



**Older People's Commissioner for Wales**  
**Comisiynydd Pobl Hŷn Cymru**

# **Response from the Older People's Commissioner for Wales**

**to the**

## **Inquiry into the use of antipsychotic medication in care homes**

**May 2017**

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## **About the Commissioner**

The Older People's Commissioner for Wales is an independent voice and champion for older people across Wales, standing up and speaking out on their behalf. She works to ensure that those who are vulnerable and at risk are kept safe and ensures that all older people have a voice that is heard, that they have choice and control, that they don't feel isolated or discriminated against and that they receive the support and services they need.

The Commissioner's work is driven by what older people say matters most to them and their voices are at the heart of all that she does. The Commissioner works to make Wales a good place to grow older - not just for some but for everyone.

The Older People's Commissioner for Wales:

- Promotes awareness of the rights and interests of older people in Wales.
- Challenges discrimination against older people in Wales.
- Encourages best practice in the treatment of older people in Wales.
- Reviews the law affecting the interests of older people in Wales.

# **Inquiry into the use of anti-psychotic medication in care homes in Wales**

## **Introduction**

1. I welcome the fact that the Committee is undertaking an Inquiry into the use of anti-psychotic medication in care homes, an issue I highlighted as part of my Care Home Review. It is deeply concerning that powerful medication is being used inappropriately to control the 'emotional and psychological' behaviours of people living with dementia in care homes across Wales.
2. It is essential to remember that at the heart of this issue are people with dementia who are often experiencing significant changes to their physical, mental, psychological and emotional functioning. These individuals are often trying to make sense of a new environment and coming to terms with a loss of things that are familiar, which provide reassurance, comfort and wellbeing for people living with dementia.
3. In many cases, individuals living with dementia who are being prescribed anti-psychotic medication inappropriately may have lost their ability to communicate and/or understand what people are saying to them, or may find themselves in pain and be unable to describe it.
4. By considering the circumstances in which a person with dementia living in a care home may find themselves (as described above), and the fact that they may be experiencing significant distress, fear and anxiety, it is understandable that they exhibit 'challenging' or 'aggressive' behaviour, which is in fact an individual's distressed response to their circumstances. Unfortunately, however, the medical model of care that prevails within this context looks only at the behaviour itself and how this can be managed, rather than looking at what unmet need may be causing it.
5. It is quite simply unacceptable that anti-psychotic medication is still being used as a primary response to 'challenging' behaviour across many residential care services, a response that contradicts the principles that underpin both the Social Services and Well-being (Wales) Act and the Regulation and Inspection of Social Care (Wales)

Act. Instead, an approach is required that seeks to understand and address the underlying causes of an individual's behaviour to improve their wellbeing.

6. Evidence of the benefits of alternative treatment options to address perceived 'challenging' behaviour can be seen in the work of HammondCare<sup>1</sup>, an Australian charity that supports staff in residential care settings to undertake non-pharmacological interventions where the use of anti-psychotic medication has been ineffective. HammondCare states that their interventions often result from a failure of carers and professionals to identify physical pain (mainly dental and arthritic)<sup>2</sup> and a lack of awareness about the importance of personalised care and the role of family carers in informing care homes about what matters most to their loved one.
7. It is essential that this Inquiry not only considers the impact of the inappropriate use of anti-psychotic medication from a medical point of view, but that it also explores and makes clear the positive impact that other, non-pharmaceutical interventions can have upon the quality of care and quality of life people of people with dementia living in care homes in Wales.

### **Evidence from my Care Home Review**

8. In 2014, I published 'A Place to Call Home?' a review into the quality of life and care of older people in care homes in Wales, the largest review of its kind ever undertaken. As part of the review, I gathered extensive evidence about the day to day experiences of residents, through visits to 101 care homes across Wales and a wide range of written and oral submissions from professionals, third sector organisations and Public Bodies, as well as care home residents and family carers.
9. A number of concerns were raised about the use of anti-psychotic medication in care homes, including the failure to follow NICE

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<sup>1</sup> HammondCare. (2017). Dementia Centre. <http://www.hammond.com.au/services/dementia-centre>

<sup>2</sup> Christie, J. (2016) 'Challenging Behaviour' – Challenging our Practice Lessons from Dementia Support Australia. <http://www.careinfo.org/wp-content/uploads/2016/10/Julie-Christie-Hammondcare-Challenging-Behaviour-Challenging-our-practice.pdf>

guidelines<sup>3</sup>, an absence of the use of non-pharmacological alternatives, and a lack of required medication reviews. Furthermore, failures were also identified in terms of assessing the potential risks to individuals being prescribed anti-psychotic medication, which can include:

- An increased risk of stroke or transient ischaemic attack (TIA)
- An increased risk of falls (which can cause serious injury or death)
- Sedation
- Parkinsonism (shaking and unsteadiness)
- An increased risk of blood clots
- An exacerbation of other dementia-related symptoms
- An increased risk of death

10. The findings of my review reflected the findings of a 2009 report by Prof. Sube Banerjee<sup>4</sup>, which concluded that the use of anti-psychotic medication was too high amongst patients with dementia. Despite limitations in the numerical data available, the report estimated that 180,000 people with dementia in the UK were being prescribed anti-psychotic medication, which was often used as a first line response to 'behaviour that challenged' medical and care practitioners, despite the fact that fewer than 36,000 patients would benefit from this type of pharmacological intervention.

