges specifically affecting people with dementia whose first language is Welsh – something recognised by the Older People's Commissioner for Wales: “[C]oncerns emerged about the lack of Welsh-speaking services available. One daughter spoke of the difficulty of finding a

residential care home with Welsh-speakers for her father and also spoke of the difficulty of finding hospital professionals who could explain issues to her parents in Welsh. Another highlighted the difficulty in conducting a capacity assessment for a patient whose first-language was Welsh and one carer commented that she felt lucky that the person for whom she cared for was not a Welsh-speaker.”¹⁹

- The same report²⁰ also identified frustrations about care services, with a feeling amongst participants that they were expected to fit into the delivery patterns of formal services, rather than the services being designed to meet their individual needs.
- There is also a potentially negative impact on access to services in rural areas due to digital exclusion. The digital exclusion heatmap²¹ (right) indicates a significant overlap between rurality and poor digital literacy/access, with Wales (and Scotland and Northern Ireland) having large pockets of digital exclusion in rural areas.
- With support services, information and resources being increasingly available “digital-only” by default, it is increasingly important to support people in rural areas where broadband access is often patchy, but conversely where digital services (if accessible) could be transformational in reaching communities and individuals who might otherwise be left totally isolated.
- A 2014 audit of access to memory clinics²² and our own research²³ has indicated that there are challenges around access to memory clinics in Wales. Not only are the travel distances involved sometimes barriers to access for people in rural areas, but the length of waiting times are also a cause for concern. Alzheimer’s Society has called for a national consensus on a guaranteed minimum level of post-diagnosis support – but it would also be beneficial to better understand the impact of restricted access to memory clinics for people in rural areas affected by dementia.



It is essential that greater research is conducted to understand the human impact that dementia is having for people in rural Wales, in order that an appropriate response can be developed.

19 Older People’s Commissioner for Wales (2016) *Dementia: more than just memory loss – the experiences of people living with dementia and those who care for them*, Cardiff: OPCW: p53.

20 Older People’s Commissioner for Wales (2016) *Dementia: more than just memory loss – the experiences of people living with dementia and those who care for them*, Cardiff: OPCW.

21 Doteveryone (2016) “Digital Exclusion Heatmap: exploring exclusion from a digital United Kingdom”, taken from <https://doteveryone.org.uk/resources/heatmap/>

22 1000 Lives (2014) *Wales National Audit: memory clinic and memory assessment services*, Walse: 1000 Lives / Public Health Wales.

23 Alzheimer’s Society (2015) *Diagnose or disempower? Receiving a diagnosis of dementia in Wales*, Cardiff: Alzheimer’s Society.

Challenge three: identifying a policy response

Whilst acknowledging that addressing the challenges set out in the previous sections is by no means simple, there are still two key opportunities in the coming months which can be used to better understand what needs to be done.

A Dementia Strategy for Wales

Recent proposals²⁴ could see a Dementia Strategy for Wales developed before the end of the year – the first time Wales will have had its own dedicated Dementia Strategy. Identifying dementia in rural areas as a priority for future work is clearly desirable, and the Rural Dementia Taskforce has an obvious role to play as a partner to that work. We would also like to see the Wales Rural Observatory involved in any work, so that they can accurately plot the location, scale and likely growth of dementia in rural areas of Wales.

Updated Rural Health Plan

Furthermore, the Welsh Government has already gone some way towards tackling rural health challenges more widely by publishing a Wales Rural Health Plan in 2009.

This set out strong aspirations to “...develop the evidence we have, here in Wales about rural health policy needs, and to embed this improved knowledge in our policymaking structures”.²⁵ Amongst other things, the document noted that the number of people with dementia in rural areas was likely to increase and that rural areas were not seen to be sufficiently well-equipped to deal with that increase. It also highlighted particular challenges in relation to the Welsh language; the health and social care workforce need to have the capability to support people who,

Much more research and analysis is required the effects of dementia in rural Wales. But what we do know already suggests a consensus about the problems which need to be addressed. These include (but are not limited to):

- distance
- lack of transport
- shortage of skilled staff
- increased cost to providers, leading to a more limited range of services
- limited access to primary care services
- poor access to care, including paid carers
- social isolation felt by unpaid carers.

Any policy responses should initially focus on these key themes.

24 Welsh Government (2016) [Together for Mental Health Delivery Plan, 2016–19: consultation document](#), Wales: Welsh Government.

25 Welsh Government (2009) [Rural Health Plan: improving integrated service delivery across Wales](#), Wales: Welsh Assembly Government: p5.

through loss of capacity because of dementia, might only be able to communicate through Welsh being their first language. However, the plan is now into its seventh year, and Wales must seize the opportunity to renew it and to pay particular attention to dementia in rural areas.

To help frame where some of these policy opportunities might focus attention, a detailed literature review is required. This should look not only at existing relevant research in Wales (not least the output of the Centre for Innovative Ageing at Swansea University and the Dementia Services Development Centre at Bangor University), but also findings on dementia in other rural parts of the UK and abroad. Existing literatures have reinforced the notion that “*there are few examples of innovative measures to provide services for people with dementia in rural areas*”,²⁶ yet where those interventions exist and can be demonstrated to have worked, Wales needs to take notice. Equally, making connections between the research which has been done in other rural communities (in the UK and further afield) will provide further understanding of the challenges facing us in Wales.

26 Innes, A., Cox, S., Smith, A. & Mason, A. (2006) “[Service provision for people with dementia in rural Scotland – difficulties and innovations](#)”, *Dementia*, vol 5, no. 2, p252.

Conclusion

We have to act now to tackle the impact of dementia in rural areas of Wales. Not only are the numbers affected large and growing – in excess of 17,000 by our estimate – but the individual experiences and stories of the individuals and families affected are heartbreaking.

Wales is at a crossroads. With a new Assembly, plans for a new Dementia Strategy and an expected new version of the Rural Health Plan, we have the opportunity to do more to understand the problems and identify policy change. But we can only hope to do so if we commit, now, to carrying out the data gathering and research needed to shine a light on dementia in rural areas and allow us to understand all of its facets – even if they make for uncomfortable reading.

Alzheimer's Society is committed to playing our part. We hope you will too.

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 3,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

If you have any concerns about Alzheimer's disease or any other form of dementia, visit alzheimers.org.uk or call the **National Dementia Helpline** on **0300 222 1122** (interpreters are available in any language).

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