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

21st April 2017

Dear Dr. Lloyd,

Re: Inquiry into the use of anti-psychotic medication in care homes

On behalf of Alzheimer's Society Cymru, please find below a response to the Health, Social Care & Sport Committee's [inquiry into the use of anti-psychotic medication in care homes](#).

Dementia can devastate lives. For someone with the condition, as well as their family and friends, dementia means the plans you made, and the future you thought you had, will not be so.

Alzheimer's Society Cymru has a simple vision: a world without dementia. We know that moment will come. Today, too many people with dementia struggle. They cannot access information, help and support. Everyday things people take for granted become difficult.

Our mission is to transform the landscape of dementia forever. Until the day we find a cure, we will strive to create a society where those affected by dementia are supported and accepted, able to live in their community without fear or prejudice.

Summary / recommendations

- a) Alzheimer's Society Cymru welcomes the Committee's focus on the use of anti-psychotics. We are deeply concerned about the inappropriate use of anti-psychotics in Wales, and strongly believe that these drugs should only ever be the last resort.
- b) We support calls by the Royal Pharmaceutical Society Wales (RPSW) and the Royal College of Psychiatrists in Wales for an end to routine prescribing and a reduction in the time and dosage where antipsychotics are required.
- c) We recommend the Welsh Government institute a cycle of national and local audits to improve clinical practice and make sure that multidisciplinary support and regular reviews are available. Non-pharmacological treatment options should be available, supported by training for staff to provide person-centred care.
- d) We believe people with dementia must have a full explanation of the medication prescribed and have meaningful choice in their treatment.

Consultation response

- 1) Alzheimer's Society Cymru welcomes the Committee's focus on the use of anti-psychotics. As we noted in our letter to the Committee in August 2016, we are deeply concerned about the over-use and inappropriate use of anti-psychotics in care homes. Alzheimer's Society Cymru believes this inquiry will help to build the evidence base around this issue.
- 2) We strongly believe that these drugs should only ever be the last resort. Antipsychotic drugs can be used to reduce psychotic experiences such as delusions and hallucinations. However, use of antipsychotics should be limited, for several reasons. These include them showing only moderate benefit, not addressing underlying causes of behavioural and psychological symptoms¹, and links to serious side effects. The use of antipsychotics can result in a number of side effects, such as drowsiness, nausea and constipation. The longer term use of antipsychotics increases the risk of fatal conditions such as stroke (though there is some debate over this in recent evidence²). Fundamentally, there is a danger that pharmacological solutions are too often used as a first, not a last, resort.
- 3) In Wales, caution has been expressed over the use of antipsychotics by the Older People's Commissioner for Wales³ and by the Welsh Government in their National Dementia Vision⁴ and the draft of the Dementia Strategic Action Plan.⁵ Alzheimer's Society Cymru supports calls by the RPSW and the Royal College of Psychiatrists in Wales for an end to routine prescribing and a reduction in the time and dosage where antipsychotics are required. We strongly support the recommendations of the recent *Improving Medicines Use for Care Home Residents* report.⁶
- 4) We welcome the Welsh Government's proposal in the draft Dementia Strategic Action Plan⁷ to reduce the percentage of people with dementia prescribed antipsychotics but want to see more information on how this will be implemented. The Welsh Government should public what they anticipate will be reported to local mental health partnership boards. There should be better data collection and publication of existing levels of prescription of anti-psychotics in care homes, to understand prevalence and patterns of use.
- 5) To improve understanding of the issue and data collection, we recommend that Welsh Government institute a cycle of national and local audits of prescribing antipsychotics in care homes to patients with dementia to improve clinical practice.
- 6) We believe that the provision of alternative (non-pharmacological) treatment options to relieving behavioural and psychological symptoms of dementia (BPSD) are preferable to the use of anti-psychotics. This should be supported by improved

¹ Alzheimer's Society (2014) [Antipsychotic drugs](#), London: Alzheimer's Society, accessed 30th March 2017.

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*, vol. 209, no. 3.

³ 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.

⁴ Alzheimer's Society (2015) [Diagnose or disempower? Receiving a diagnosis of dementia in Wales](#), Cardiff: Alzheimer's Society.

⁵ Welsh Government (2017) [Draft national dementia strategy](#), Cardiff: Welsh Government.

⁶ Royal Pharmaceutical Society Wales [Improving Medicines Use for Care Home Residents](#), RPS Wales.

⁷ Welsh Government (2017) [Draft national dementia strategy](#), Cardiff: Welsh Government.

training for health and social care staff to provide person-centred care, which itself can reduce the risk of BPSD.

- 7) Behavioural and psychological symptoms of dementia are often a reaction to distress, unfamiliarity with the environment, or lack of ability to communicate and can often be managed without medication by avoiding situations likely to cause upset, avoiding confrontations arising from attempting to ‘correct’ the person with dementia, and by ensuring care is person-centred from staff who have the time and skills to support people with dementia, not by use of “medical clubbers”.⁸ People with dementia should have the opportunity to participate in meaningful activities. This involves tailoring the person’s care to their interests, abilities, history and personality to make sure they are comfortable and engaged. It is important to give them the chance to take part in one-to-one conversation and activities that interest them.⁹ Positive interactions and supportive contexts can help to mitigate the impact of particular difficulties or symptoms.¹⁰
- 8) Communication problems often occur for people with dementia and can become increasingly challenging. People with dementia should have access to communication support through speech and language therapy, to assess difficulties in communication and to maximise their ability to communicate. Training should incorporate an understanding of speech, language and communication issues. Education, support and training should set the highest standards for health, care home and agency staff to understand the communication difficulties experienced by people with dementia and identification of the early signs of eating, drinking and swallowing difficulties to ensure people’s nutritional needs are met.
- 9) If and when antipsychotics are necessary, as per NICE guidelines only the lowest dose should be prescribed for the shortest time, with regular review by an appropriately skilled pharmacist as part of a multidisciplinary team.^{11,12} This is a particular issue for dementia – according to a 2009 report by Professor Sube Banerjee, *The use of antipsychotic medication for people with dementia*, of 180,000 prescriptions for people with dementia, 140,000 were inappropriate.
- 10) Existing prescribing practices, medication reviews and the importance of informed consent were a strong theme of our engagement events that informed responses from Alzheimer’s Society Cymru to the consultation on the draft dementia strategy - a number of people with dementia and their carers told us they weren’t aware of the name of their medication or why they were taking it. This is of great concern. People affected by dementia need to be aware of their rights when it comes to deciding to take medication; their individual choice should be supported.
- 11) We recommend that the Welsh Government:
 - End routine prescribing and work towards a reduction in the time and dosage where antipsychotics are required.

