

Alzheimer's Society Cymru,
16 Columbus Walk,
Brigantine Place,
Cardiff, CF10 4BY

alzheimer.org.uk

LI 05
Ymchwiliad i unigrwydd ac unigedd
Inquiry into loneliness and isolation
Ymateb gan: Cymdeithas Alzheimer's
Response from: Alzheimer's Society



Dr. Dai Lloyd AM,
Health, Social Care & Sport Committee,
National Assembly for Wales,
Cardiff, CF99 1NA
seneddhealth@assembly.wales

4th March 2017

Dear Dr. Lloyd,

Re: Inquiry into loneliness and isolation

On behalf of Alzheimer's Society Cymru, please find below a response to the Health, Social Care & Sport Committee's [inquiry into loneliness and isolation](#).

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 2,000 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.

Overview

Alzheimer's Society Cymru welcome the Committee's focus on loneliness and isolation. As we noted in our letter to the Committee in August 2016, loneliness and isolation are a growing concern in Wales, with clear links to dementia.

From a definitional standpoint, Alzheimer's Society has made clear¹ that we regard loneliness and isolation as two separate states. In general terms, we support the differentiation made by the LGiU²:

- **Social isolation:** an objective state determined by the quantity of social relationships and contacts between individuals, across groups and communities.
- **Loneliness:** a subjective state based on a person's emotional perception of the quality of social connection they need compared to what is currently being experienced.

We also note academic work³ which has identified the differences between emotional and social loneliness – with the former being an absence of a significant other with whom a close

¹ Alzheimer's Society (2013) [Dementia 2013: the hidden voice of loneliness](#), London: Alzheimer's Society.

² LGiU (2016) [Loneliness and social isolation in older people](#), London: LGiU.

³ Weiss, S (1973). *Loneliness: the experience of emotional and social isolation*, Massachusetts: MIT Press.

emotional attachment is formed⁴ and the latter relating⁵ more to a lack of a social network or group of friends, neighbours or colleagues.

Within a Welsh context, our increasingly older population means that Wales is likely to have an increasingly large population of lonely older people, and we are concerned that data suggests⁶ older men in Wales are the loneliest cohort of people in the UK. The Older People's Commissioner for Wales has said that loneliness and isolation is a "*modern day epidemic*"⁷ in Wales, whilst at a UK level nearly 10% of over-65s see friends or relatives less than once a month.⁸

Transport and rurality

Alzheimer's Society Cymru also want to stress the important role played by transport in people's social connections. We strongly believe that local authorities have a responsibility to make sure people with dementia can access appropriate activities. Among the people with dementia who participated in our *Dementia 2013: the hidden voice of loneliness* report⁹, there was an overwhelming feeling among people with dementia who lived alone that a lack of transport prevents them from getting out and taking part in activities. 88% of people with dementia who responded to the survey said they rely on family and friends for transport.

We have found that many of the concerns around isolation and loneliness for people living with dementia and their carers and families are often more pronounced in rural areas. Our *Dementia in Rural Wales* report¹⁰ showed that the isolation felt by people with dementia and their carers was intensified by rurality. In particular, unpaid carers often face social isolation and a lack of support networks – this is exacerbated in rural areas by distance, lack of public transport and other factors. We also know that if people with dementia are not signposted to appropriate services at the time of their diagnosis, there is an increased risk that they will become isolated and at risk of reaching crisis point before they access services.¹¹ Even when services and support are available, distances and travel times often mean that their usefulness was limited.

The impact on physical and mental health and wellbeing

We welcome that the Committee's terms of reference for this inquiry asks whether loneliness and isolation "*disproportionately affect certain groups such as those with dementia*". There are clear links between loneliness and dementia.

From our *Dementia 2013: the hidden voice of loneliness*¹² report, we know that 39% of people with dementia said they felt lonely, rising to 62% of people with dementia who live on

⁴ Burholt, V (2011). "Loneliness of older men and women in rural areas of the UK" in [Safeguarding the Convoy: a call to action](#), Abingdon: Campaign to End Loneliness / Age UK.

⁵ Alzheimer's Society (2013) [Dementia 2013: the hidden voice of loneliness](#), London: Alzheimer's Society.

⁶ WRVS (2012) [Loneliness rife amongst older men](#), Cardiff: WRVS.

⁷ Care & Repair Cymru (2013) [Older People's Commissioner sings Care & Repair praises](#), Cardiff: Care & Repair Cymru.

⁸ Rodrigues, R., Huber, M. & Lamura, G. (eds.) (2012) "[Facts and Figures on Healthy Ageing and Long-term Care: Europe and North America](#)", Vienna: *European Centre for Social Welfare Policy and Research*: p35/6.

⁹ Alzheimer's Society (2013) [Dementia 2013: the hidden voice of loneliness](#), London: Alzheimer's Society.

¹⁰ Alzheimer's Society (2016) [Dementia in Rural Wales: the three challenges](#), Cardiff: Alzheimer's Society.

¹¹ Alzheimer's Society (2015) [Diagnose or disempower? Receiving a diagnosis of dementia in Wales](#), Cardiff: Alzheimer's Society.