11. As it was clear that the inappropriate use of anti-psychotic medication in care homes has a significant impact on the lives of older people living in care homes, I included two Requirements for Action within my review report to ensure that action would be taken by health boards to address the issues I identified:

- Requirement for Action 3.5 stated that information should be published annually about the use of anti-psychotic medication in

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<sup>3</sup> National Institute for Health and Care Excellence (2014) Managing Medicines in Care Homes. <https://www.nice.org.uk/guidance/sc1>

<sup>4</sup> Banerjee, S. (2009). The use of antipsychotic medication for people with dementia: Time for action. Department for Health. <https://www.rcpsych.ac.uk/pdf/Antipsychotic%20Bannerjee%20Report.pdf>

care homes, benchmarked against NICE guidelines and the Welsh Government Intelligent Targets for Dementia.

- Requirement for Action 4.4 stated that older people should receive medication reviews by a clinically qualified professional upon arrival at a care home, with regular medicine reviews undertaken in line with published best practice.
12. If presented in an accessible way that provides context and sets out what good practice looks like, the availability of data about the use of anti-psychotic medication in care homes has the potential to make a meaningful difference to the lives of residents. Family members and the general public will be able to see for themselves the extent to which anti-psychotic medication is being prescribed to care home residents. This also provides the information that Health Boards, and their Quality and Safety Committees, need to assess the appropriate use of anti-psychotic medication.
  13. Furthermore, regular medicine reviews will help to ensure that individuals are not being prescribed medication that is not effective, or is producing potentially dangerous side effects.
  14. In correspondence following the publication of my review report, health boards provided me with assurance that they would take action needed to deliver the required change.

### **Care Home Review follow-up work**

15. Due to the potential impact that the inappropriate use of anti-psychotic medication can have on an individual's life, I chose to include this as a priority area for the follow-up work linked to my review that began in January 2017.
16. When I requested information from health boards, I was clear that I wanted to see evidence of the impact of the action they have taken in response to my review, rather than simply a list of the action underway or planned.
17. I have analysed the responses from health boards against a judgement framework that clearly sets out what success looks like in terms of creating a culture where the use of anti-psychotic medication

is no longer the primary response to 'challenging' behaviour by care home residents with dementia.

18. The judgement framework includes the following examples of key success criteria:

- The Health Board has taken steps to ensure that adequate training and support in medicines management has been and is provided to relevant care home staff such as senior carers, nurses and care home managers.
- There is evidence that Residents and family members are actively engaged in medication reviews and the principles of patient choice are upheld.
- Evidence that pain relief medication is understood and best practice followed.
- There is evidence that the human rights of residents are upheld and protected.

### **Key findings from follow-up evidence provided by Health Boards**

19. Whilst Health Boards provided a wide range of information to me, setting out the action they have taken since 2015, a number of key cross-cutting findings have emerged based on their responses.

20. All Health Boards have made references to services or projects that have been established to review the prescribing of anti-psychotic medication and/or training care home staff to use non-pharmacological interventions. I particularly welcome the introduction of Multidisciplinary teams (in some areas) that will review current prescriptions and develop non-pharmacological intervention plans following a person-centred assessment.

21. I also welcome the review and reconfiguration of the Community Psychiatric Nurse in-reach service currently underway in one Health Board area, which aims to ensure that there is adequate support for care homes to undertake a six-month review of anti-psychotic medication use, and the plans to further expand this service to meet a target of undertaking medication reviews every 12 weeks.

