

# Use of antipsychotic medication in care homes

May 2018



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# About the Committee

The Committee was established on 28 June 2016 to examine legislation and hold the Welsh Government to account by scrutinising expenditure, administration and policy matters, encompassing (but not restricted to): the physical, mental and public health and well-being of the people of Wales, including the social care system.

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## Committee Chair:



**Dai Lloyd AM**  
Plaid Cymru  
South Wales West

## Current Committee membership:



**Dawn Bowden AM**  
Welsh Labour  
Merthyr Tydfil and Rhymney



**Jayne Bryant AM**  
Welsh Labour  
Newport West



**Angela Burns AM**  
Welsh Conservatives  
Carmarthen West and South  
Pembrokeshire



**Rhun ap Iorwerth AM**  
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## Chair's foreword

It is extremely worrying that nearly ten years after the publication of Professor Sube Banerjee's report on the use of antipsychotic medication for people with dementia there still remain significant concerns about the inappropriate use of antipsychotics in care home settings.

It is also of considerable concern that the lack of data and records means there is great difficulty in determining a national picture of prevalence and patterns of prescribing antipsychotic medications within care homes.

We are not suggesting that antipsychotics should never be prescribed for people with dementia; it is the appropriateness of their prescription that is under question. Given the increased risk of heart attack or stroke associated with their use in people with dementia, we are very concerned that in many cases they appear to be an option of first choice rather than a last resort, when people who are living with dementia are demonstrating challenging behaviours. Unnecessarily medicating vulnerable people in care is a profound human rights issue which must be addressed.

Patients living with dementia have specific and complex needs and are likely to require greater levels of care than other patients. We were told that a person living with dementia presenting challenging behaviour often has an unmet need which they may be unable to communicate. As such, we believe it is vitally important to look at the person as a whole in order to understand what may be causing a particular behaviour.

While our inquiry has predominantly focused on care homes, inappropriate use of antipsychotics is not limited to this sector. We heard of similar problems in hospital settings, and we are very grateful to the individuals who took the time to come and talk to us about their experiences. It is also important to acknowledge that responsibility for prescribing antipsychotic medication lies with GPs and/or hospital psychiatrists or clinicians, not care home staff.

We are disappointed with the apparent lack of commitment to tackling this issue as a priority. We believe cultural and systemic changes are needed to ensure antipsychotic medications are prescribed appropriately, and not as a first option.

We urge the Welsh Government to take action on the evidence we have gathered and the recommendations we have made to drive progress and deliver the solutions needed to protect some of our most vulnerable citizens.

Dr Dai Lloyd, AM  
Chair



## Recommendations

**Recommendation 1.** The Welsh Government should ensure that, within 12 months, all health boards are collecting and publishing standardised data on the use of antipsychotic medication in care homes and report back to this Committee on progress at the end of that 12 month period..... Page 16

**Recommendation 2.** The Welsh Government should ensure that, within 12 months, all health boards are fully compliant with NICE guidelines on dementia, which advise against the use of any antipsychotics for non-cognitive symptoms or challenging behaviour of dementia unless the person is severely distressed or there is an immediate risk of harm to them or others, and report back to this Committee on rates of compliance at the end of that 12 month period. .... Page 21

**Recommendation 3.** The Welsh Government should ensure that every person with dementia presenting challenging behaviour receives a comprehensive person-centred care assessment of their needs. It should work with relevant health professionals to develop a standardised checklist tool to be used by health and social care staff to identify and address/rule out possible causes of challenging behaviour, including unmet physical or emotional needs. It must include a requirement for consultation with the individual and their carer or family. The checklist should be available within six months and must record the action taken to demonstrate that all other options have been considered before antipsychotics are prescribed for people with dementia. .... Page 33

**Recommendation 4.** We recommend the introduction of mandatory three monthly medication reviews for people with dementia who have been prescribed antipsychotic medication, with a view to reducing or stopping the medication following the first review where possible..... Page 34

**Recommendation 5.** The Welsh Government should explore ways in which the repeat prescription system could trigger the need for a medication review at the three month point..... Page 34

**Recommendation 6.** We recommend that medicines monitoring should be a key part of care homes inspection, and that Care Inspectorate Wales mandates documented evidence of medicines' monitoring for older people prescribed antipsychotic medication in patient records. .... Page 34

**Recommendation 7.** We recommend that the role of the allied health professional dementia consultant includes a requirement to work with care homes to improve access to allied health professionals for care home residents. .... Page 35

**Recommendation 8.** The Welsh Government should take action to address the shortage of speech and language therapists, given their value in improving outcomes for people with dementia, and report its progress to this Committee within 12 months..... Page 35

**Recommendation 9.** The Welsh Government should develop a method for assessing the appropriate skills mix required for care home staff, and produce guidance on this to ensure that there are safe and appropriate staffing levels in every care home, and that staff have time to provide high quality care. .... Page 46

**Recommendation 10.** We recommend that, within six months, national standards for dementia-care training be developed to equip care home staff with the necessary skills to deal with challenging behaviour. Dementia-care training and specific training to deal with challenging behaviour (as stated in NICE guidelines: including de-escalation techniques and physical restraint methods) should be mandatory requirements for all care home staff, and compliance with this should be scrutinised as part of CIW’s inspection regime. .... Page 47

**Recommendation 11.** The Welsh Government should commission a review of the levels and appropriateness of the use of antipsychotic medication in people with dementia in secondary care. The findings of this review should be published and reported back to this Committee..... Page 52