⁸ Fenton-May, J. (2017) [Health, Social Care and Sport Committee](#), National Assembly for Wales, 25th January 2017 (para.241)

⁹ Alzheimer’s Society, [Treating behavioural and psychological symptoms of dementia](#), London: Alzheimer’s Society, date accessed 21/03/2017.

¹⁰ British Psychological Society (2016) [Psychological dimensions of dementia: Putting the person at the centre of care](#), BPS: London.

¹¹ Royal Pharmaceutical Society Wales (2016) [Improving Medicines use for Care Home Residents](#), Cardiff: RPSW.

¹² Older People’s Commissioner for Wales (2014) [A Place to Call Home? A Review into the Quality of Life and Care of Older People living in Care Homes in Wales](#), Cardiff: OPCW.

- Ensure people have a full explanation of the medication they may be prescribed and choice in their treatment. We should ensure that people with dementia prescribed antipsychotics have support from carers, loved ones, or advocates.
- Ensure that multidisciplinary support and regular reviews should be available to reduce over-use of antipsychotics. Reviews and reductions of antipsychotics are most effective when nonpharmacological interventions were available to replace antipsychotics.¹³ Non-pharmacological interventions could include occupational therapy, sensory therapy, gardening, talking therapy, art therapy, creative activities (for example, visual arts, music, gallery and museum visits), intergenerational activities, exercise programmes in a social context, and more.
- Ensure health boards work with pharmacists and other medical professionals who deliver enhanced support for care homes to reduce the use of antipsychotics in care homes through ensuring MDT support is available to go into care homes to deliver medication reviews on arrival and at regular intervals (for example every six months).

12) We recommend that the care homes' inspectorate mandates documented evidence of medicines' monitoring for older people prescribed mental health medicines. This monitoring should be shared with prescribers and pharmacists, and evidence of this should be placed in patients' records, alongside other mandatory records, such as those for nutritional status.

13) We also have concerns over polypharmacy, whereby four or more medicines are prescribed for an individual. The proportion of patients receiving 10 or more medicines has increased from 1.9% in 1995 to 5.8% in 2010.¹⁴ Medicines should be reviewed regularly for people with dementia; for many patients, dealing with multiple medicines can be confusing, and this is of particular concern for people living with cognitive impairment such as dementia. Research¹⁵ has shown that between 30% and 50% of other patients fail to take their medicines correctly or are otherwise noncompliant with their prescribed medicines regime. Support in ensuring medication is taken as prescribed is an important factor in maintaining independence for as long as possible. We recommend that:

- It may be appropriate for individuals to receive weekly prescriptions, to have carers support medication taking or to receive medication aids.
- As part of a multidisciplinary review, all care home residents should receive a review of their medication by a pharmacist when they first move into a care home in order to optimise their medication regimen.
- Residents of care homes should receive a minimum of one annual medication review from a pharmacist, with additional support for

¹³ 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 cluster-randomised controlled trial by the well-being and health for people with dementia \(WHELD\) program](#)", *American Journal of Psychiatry*, vol. 173, no. 3, pp.252-62.

¹⁴ Duerden, M., Avery, T. & Payne, R.. (2013) [Polypharmacy and Medicines Optimisation: making it safe and sound](#). London: The King's Fund.

¹⁵ Royal Pharmaceutical Society (2013) [Medicines Optimisation: The evidence in practice](#). London: RPS.

significant medication changes. For patients with complex medication regimens, this review should increase to every 3-6 months.

- With patient consent, all pharmacists directly involved in patient care should have full 'read and write' access to the patient health record in the interest of high quality, safe and effective patient care.
 - The Welsh Government must ensure that people have a full explanation of the medication they may be prescribed and be enabled to make an informed choice about their treatment and medication.
- 14) There is a great deal of excellent best practice 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 nurses¹⁶ 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 Psychiatrists,¹⁷ both of which demonstrate interesting routes for further inquiry and best practice development. In some Local Health Boards, SLTs provide for triage over the telephone for care homes in managing the communication and swallowing problems of those in their care, removing the need for a GP visit. Cwm Taf Health Board's Care Home Dementia Intervention Team is an innovative project that explores possible reasons for distress, enabling the service to work with care home staff in developing a person-centred care plan. Interventions include reminiscence, music therapy, life story work and doll therapy¹⁸
- 15) 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)

¹⁶ Swansea University (2015) [Structured scrutiny could reduce drug side effects for people with dementia](#), Swansea: Swansea University.

¹⁷ Aziz, V. (2015) [Potentially Inappropriate Medications for older people: the STOPP/START tool](#), Cardiff: Royal College of Psychiatrists in Wales.

¹⁸ Cwm Taf University Health Board (2016) [Innovative teamwork in Cwm Taf enables care home residents to live well with dementia](#), date accessed 20/04/2017.