22. Similarly, I welcome the fact that some Health Boards are now developing services designed to not only support individuals, but also to support care homes in developing individual intervention plans to prevent the inappropriate prescribing of anti-psychotic medication.
23. Evidence provided about training and education for care home staff to enable them to support individuals in a personalised way demonstrates a growing recognition of the importance of person-centred care, which engages with and responds to an individual's needs, an approach that should reduce the need for anti-psychotic medication and deliver measurable improvements in residents' quality of life.
24. However, Health Boards were generally unable to provide evidence about the specific benefits that this action had delivered. Furthermore, much of the activity described was limited, applying only to nursing homes, for example, or being delivered in only one geographical area. There was also a lack of clarity in the information provided about how specialist mental health in-reach services are communicating with other professionals working in care homes, who play an essential role in maintaining the physical, intellectual, emotional and social functioning of residents.
25. Furthermore, given the known triggers for distressed responses, such as communication difficulties (e.g. dysphasia) and a lack of personalisation in the delivery of care and support, I had expected to see evidence of a more holistic approach being taken, using the skills of Allied Health Professionals to innovate and challenge current practice in delivering dementia care.
26. I was also disappointed that little evidence was provided about the impact of interventions by Health Boards on the quality of life of individuals. Responses often made an assumption that by reducing or stopping a prescription of anti-psychotic medication, the risk of harm for individuals must be reduced. Whilst this may be the case, without specific processes in place to measure the improvements achieved for an individual, it is impossible to know for certain whether a positive difference is being made.



27. Only one Health Board provided evidence that demonstrated the prescribing of anti-psychotic medication in care homes was being actively monitored within the corporate governance structure. A lack of oversight at a senior level suggests that there are still significant gaps in monitoring the use of anti-psychotic medication in care homes and the potential harm that may occur as a result of inappropriate prescribing.
28. The majority of responses from Health Boards stated that they follow NICE guidance and the evidence supplied suggests that Health Boards have put in place services and projects to address the use of anti-psychotic medication or are in the process of doing so. Whether this is sufficient to challenge current practice is unclear, however, for the following reasons:
- The impact of any alternative interventions on residents is poorly evidenced.
  - Non-nursing care homes are still not receiving an equitable service.
  - There is a lack of evidence about wider engagement with other professionals.
  - The use of the expertise of family members in medication reviews or non-pharmacological alternatives appears to still be absent.
29. Finally, data providing information about the current levels the prescribing of anti-psychotic medication in care homes is still not being published, despite a commitment by all Health Boards to do so.
30. Based on the evidence provided to me by Health Boards, I remain concerned that there are still significant gaps in terms of data relating to the use of anti-psychotic medication in care homes. There is also little evidence of activities taking place across whole health boards (as opposed to the small-scale pilot projects currently underway or planned) to drive the cultural change needed to move away from prescribing anti-psychotic medication inappropriately towards using alternative (non-pharmacological) treatment options instead.

31. Furthermore, it is disappointing that Health Boards have not fulfilled the commitments they made to meet my Requirements for Action relating to the use of anti-psychotic medication, and that there still seems to be a lack of oversight within governance structures at a senior level.

## **Recommendations**

32. To ensure that progress continues to be made in addressing the issue of anti-psychotic medication being prescribed inappropriately to people with dementia living in care homes in Wales, I would recommend the following action:

- A national mechanism for the collection of prescribing data for anti-psychotic medication within care homes should be developed and implemented by the Welsh Government. Information should then be published annually about the use of anti-psychotic medication in care homes, benchmarked against NICE guidelines and Welsh Government Intelligent Targets for Dementia.
- When commissioning care home placements, there should be a requirement on Local Authorities and Health Boards to ensure that alternative (i.e. non-pharmacological) treatment options are available and that staff have the skills they need to enable them to appropriately manage and respond to residents that exhibit distressed responses. There should also be a requirement to ensure that in-reach, multi-disciplinary specialist mental health and wellbeing support is available for older people in care homes, which includes:
  - An assessment of the mental health and wellbeing of residents as part of their initial care plan development and their on-going care planning.
  - Active pain management
  - Advice and support to care staff about how to care effectively for older people with mental wellbeing and mental health needs, including dementia, and when to make referrals.
  - Explicit referral pathways and criteria for referrals.

- All residents on anti-psychotic medication are monitored and assessed to identify whether these drugs can be withdrawn. Reviews must be conducted in line with NICE guidelines.
- Upon arrival at a care home, older people should receive a medication review undertaken by a clinically qualified professional, with regular medication reviews undertaken in line with published best practice. Anti-psychotic medication should not be routinely prescribed to treat 'distressed responses' or 'behaviour that challenges'.
- Residents and family members should be actively engaged in medication reviews and the principles of patient choice should be upheld.
- In line with NICE guidance, when anti-psychotic medication is required, the lowest dose should be prescribed for the shortest time with regular review by an appropriately skilled medical practitioner as part of a multidisciplinary team.
- Reconciliation of medicines should be undertaken by a pharmacist when a person moves to a care home from their own home (or another care setting) to ensure that their medication record is maintained accurately.
- The Welsh Government should ensure that multidisciplinary team services are made available to all residents in care homes to reduce the tendency to prescribe anti-psychotic medication, improve outcomes for residents, and address current inequalities in provisions for residents and older people living in the community.