## 1. Background

1. Antipsychotics are a group of medications usually used in the treatment of mental health conditions such as schizophrenia. There have been increasing concerns over recent years about the use of antipsychotics to treat the behavioural and psychological symptoms of dementia (BPSD).
2. Antipsychotics are associated with an increased risk of cerebrovascular adverse events and greater mortality when used in people with dementia.<sup>1</sup> Studies estimate that there are at least 1,800 extra deaths each year among people with dementia as a result of their taking antipsychotics, and that the likelihood of premature death increases if people take these drugs for months or years rather than weeks.<sup>2</sup>
3. No antipsychotic (with the exception of risperidone in some circumstances) is licensed in the UK for the treatment of BPSD. However, antipsychotics are often prescribed off-label<sup>3</sup> for this purpose. It has been suggested that around two thirds of prescriptions of antipsychotics for people with dementia are inappropriate.
4. During our scrutiny of the Welsh Government's draft dementia strategy<sup>4</sup> we heard that the use of antipsychotics is of great concern to people with dementia and their families. We were told that work is needed to make sure that antipsychotics are only used where absolutely necessary, reviewed regularly, and only the lowest doses are given.
5. We therefore agreed to undertake a short inquiry to look at the use of antipsychotic medication in care home settings and the ways in which its inappropriate use could be reduced, including the consideration of:
  - the availability of data on the prescribing of antipsychotics in care homes, to understand prevalence and patterns of use;

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<sup>1</sup> Medicines & Healthcare products Regulatory Agency – **Drug Safety Update, March 2009**

<sup>2</sup> **Social Care Institute for Excellence – Antipsychotic medication and dementia**

<sup>3</sup> There are clinical situations when the use of unlicensed medicines or use of medicines outside the terms of the licence (ie, “off-label”) may be judged by the prescriber to be in the best interest of the patient on the basis of available evidence – **MHRA Drug Safety Update, April 2009**

<sup>4</sup> Welsh Government Consultation Document, **Together for a Dementia Friendly Wales 2017-22** – January 2017

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- prescribing practices, including implementation of clinical guidance and medication reviews;
- provision of alternative (non-pharmacological) treatment options;
- training for health and care staff to support the provision of person-centred care for care home residents living with dementia;
- identifying best practice, and the effectiveness of initiatives introduced so far to reduce inappropriate prescribing of antipsychotics;
- use of antipsychotic medication for people with dementia in other types of care settings.

## Engaging and gathering evidence

**6.** From 3 March to 21 April 2017 we ran a public consultation. We received 18 **written responses**, representing a range of healthcare organisations and professional groups. In addition, we heard **oral evidence** from a number of witnesses. We are particularly grateful to the people who had been affected by the use of antipsychotic medication for sharing their experiences with us. We heard evidence from the Cabinet Secretary for Health and Social Services “the Cabinet Secretary” at our meeting on 17 January 2018.

**7.** We would like to thank all those who have contributed to our work.

## 2. Availability of data on the prescribing of antipsychotics in care homes

### Prevalence

**8.** There is significant concern about the inappropriate use of antipsychotics in care home settings. However, it is important to note that responsibility for prescribing antipsychotic medication lies with GPs and/or hospital psychiatrists or clinicians rather than care home staff.

**9.** A number of witnesses referred to the findings of the 2009 report by Professor Sube Banerjee: *The use of antipsychotic medication for people with dementia* which concluded that antipsychotics “appear to be used too often in dementia and, at their likely level of use, potential benefits are most probably outweighed by their risks overall”.<sup>5</sup> Evidence from 1000 Lives Plus to the Older People’s Commissioner for Wales suggests that for 70% of people with BPSD antipsychotics can be discontinued without worsening symptoms.<sup>6</sup>

**10.** According to Professor Banerjee’s report:

“Using the best available information, I estimate that we are treating 180,000 people with dementia with antipsychotic medication across the country per year. Of these, up to 36,000 will derive some benefit from the treatment. In terms of negative effects that are directly attributable to the use of antipsychotic medication, use at this level equates to an additional 1,620 cerebrovascular adverse events, around half of which may be severe, and to an additional 1,800 deaths per year on top of those that would be expected in this frail population.”

**11.** It also found that antipsychotic drugs have been used inappropriately in all care settings.<sup>7</sup>

**12.** Tim Banner, Consultant Pharmacist, Cardiff and Vale University Health Board (UHB) suggested that:

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<sup>5</sup> The use of antipsychotic medication for people with dementia, October 2009

<sup>6</sup> **A Place to Call Home** – A Review of the Quality of Life and Care of Older Peoples Living in Care Homes in Wales

<sup>7</sup> The use of antipsychotic medication for people with dementia, October 2009

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“... we don’t know the levels of prescribing of antipsychotics within care homes. We don’t know what is appropriate, what is inappropriate. Anecdotal evidence is there is a degree of inappropriate prescribing going on, going back to 2009 with the Banerjee report. So, there is going to be some use for antipsychotics. We just haven’t got a gauge of what is appropriate and what is inappropriate at this point in time ...”<sup>8</sup>

**13.** Andrew Evans, the Welsh Government’s Chief Pharmaceutical Officer told us:

“There are times when it is appropriate to prescribe antipsychotics, and that gives us a challenge in trying to determine, at a population level, what is appropriate use and what isn’t. What we are able to do, and the plan we’ve been putting in place, which we hope will be ready for April 2018, around understanding how antipsychotics are being used in the care home sector, is to look at the data we can collect nationally that will allow us to identify clinical variation, particularly in those areas where it would appear that antipsychotic prescribing in older people is particularly high, and then allow the health service to implement interventions that would reduce the rate of antipsychotic prescribing in those areas.”<sup>9</sup>

## Data collection and audit

**14.** A number of witnesses highlighted the difficulty in determining prevalence and patterns of antipsychotic prescribing within care homes due to lack of data.<sup>10</sup> According to the Older People’s Commissioner, “the complete absence of any data coupled with the impact of this on people is a hugely worrying issue”.<sup>11</sup> The Commissioner went on to say that the lack of data is “leading to and supporting the lack of strategic prioritisation” of this issue. The Commissioner suggested a self-scrutiny toolkit should be developed for health boards to improve the situation.<sup>12</sup>