¹² Alzheimer's Society (2013) [Dementia 2013: the hidden voice of loneliness](#), London: Alzheimer's Society.

their own. Difficulties in maintaining social relationships and other features of dementia contributed to this, with 35% of people with dementia saying they'd lost friends after a diagnosis. Nearly two-thirds (63%) of people with dementia surveyed said that they felt anxious or depressed. We also know that 70% of respondents had stopped doing things they used to because of a lack of confidence. Diminished confidence can lead to a loss of independence, as people with dementia may feel concerned about what could happen if they leave their home, or reactions from other people.

We are aware of research¹³ suggesting that feelings of loneliness (but not social isolation) can predict the onset of dementia, with feelings of loneliness being associated with the development of dementia, even when objective indicators of social isolation and other covariates were controlled for. However, conflicting research¹⁴ has argued that whilst there is some evidence to support the proposition that loneliness is a consequence of dementia there is little evidence to support the notion that loneliness 'causes' dementia.

Addressing the problem and policy solutions

Whilst the following is not an exhaustive list, we believe the following suggestions could all form part of any action plan to help reduce isolation and loneliness in Wales:

- Alzheimer's Society Cymru note that Welsh Labour committed¹⁵ ahead of the 2016 Assembly election to "*develop a national strategy and take action to tackle loneliness and isolation*". We welcome this, and strongly recommend that any strategy should include a discrete section on dementia, given the particular effects on this community.
- Alzheimer's Society has recently launched our innovative Side By Side¹⁶ befriending service, in a bid to reconnect people with dementia with their communities and favourite pastimes. Launched in response to the loneliness and isolation so many people with dementia report experiencing, the service has been piloted since 2014, and now has a waiting list of almost two thousand people with dementia across England, Wales and Northern Ireland.
- Work being done to create Dementia Friendly Communities across Wales have made important steps in reducing loneliness and isolation. We now have over 30 Dementia Friendly Communities, and these are an important vehicle for reducing social isolation and loneliness. Work undertaken has already begun to identify what it means to be dementia friendly; more now needs to be done to raise awareness of what it means and encourage businesses, organisations and communities to commit to becoming dementia friendly.
- There is also evidence¹⁷ to suggest that intergenerational contact is more effective in combating loneliness than contact with one's own age group although both are important). Intergenerational practice and change negative perceptions, increase participation of older people in lifelong learning, enhance civic participation and active

¹³ Holwerda, T., Deeg, D., Beekman, A., van Tilburg, T., Stek, M., Jonker, C. & Schoevers, R. (2012) "[Feelings of loneliness, but not social isolation, predict dementia onset: results from the Amsterdam Study of the Elderly \(AMSTEL\)](#)", *Journal of Neurology Neurosurgery & Psychiatry*, BMJ Journals.

¹⁴ Victor C., Pikhartova, J., Woodrbridge, R. (2015) "[Is loneliness a cause or consequence of dementia?](#)", *Gerontologist*, vol.55, p.593.

¹⁵ Welsh Labour (2016) [Tackling loneliness and isolation in our Welsh communities](#), Welsh Labour website.

¹⁶ Alzheimer's Society (2017) [Side By Side](#), Alzheimer's Society website.

¹⁷ Age UK (2010) [Loneliness and Isolation Evidence Review](#), London: Age UK.

citizen, reduce fear of crime, improve community cohesion and more.¹⁸ There should be more support to help spread best practice for intergenerational projects.

- We note the comments¹⁹ of the Campaign to End Loneliness and Age UK that action to reduce loneliness should primarily be driven by local authorities. We would encourage local authorities in Wales to use resources such as those produced by the LGA and Age UK²⁰, the LGiU,²¹ and the JRF²² to combat loneliness. We would also recommend that mapping and addressing loneliness and isolation should form an outcome measure for local authorities' strategies and part of Public Service Boards' Local Wellbeing Plans. Those experiencing or at risk of loneliness should be involved in mapping local assets, determining responses, and co-producing solutions.²³
- Finally, we would propose that the Welsh Government's draft Dementia Strategic Action Plan should include an awareness of the impact of loneliness and isolation on people affected by dementia.

We trust this information is of assistance. Alzheimer's Society Cymru would be only too happy to give oral evidence as part of the inquiry; please contact me if you would like to arrange this or if you have any queries in relation to our submission.

Yours sincerely,



Dr. Ed Bridges

External Affairs Manager (Wales)

████████████████████

¹⁸ Beth Johnson Foundation (2011) [A Guide to Intergenerational Practice](#), BJB: Stoke-on-Trent.

¹⁹ Campaign to End Loneliness and Age UK (2015) [Promising approaches to reducing loneliness and isolation in later life](#), Age UK: London.

²⁰ LGA, Campaign to End Loneliness, and Age UK (2016) [Combating loneliness – A guide for local authorities](#), LGA: London.

²¹ LGiU (2016) [Loneliness and social isolation in older people](#), LGiU: London.

²² Joseph Rowntree Foundation (2013) [Loneliness resource pack](#), Joseph Rowntree Foundation: York.

²³ LGA, Campaign to End Loneliness and Age UK (2016) [Combating loneliness: A guide for local authorities](#), London: LGA.