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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal
Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

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

25th August 2016

Dear Dr. Lloyd,

Re: Priorities for the Health, Social Care and Sport Committee

On behalf of Alzheimer's Society in Wales, please find below a response to the [proposed priorities](#) for the Health, Social Care & Sport Committee.

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.

Alzheimer's Society welcomes the Committee's consultation on priorities for the Forward Work Plan. We agree with many of the key priorities, and welcome the direction of travel. We anticipate that the Committee will be monitoring the development of the proposed new Dementia Strategy¹, and we would welcome the opportunity to feed in on that project. Alzheimer's Society particularly welcomes the Committee's interest in the use of antipsychotic medication in care homes and loneliness and isolation among older people, and strongly supports the idea of inquiries on these two extremely important issues.

Use of antipsychotic medication in care homes

Alzheimer's Society is concerned about the over-use and inappropriate use of anti-psychotics in care home settings. Antipsychotic drugs can serve to reduce psychotic experiences such as delusions and hallucinations. However, use of antipsychotics should be limited, due to potential links to serious side effects such as risk of stroke (though there is debate over this in recent evidence²), only moderate benefit, and not addressing underlying causes of behavioural and psychological symptoms (BPSD).³ There is a danger that pharmacological solutions such as antipsychotics are too often used as a first, not a last, resort. Additionally, reviews and reductions of antipsychotics are most effective when nonpharmacological interventions were available to replace antipsychotics.⁴ The Older

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

² Howard. R, (2016) [Baseline characteristics and treatment-emergent risk factors associated with cerebrovascular event and death with risperidone in dementia patients](#), *British Journal of Psychiatry*, 209/3.

³ Alzheimer's Society (2014) [Antipsychotic drugs](#), London: Alzheimer's Society.

⁴ Ballard C (2016) [Impact of Antipsychotic Review and Nonpharmacological Intervention on Antipsychotic Use, Neuropsychiatric Symptoms, and Mortality in People With Dementia Living in Nursing Homes: A Factorial](#)

People's Commissioner for Wales has said that we must “*ensure that care homes are places of belonging and significance, and that the risks of institutionalisation, often characterised by an inappropriate use of antipsychotics and a failure to recognise the emotional neglect of older people, are eradicated.*”⁵ The Committee could explore the need to ensure that use of antipsychotics is appropriate.

There is a great deal of excellent work being carried out in Wales regarding improving the use of antipsychotics for people with dementia. This includes research at Swansea University regarding structured scrutiny by nurses⁶ which has “*led to improvements in prescribing practice and pain management and greater awareness of adverse side effects*”, as well as the STOPP/START toolkit developed by Dr Victor Aziz of the Royal College of Psychiatrists⁷, both of which demonstrate interesting routes for further inquiry and best practice development.

Within the National Dementia Vision for Wales, there are commitments to ensure appropriate use of antipsychotic drugs⁸; however, Alzheimer's Society believes an inquiry from the Committee into this issue would help to build the evidence base around their use.

Loneliness and isolation among older people

Loneliness and isolation are a growing concern in Wales. Demographic changes mean that Wales has an increasingly large population of older people (in particular over 80s) and an increasingly older population as a whole – this means that Wales is likely to have an increasingly large population of lonely older people. This is particularly true of older men in Wales, who represent the loneliest cohort of people in the UK.⁹ The Older People's Commissioner for Wales has said that loneliness and isolation is a “*modern day epidemic*”¹⁰ in Wales, whilst at a UK level nearly 10% of over-65s see friends or relatives less than once a month.¹¹

There are clear links between loneliness and dementia¹². 39% of people with dementia said they felt lonely, rising to 62% of people with dementia who live on their own. Meanwhile, 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.

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

[Cluster-Randomized Controlled Trial by the Well-Being and Health for People With Dementia \(WHELD\) Program](#), *American Journal of Psychiatry*, 173(3), pp.252-62.

⁵ Older People's Commissioner for Wales (2015) [Response from the Older People's Commissioner for Wales to the National Assembly for Wales, Health and Social Care Committee on the actions taken to implement recommendations made in the Committee's report on residential care for older people and 'A Place to Call Home'](#), Cardiff: OPCW, p15.

⁶ Swansea University (2015) [Structured scrutiny could reduce drug side effects for people with dementia](#), Swansea: Swansea University.

⁷ Aziz, V. (2015) [Potentially Inappropriate Medications for older people: the STOPP/START tool](#), Cardiff: Royal College of Psychiatrists in Wales.

⁸ Alzheimer's Society (2015) [Diagnose or disempower? Receiving a diagnosis of dementia in Wales](#), Cardiff: Alzheimer's Society.

⁹ WRVS (2012) [Loneliness rife amongst older men](#), Cardiff: WRVS.

¹⁰ Care & Repair Cymru (2013) [Older People's Commissioner sings Care & Repair praises](#), Cardiff: Care & Repair Cymru.

¹¹ 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.

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

recently launched project *Dementia in Rural Wales*¹³ carried out a series of interviews with people affected by dementia in rural areas of Wales, and it was clear from the responses 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. The broader lack of coverage for support services in rural Wales has a particular impact on dementia, as 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.¹⁴ Even when services and support were available, distances and travel times often meant that their usefulness was limited.

Integration of Health and Social Care services

We also welcome the Committee's interest into issues of integration of health and social care. The developing work around integration in Manchester, following the devolution of health and social care, could prove an interesting model to monitor. Alzheimer's Society is playing a role in this process, supporting the "Dementia United" initiative in establishing a five-year improvement plan to make Greater Manchester "the best place in the world" for people with dementia, with input from local government, health and social care organisations, charities, universities, sports clubs, and more.¹⁵

Sport and public health

Welsh Government recently ran its ACT NOW campaign¹⁶ advising the public on physical activity and how to reduce the risk of developing dementia. Evaluating such campaigns to ensure their effectiveness is critical, and we would be very happy to contribute to an inquiry along these lines.

We look forward to seeing the Committee's final Forward Work Plan, and very much hope to have the opportunity to contribute to any inquiries on the above two issues. If you require any further information, please do not hesitate to contact me.

Yours faithfully,



Dr. Ed Bridges

External Affairs Manager (Wales)



¹³ Alzheimer's Society (2016) [Dementia in Rural Wales: the three challenges](#), Cardiff: Alzheimer's Society.

¹⁴ Alzheimer's Society (2015) [Diagnose or disempower? Receiving a diagnosis of dementia in Wales](#), Cardiff: Alzheimer's Society.

¹⁵ Dementia United (2016) [What is it?](#), Dementia United website, Dementia United.

¹⁶ Welsh Government (2016) [ACT NOW to reduce your risk of developing dementia](#), Change 4 Life website, Welsh Government.