**15.** The Welsh NHS Confederation’s written evidence stated:

“The lack of a central point of data makes it difficult to benchmark the level of anti-psychotic prescribing at a care home level as such data is

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<sup>8</sup> RoP, 21 September 2017, paragraph 146

<sup>9</sup> RoP, 17 January 2018, paragraph 10

<sup>10</sup> RoP, 5 October 2017, paragraphs 28, 78, 242, 348

<sup>11</sup> RoP, 21 September 2017, paragraph 27

<sup>12</sup> Health, Social Care & Sport Committee, 21 September 2017, Paper 1

linked back to the prescribing GP, of which there may be many covering one care home. This makes it difficult to identify patterns of use. As such, the only data available to our members in relation to the use of anti-psychotic medication across the relevant Local Health Board would be available only as a result of a manual audit of GP records or an analysis of individual care home prescribing records. However, this can be more difficult for Health Boards with large population bases.”<sup>13</sup>

**16.** The Faculty of Old Age Psychiatry and the Royal College of Psychiatrists in Wales<sup>14</sup>, supported by Alzheimer’s Society Cymru,<sup>15</sup> the Royal Pharmaceutical Society Wales<sup>16</sup> and the Royal College of Speech and Language Therapists,<sup>17</sup> is calling for a Wales-wide cycle of audits to gather data on antipsychotic prescribing practices, as they say the availability of hard data on prescribing practices is critical to understand prevalence and patterns of use.<sup>18</sup>

**17.** Representatives of local health boards outlined the work they were doing locally to develop audits. Staff of Hywel Dda UHB told us that when asked to provide the Older People’s Commissioner with information on prescribing of antipsychotics, they realised that they did not really have an understanding of how many patients were on antipsychotics. Sarah Isaac, Senior Pharmacist Manager – Primary Care, told us:

“What we’ve done locally is developed an audit to generate data on the use of antipsychotics across primary care, but we’ve also got a subsection where we’re recording how many of those patients are also in care settings.”<sup>19</sup>

**18.** Representatives of Aneurin Bevan UHB told us that since 2012 they had been conducting audits within the Newport borough on the use of antipsychotic medication with patients who have dementia living in care home settings. As a result, they had been able to establish the prevalence and patterns of prescribing

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<sup>13</sup> Written evidence, APS 12

<sup>14</sup> Written evidence, APS 07

<sup>15</sup> Written evidence, APS 08

<sup>16</sup> Written evidence, APS 09

<sup>17</sup> Written evidence, APS 10

<sup>18</sup> Written evidence, APS 07

<sup>19</sup> RoP, 19 October 2017, paragraph 417

in that borough and were now in the process of collating information from other boroughs in this respect.<sup>20</sup>

**19.** Kim Williams of Cwm Taf UHB highlighted some of the difficulties associated with collating prescribing information:

“Can I just say, when we were putting together the briefing for this, and in looking at our annual reports for the specialist dementia intervention team, we had to look at about five different sets of notes, not all of which are very readily available, to follow through what’s happened to a single person who’s known to our team. So, they might start in the community, then they’ll have a GP set of notes; we’ve got the care home notes, and then we’ve got the secondary care mental health notes. We have a whole series, so, it’s really very difficult to pull that together...”<sup>21</sup>

**20.** The use of different IT systems across the NHS in Wales was also seen as an impediment to effective data collection. Victoria Gimson, representing Cardiff and Vale UHB, said:

“Communication across teams, even within mental health—it’s a challenge to get, sometimes, information across the same health board to different mental health teams. Trying to pick that data out from the GPs as well—it’s a nightmare not having one single prescribing system that you can all access, where you can access the same notes. We really need it.”<sup>22</sup>

**21.** Claire Aston of Aneurin Bevan UHB agreed, saying

“There is something about our IT systems that don’t talk to each other. So, the discharge information from an acute episode may not get to the GP or to the nursing home. Communications get lost.”<sup>23</sup>

**22.** The Cabinet Secretary acknowledged the concerns of witnesses in relation to data collection:

“We think this is an area for improvement. We think our current data collection isn’t where it should be. That’s why, from April, we’ll have a

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<sup>20</sup> RoP, 19 October 2017, paragraph 425

<sup>21</sup> RoP, 19 October 2017, paragraph 359

<sup>22</sup> RoP, 19 October 2017, paragraph 360

<sup>23</sup> RoP, 19 October 2017, paragraph 495



firmer base on which to do that, and after the first quarter we'll have figures, and we'll learn more as we go through, and it's then about how we use that data intelligently to improve the quality of care and the outcomes from care."<sup>24</sup>

**23.** Andrew Evans confirmed that work had been ongoing with the NHS Wales Informatics Service and the NHS Wales Shared Services Partnership to understand what alternative systems were in place to collect and link data:

“We've been trialling that for the last year, and we're pretty confident now that we will be able to collect data looking at certain demographic characteristics of patients in general practice with prescriptions for antipsychotics. So, we are proposing, from April 2018, to collect data for every general practice in Wales, looking at the rate of antipsychotic prescribing amongst patients who are aged 65 years or over.”<sup>25</sup>

**24.** He also highlighted work being undertaken by the All Wales Medicines Strategy Group to define a national audit, based on the one developed by Aneurin Bevan UHB, which can be used by individual GP practices or other prescribers of antipsychotics to determine not just the rate of antipsychotic prescribing in their practice, but how appropriate it is in the context of the NICE guidance.<sup>26</sup>

**25.** The Welsh Government's written evidence paper explained that whilst linking details of medicines prescribed to patient age, gender and partial post code area will improve understanding of how medicines are used, it will not allow prescribing to be analysed either by residence in a care home or by the reason for prescribing or diagnosis.<sup>27</sup>

## Our view

**26.** We were pleased to see the Welsh Government's commitment to reducing “the percentage of people with a diagnosis of dementia prescribed antipsychotic medications and a reduction in duration of treatment, particularly in care homes” in the draft Dementia Action Plan.<sup>28</sup> It is therefore of great concern to us that the reference to care homes has been removed from this key action in the final Plan, published in February 2018.

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<sup>24</sup> RoP, 17 January 2018, paragraph 115

<sup>25</sup> RoP, 17 January 2018, paragraph 101

<sup>26</sup> RoP, 17 January 2018, paragraph 11

<sup>27</sup> Health, Social Care & Sport Committee, 17 January 2018, Paper 1

<sup>28</sup> Welsh Government, **Together for a Dementia Friendly Wales 2017-2022**

- 27.** It is unacceptable that there remain significant concerns about the inappropriate use of antipsychotics in care home settings almost a decade after the publication of Professor Banerjee's report on the use of antipsychotic medication for people with dementia.
- 28.** The lack of data and records means there is great difficulty in determining a national picture of prevalence and patterns of prescribing antipsychotic medications within care homes. We are concerned that the use of different IT systems across the NHS in Wales is obstructing effective data collection.
- 29.** We note the Cabinet Secretary has acknowledged the concerns of witnesses in relation to data collection, and we are pleased that relevant work is ongoing with the NHS Wales Informatics Service and the NHS Wales Shared Services Partnership to make improvements and collect new data. However, we note that there will still be limitations with the new data being collected, and there will still be gaps in our understanding of the number of older people in care homes being inappropriately prescribed antipsychotic medication.
- 30.** We note that audits of the prescribing of antipsychotic medication to patients with dementia are already taking place in some health boards, e.g. Aneurin Bevan UHB, and believe that this needs to be rolled out across all health boards as a matter of urgency.
- 31.** We agree with the Older People's Commissioner that the absence of data, coupled with the obvious personal impact on individuals, is very worrying.

**Recommendation 1.** The Welsh Government should ensure that, within 12 months, all health boards are collecting and publishing standardised data on the use of antipsychotic medication in care homes and report back to this Committee on progress at the end of that 12 month period.

## 3. Prescribing practices

### Implementation of clinical guidance

**32.** The NICE guidelines on dementia advise against the use of any antipsychotics for non-cognitive symptoms or challenging behaviour of dementia unless the person is severely distressed or there is an immediate risk of harm to them or others.<sup>29</sup>

**33.** However, a number of witnesses raised concerns that antipsychotics are being used as a default position in care homes and some hospital wards, when people with dementia are difficult to deal with. ADSS Cymru stated:

“these drugs have been used to manage psychological and behavioural symptoms in dementia. Symptoms include aggression, agitation, shouting and sleep disturbance. However, uncooperativeness, restlessness, wandering, or unsociability are not sufficient reasons to justify their use.”<sup>30</sup>

**34.** The British Psychological Society (BPS) told us that current practice almost assumes a diagnosis of challenging behaviour and there is this medication for it, but this is not appropriate:

“It’s not like, ‘You’ve got pneumonia and here’s an antibiotic.’”<sup>31</sup>

**35.** Sue Phelps of Alzheimer’s Society Cymru told us:

“... what’s the biggest issue here – that, where you have somebody with behavioural or psychological problems relating to their dementia, to routinely prescribe an antipsychotic medication without looking at what is underpinning those behaviours and causing them is wrong, and it does, as I say, seem to be the default position, which needs to be addressed.”<sup>32</sup>

**36.** While the Older People’s Commissioner stated:

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<sup>29</sup> NICE Guidance: **Dementia: supporting people with dementia and their carers in health and social care** – November 2006

<sup>30</sup> Written evidence, APS 19

<sup>31</sup> RoP, 5 October 2017, paragraph 371

<sup>32</sup> RoP, 21 September 2017, paragraph 66

“It is quite simply unacceptable that antipsychotic medication is still being used as a primary response to ‘challenging’ behaviour across many residential care services.”<sup>33</sup>

**37.** Care Forum Wales told us that the use of antipsychotics in care homes has “become something of a national scandal”.

**38.** ADSS Cymru reported that concerns were raised in Operation Jasmine and the Flynn review<sup>34</sup> (on neglect of older people living in care homes in Gwent) about the use of antipsychotic medication as a form of chemical restraint. ADSS continued:

“Improper use of any form of restrictive physical intervention or restraint can constitute assault or negligence. It is also true for chemical restraint where its use is inappropriate.”<sup>35</sup>

**39.** ADSS further states that any restraint, including chemical, should be based on the principles enshrined in the Mental Capacity Act 2005 and Mental Health Act 2007, that everything done for or on behalf of a person who lacks capacity must be in that person’s best interests.

**40.** The Cabinet Secretary’s written evidence acknowledged that “there is evidence and concern” that antipsychotic medicines are used for the management of behavioural and psychological symptoms in dementia.

**41.** The Cabinet Secretary asserted that the Welsh Government expects all clinicians and NHS bodies to follow the NICE clinical guidance on this issue, and NHS bodies are expected to have processes in place to monitor and assure themselves that NICE guidance is followed.<sup>36</sup>

**42.** However, the Older People’s Commissioner and Alzheimer’s Society Cymru both raised concerns that current practice is not fully compliant with the NICE guidelines. Sue Phelps from Alzheimer’s Society Cymru said that “we’re currently in breach of NICE guidelines”<sup>37</sup> in terms of the duration of prescriptions and lack of reviews (the NICE guidelines state “treatment should be time limited and regularly reviewed (every 3 months or according to clinical need)”). The Older People’s Commissioner told the Committee:

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<sup>33</sup> Health, Social Care & Sport Committee, 21 September 2017, Paper 1

<sup>34</sup> The Flynn report – **In search of accountability** – July 2015

<sup>35</sup> Written evidence, APS 19

<sup>36</sup> Health, Social Care & Sport Committee, 17 January 2018, Paper 1

<sup>37</sup> RoP, 21 September 2017, paragraph 75

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“It’s not just NICE guidelines; section 27 regulations—I think it’s section 29 within that—on control and restraint. I cannot see how the current position is compliant with that. The national outcomes framework that we have for Wales: I cannot see how that is being made real for these people and it seems to me an example of what prudent healthcare is not. This is one of those perfect examples of something that is bad for everyone but worst of all for some of our most vulnerable people for whom our duty should have been highest.”<sup>38</sup>

**43.** She went on to say:

“[...] that’s my ultimate question to health boards, Welsh Government and others: when will we be compliant in Wales with those NICE guidelines—full compliance?”<sup>39</sup>

**44.** The Cabinet Secretary acknowledged that “there may be challenges in some parts of the care home sector” and went on to say:

“I wouldn’t want to give the impression that we think that every single care home is not compliant with NICE guidance, but there needs to be a recognition of the problem to be able to deal with it.”<sup>40</sup>

## Prescribing practices

**45.** It was suggested that there can be pressure on health professionals from various sources to prescribe antipsychotics when a person with dementia is agitated or aggressive.

**46.** Sue Phelps of Alzheimer’s Society Cymru told us that caring for someone with dementia is not easy and sometimes pressure can come from within the family for help in coping:

“If somebody is exhibiting quite difficult behaviours then, if they are agitated, if they are aggressive, et cetera, et cetera, then sometimes the plea is, ‘Can you please do something? I need to get some sleep. I need a break. Can you calm this person down?’”<sup>41</sup>

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<sup>38</sup> RoP, 21 September 2017, paragraph 54

<sup>39</sup> RoP, 21 September 2017, paragraph 11

<sup>40</sup> RoP, 17 January 2018, paragraph 5

<sup>41</sup> RoP, 21 September 2017, paragraph 114

**47.** According to the Royal College of General Practitioners (RCGP), GPs are often put under pressure from care home staff to use medication to manage disturbed behaviour in patients. RCGP stated that GPs come under pressure from psychiatrists to prescribe antipsychotics and called for better support for GPs from mental health colleagues to “follow the good clinical guidelines set out by NICE and reduce the use of antipsychotics for these unlicensed uses of managing behaviour problems”.<sup>42</sup>

**48.** The Welsh NHS Confederation suggested that once an antipsychotic has been prescribed there can be resistance or a reluctance to stop it for fear of relapse.<sup>43</sup> This was supported by Wendy Davies of the Royal Pharmaceutical Society Wales, who said:

“... I think sometimes it’s quite hard for carers. They know that in the past, if the antipsychotic has been stopped, then their behaviour—you know, it gets really hard to look after that person at home. So, their fear is that if they stop the medication, they’re going to be wandering, they might hurt themselves.”

## Our view

**49.** We note that NICE guidelines advise against the use of antipsychotic medications for non-cognitive symptoms or challenging behaviour of dementia unless a person is severely distressed or there is an immediate risk of harm to them or others. We are concerned that the evidence we have heard suggests these NICE guidelines are not being fully met. We are deeply concerned by the evidence from a number of witnesses who told us that antipsychotic medication is being used as a default position in care homes when people who are living with dementia are demonstrating behaviours which are difficult to deal with.

**50.** Unnecessarily medicating vulnerable people in care is a profound human rights issue which must be addressed.

**51.** We have heard suggestions that pressure is being placed on health professionals from various sources to prescribe antipsychotic medication when a person living with dementia is agitated or aggressive. We agree with witnesses that it is vital that there is full compliance with the NICE clinical guidelines.

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<sup>42</sup> Written evidence, APS 03

<sup>43</sup> Written evidence, APS 12

**Recommendation 2.** The Welsh Government should ensure that, within 12 months, all health boards are fully compliant with NICE guidelines on dementia, which advise against the use of any antipsychotics for non-cognitive symptoms or challenging behaviour of dementia unless the person is severely distressed or there is an immediate risk of harm to them or others, and report back to this Committee on rates of compliance at the end of that 12 month period.

## 4. Provision of person-centred care

**52.** As previously stated, we have heard evidence to suggest that increasingly antipsychotic medication is being used in response to challenging behaviour rather than trying to identify and address the root cause of the behaviour.

**53.** Challenging behaviour is often due to an unmet need which a person with dementia may be unable to communicate, and if that need can be identified, the situation can be greatly improved without antipsychotic medication. The Older People's Commissioner explained:

“[...] if you fail to really realise what's sitting behind so-called challenging behaviour, you leave the person with something that is unaddressed, and that includes pain. We know that pain is a big issue that can sit behind perceived challenging behaviour. [...] So, not only do you unnecessarily prescribe, but you fail to treat the issues that really sit behind it as well. So, that makes it of double concern.”<sup>44</sup>

**54.** Wendy Davies of the Royal Pharmaceutical Society Wales also talked about the importance of looking at the person as a whole to understand what is causing a particular behaviour – for example frustration, that cannot be articulated, about pain or helplessness:

“It's really important to be able to assess that and put them on painkillers, paracetamol. If they're constipated, if they've got a urinary tract infection, all things like that, if they've got low sodium because of some of the other meds they might be on: it's really important to look at all those things to look at why they're presenting in the way they are rather than saying, 'This needs an antipsychotic'. So, it's taking that step back to look at the person as a whole.”<sup>45</sup>

**55.** Evidence from the British Psychological Society suggests that often challenging behaviour occurs when intimate care tasks are being performed and actually it is a natural reaction when a person does not understand what is happening and perhaps is not being treated in the most sensitive manner. Dr Carolien Lamers told us:

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<sup>44</sup> RoP, 29 September 2017, paragraph 53

<sup>45</sup> RoP, 5 October 2017, paragraph 264



“Some behaviours might be driven by some damage in the brain, but, with a lot of it, you are dealing with people who are going through a very scary time in their lives, and who will respond, like all of us would be responding, if we were taken into a small room and our clothes would be taken off by a total stranger, and perhaps in a language, again—we need to be aware of different cultures, the Welsh language—that you wouldn’t understand. I bet you all of us would start hitting out, because that would be a real violation of our privacy.

You wouldn’t prescribe antipsychotics for that behaviour, which actually comes from a very normal, human response to a situation that might be very difficult for people to understand.”<sup>46</sup>

**56.** A number of witnesses highlighted various good practice checklists that can be used by staff to rule out and identify the reasons behind an individual’s challenging behaviour, including medical, psychological and personal comfort issues. One such intervention is the Adverse Drug Reaction (ADRe) Profile for mental health medicines developed by Professor Sue Jordan of the College of Human and Health Sciences at Swansea University, which has been shown to reduce the use of sedative medicines, including antipsychotics, in care homes. The intervention lists problems that might be associated with or exacerbated by these medicines, and asks nurses to monitor these and inform prescribers or pharmacists. Another example is the checklist tool developed by Care Forum Wales, “A Champions” (Assessment of Challenging and Management Problems Initiating Options for New Solutions), to assist care providers to find individualised appropriate care interventions to safely manage behaviour that challenges, and avoid unnecessary administration of antipsychotic medications.

**57.** We heard about the importance of family involvement. Claire Aston of Aneurin Bevan UHB talked about her experience of the “This is me”<sup>47</sup> document, which is a support tool developed by the Alzheimer’s Society to provide an easy and practical way of recording who the person is. The form has space to include details on the person’s cultural and family background; events, people and places from their lives; preferences, routines and their personality, and enables health and social care professionals to see the person as an individual and deliver person-centred care that is tailored specifically to their needs:

“I have personal experience of using it for my mother-in-law, and it was a very powerful tool when she was in hospital in England. I updated it

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<sup>46</sup> RoP, 5 October 2017, paragraph 370

<sup>47</sup> Alzheimer’s Society, **This is me**

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when she came into a care home in Wales, and it was very useful for the carers when we weren't there to be able to understand her previous life and to talk to her about her pets, her animals, those sorts of things, because they were documented."<sup>48</sup>

**58.** Dr Carolien Lamers also highlighted the crucial role of the family as part of the multidisciplinary team:

"... because they'll know that, I don't know, mum always got out of the bed that way, and now you've put the bed the other way, and it actually makes her really confused and anxious because she's trapped. You know, it's the little things that we just don't know."<sup>49</sup>

**59.** We heard that there are lots of examples of relatively simple, inexpensive, non-pharmacological interventions available, such as dance or music therapy, use of calming lights, reminiscence therapy and even pet therapy – if somebody has always had a dog or a cat at home and they have to move to a residential care setting, they miss that interaction with an animal. We also heard about the benefits of intergenerational contact, something we have previously taken evidence on as part of our inquiry into tackling loneliness and isolation.<sup>50</sup> Sue Phelps of Alzheimer's Society Cymru told us:

"There are pockets of that where it's brilliant. We've got schools up in Brecon who go into a local residential home and befriend the residents—help them garden, take them for walks. There are so many things that can be done. As I say, there is good practice out there, we just need to share it and spread it."<sup>51</sup>

**60.** Tim Banner of Cardiff and Vale UHB also highlighted the need to share good practice, saying there are some good localised applications of therapy, and development of non-pharmacological action plans but it is not wholesale across the board:

"It's either in a certain locality or a certain home setting, be it nursing or residential. I think there is a lot more work to be done to pick up on

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<sup>48</sup> RoP, 19 October 2017, paragraph 487

<sup>49</sup> RoP, 5 October 2017, paragraph 420

<sup>50</sup> **Inquiry into Loneliness and Isolation**, December 2017

<sup>51</sup> RoP, 21 September 2017, paragraph 86

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that good practice and really promote and push it forward across Wales.”<sup>52</sup>

**61.** The Welsh Government’s evidence paper stated that “delivering therapeutic approaches to the care of people living with dementia and behavioural distress requires a culture to support implementation and cultural change is a process that takes time to achieve”.<sup>53</sup> Dr Jean White, Chief Nursing Officer, told us:

“We have got a wide range of examples across Wales about the types of interventions that care homes are doing, but more importantly about what health boards are supporting the care homes in their area to do. A lot of the areas now have inreach teams that are working with the care homes to show them the variety of alternative types of approaches, but a lot of what care homes are doing already don’t require a great deal of equipment or anything like that. The types of interventions that we need to do is to assess people’s pain appropriately, to do things like music and drama and some life-course-type conversations to help people to keep in touch with themselves as a person. We have a wide range of examples across Wales. I think the challenge we have is that it’s not consistent everywhere.”<sup>54</sup>

## Access to Allied Health Professionals

**62.** We heard evidence that there is a clear link between communication difficulties and challenging behaviour. We also heard that there are barriers to accessing allied health professionals in care homes. The Older People’s Commissioner told us that as part of her original care home review she had seen differential access to support services and she was aware that it was harder for people in care homes to access services.<sup>55</sup>

**63.** This was supported by Sue Phelps of Alzheimer’s Society Cymru, who had received feedback that therapies such as occupational therapy, physiotherapy, speech therapy, dietician, chiropody—all the services that can be accessed when living in the community—tended to stop on entering residential care.<sup>56</sup>

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<sup>52</sup> RoP, 21 September, paragraph 171

<sup>53</sup> Health, Social Care & Sport Committee, 17 January 2018, Paper 1

<sup>54</sup> RoP, 17 January 2018, paragraph 58

<sup>55</sup> RoP, 21 September 2017, paragraph 43

<sup>56</sup> RoP, 21 September 2017, paragraph 101

**64.** A joint submission from the Royal College of Occupation Therapists (RCOT) and Royal College of Speech and Language Therapists (RCSLT) states:

“Care home residents have arguably the greatest health and social care needs yet currently may struggle to access community services available to those living in their own homes. It is not routine for speech and language therapists (SLTs), occupational therapists and other therapy professions to support care home staff and residents. This prevents residents from accessing provision such as reablement, non pharmacological interventions and behaviour support.”<sup>57</sup>

**65.** Karin Orman of the RCOT suggested that one barrier can be gaining access to care homes, as there can be a view amongst some managers that issues should be dealt with internally:

“Part of that barrier traditionally is that many of the care homes are privately owned, and so we’ll go in and support that individual citizen, but we won’t go in and support the whole care home; there’s an expectation that the care home should be providing all the training and meeting all those needs. And I think those barriers really need to start changing because we can’t support that individual citizen and give them the equality of access that they would have if they were living in their own home in the community if we don’t work with the whole care staff team.”<sup>58</sup>

**66.** Many organisations noted the value of access to specialist support provided by professionals such as Speech and Language Therapists (SLTs) and Occupational Therapists (OTs) in improving outcomes for the person and as a result, reducing “challenging” behaviour. Evidence from the RCSLT states that:

“SLTs have the specialist knowledge and skills to directly assess the contribution that unmet speech, language and communication support needs make to behaviour that challenges and provide advice on maintaining and maximising communication function to the person with dementia, their family and carers.”<sup>59</sup>

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<sup>57</sup> Additional information, APS AI 05

<sup>58</sup> RoP, 19 October 2017, paragraph 25

<sup>59</sup> Written evidence, APS 10

### Case Study 1

David lived in a care home where he often argued with staff and residents making it difficult for everyone to live and work with him. Although, David's speech was limited to a few words, staff thought David knew what he was doing and saying.

- An SLT assessment showed David had significant difficulties understanding what was said to him so he became confused, he didn't always know why people wanted him to do things and he made unintentional mistakes which of course frustrated him and others.
- The SLT gave staff guidance on how best to interact with David to help his understanding. This greatly reduced his confusion and the arguments and stress which had been caused by it.

### Royal College of Speech and Language Therapists

**67.** In spite of this, provision of services in Wales is extremely patchy. The RCSLT stated this is:

“in sharp contrast to other nations, such as Scotland, where there have been significant developments with regard to speech and language therapy provision for people with dementia. The recent audit of memory loss services by 1000 Lives (Public Health Wales, 2016) highlighted only 0.6 full time equivalent provision of speech and language therapy in specialist teams across Wales.”<sup>60</sup>

**68.** Evidence from the NHS confederation suggested that:

“reduced occupational therapy resources often mean that opportunities for alternative treatments become even more challenging, despite the fact that our members have made it clear that such functions could be delivered and promoted more effectively by an in-reach worker.”<sup>61</sup>

**69.** The Cabinet Secretary told us of the importance of investing in the future “health and care” workforce:

“This year, again, I've announced £107 million, which is a real increase, and that's not an easy choice because you're taking money from somewhere else. But that's for the future of the workforce because we

<sup>60</sup> Written evidence, APS 10

<sup>61</sup> Written evidence, APS 12

really do recognise that allied health professionals, whether they're in the care home sector, whether they can get people into their own home—you generally recognise their value to the service. We recognise they're a partner and not just an enabler of the future as well, and it's a greater recognition of the role that they can bring as part of that wider team. That has to be the case in the care home sector as well.”<sup>62</sup>

**70.** He went on to say that he recognised the value of speech and language therapists in providing health and care in a wide range of areas, not just the care home sector, and would continue to invest in their training.

**71.** The Welsh Government's Dementia Action Plan for Wales 2018-2022 was subsequently published in February 2018 and includes a commitment to:

“Develop an All Wales Dementia Allied Health Practitioner Consultant post who will give advice and support to health boards and local authorities to enable the delivery of person-centred care and drive forward service improvements. (April 2018).”<sup>63</sup>

## Medication reviews and monitoring

**72.** The NICE guidelines on dementia advise that any use of antipsychotics should include a full discussion with the person and carers about the possible benefits and risks of treatment and that treatment should be time limited and regularly reviewed (every three months or according to clinical need).<sup>64</sup>

**73.** However, according to evidence from Alzheimer's Society Cymru:

“A number of people with dementia and their carers told us they weren't aware of the name of the 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.”<sup>65</sup>

**74.** There was a clear message in the evidence we received that medication reviews are not happening frequently enough for people with dementia, and that

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<sup>62</sup> RoP, 17 January 2018, paragraph 88

<sup>63</sup> Welsh Government, **Dementia Action Plan for Wales 2018-2022**

<sup>64</sup> NICE Guidance: **Dementia: supporting people with dementia and their carers in health and social care** – November 2006

<sup>65</sup> Written evidence, APS 08

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once medication is prescribed (including antipsychotics) it often rolls on with repeat prescriptions for long periods without being monitored effectively.

**75.** This is particularly concerning as older people are more likely to have chronic and multiple illnesses which require multiple medications (polypharmacy). Evidence from Alzheimer’s Society Cymru states that the proportion of patients receiving 10 or more medicines has increased from 1.9% in 1995 to 5.8% in 2010.<sup>66</sup> The RCGP told us that “there are suggestions that side effects are more frequent with long term usage of antipsychotics and in those who have repeat use, as well as those who have other co-morbidities”.

**76.** Information on the Alzheimer’s Society website states:

“Antipsychotic drugs can cause serious side effects, especially when used for longer than 12 weeks. This is why all prescriptions should be monitored and if possible stopped after 12 weeks.”<sup>67</sup>

**77.** We heard from an individual affected by the use of antipsychotic medication, whose mother had been diagnosed with dementia and placed in a total of three care homes as a result of her challenging behaviour. The Community Psychiatric Nurse (CPN) became involved and prescribed Quetiapine, Lorazepam and Diazepam in the first care home. Initially, the CPN came once a month to perform medication reviews but that stopped when the CPN went on sick leave and no replacement was put in place. The individual’s mother remained on antipsychotic medication and in the individual’s words a “huge chemical cosh” until her final days.<sup>68</sup>

**78.** Care Forum Wales called for mandatory three month reviews. Steve Ford told us:

“I’d like to see the circumstance whereby people are not caught in this dreadful repeat prescription mechanism, whereby it rolls on and on and on, and you could go for two years and nobody refers to it. Some GPs, some practices, are better at reviewing than others. But, theoretically, because you’re caught up in this repeat prescription mechanism, it could carry on and on and on. I’d like to see—if you’re prescribed an antipsychotic and you have a diagnosis of dementia, there should be a three-month mandatory review, with a second GP

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<sup>66</sup> Written evidence, APS 08

<sup>67</sup> Alzheimer’s Society, **Drugs for behavioural and psychological symptoms**

<sup>68</sup> Health, Social Care & Sport Committee, 5 October 2017, Paper 8

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having to sign it off, rather than the responsibility of just one individual.”<sup>69</sup>

**79.** The importance of the role of the multi-disciplinary team (MDT) in undertaking medication reviews was highlighted by a number of witnesses.

**80.** Dr Jane Fenton-May, representing the RCGP, told us:

“I think pharmacists do a great job, but their kind of medication review is not the same as a doctor would do and I think we mustn’t forget the importance of the holistic care that potentially somebody like a GP can do for a patient, that they can look at the mental health and the physical side of things, and we need to have the wider team—the speech and language therapist, the physiotherapist, the occupational therapists, and the pharmacist and the psychiatrist and the psychiatric nurses.”<sup>70</sup>

**81.** However, a number of witnesses suggested an enhanced role for pharmacists within the MDT.

**82.** The Royal Pharmaceutical Society told us:

“As part of a multi-disciplinary review, all 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.”<sup>71</sup>

**83.** It went on to suggest that residents should then receive a minimum of one annual medication review from a pharmacist, with additional support for significant medication changes. For patients with complex medication regimens, this review should increase to every three to six months.

**84.** Steve Simmonds of Community Pharmacy Wales told us:

“I think it’s clear from all the submissions that everybody is saying that an integrated, multidisciplinary approach is the way forward. To me, I think it must start at community pharmacy level. The reason it should start with community pharmacy that actually supplies the medicines to

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<sup>69</sup> RoP, 19 October 2017, paragraph 151

<sup>70</sup> RoP, 5 October 2017, paragraph 124

<sup>71</sup> Written evidence, APS 09



the care home is because, if you think about it, they already have a list of all the care home residents and of all the medicines they're taking."<sup>72</sup>

**85.** He went on to highlight a trial in a pharmacy chain in England where, over a two year period, pharmacists had worked with 463 care homes with the aim of reducing the use of antipsychotics. The end result was a 20 per cent reduction in doses, a 17 per cent drug discontinuation and a significant improvement in quality of life.<sup>73</sup>

**86.** The Cabinet Secretary's written evidence stated:

"In 2017-18, the Welsh Government agreed a GMS directed enhanced service (DES) for care homes which aims to enhance the care provided for residents in care homes through a proactive, holistic coordinated model of care. GP practices participating in the DES are required to undertake at least one medication review with particular reference to polypharmacy, antipsychotic prescribing and other high risk medicines, for each resident in the care home."<sup>74</sup>

**87.** The Cabinet Secretary told us:

"The new directed enhanced service is about improving the quality of care that people receive in care homes, and I'm pleased that we were able to conclude that agreement with the BMA to ensure that that service is more consistently available for care home residents.

The requirement for at least one medication review is exactly that: at least. So, we are setting a baseline for every resident, and not every resident in a care home, of course, will be on antipsychotic medication."<sup>75</sup>

**88.** The Royal College of Psychiatrists in Wales (RCPsych)<sup>76</sup> and the Welsh NHS Confederation<sup>77</sup> called for all necessary antipsychotic prescribing to be supported by a risk/benefit analysis for each patient performed by an appropriately trained specialist as part of the multi-disciplinary team, and monitored closely with review every three months at least. It was suggested that the monitoring of whether

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<sup>72</sup> RoP, 5 October 2017, paragraph 286

<sup>73</sup> RoP, 5 October 2017, paragraph 281

<sup>74</sup> Health, Social Care & Sport Committee, 17 January 2018, Paper 1

<sup>75</sup> RoP, 17 January 2018, paragraphs 44-45

<sup>76</sup> Written evidence, APS 07

<sup>77</sup> Written evidence, APS 12

those reviews are taking place could form part of the inspections carried out by Care and Social Services Inspectorate Wales (Care Inspectorate Wales (CIW) since 15 January 2018).<sup>78</sup>

**89.** A message that came through in written evidence was a view that CIW should place a greater emphasis on medicines management in its scrutiny of care homes. Alzheimer's Society Cymru and other organisations recommended in written evidence that CIW mandates documented evidence of medicines' monitoring for older people prescribed mental health medicines. They called for such evidence to be placed in patients' records, alongside other mandatory records, such as those for nutritional status.<sup>79</sup>

**90.** In response to concerns raised by Committee Members at the meeting on 19 October about the priority CIW places on medication monitoring.<sup>80</sup> David Francis, Assistant Chief Inspector, CIW, subsequently wrote to us confirming that CIW had reviewed its inspection frameworks in light of the feedback from the Committee and would be updating them to make specific reference to the timeliness of medication reviews and the use of antipsychotics as areas inspectors must consider on inspection.

**91.** He also said it would be exploring how it could obtain feedback from community pharmacists linked to homes who will be funded under the new enhanced contract to check medication reviews and the use of antipsychotics in care homes and will be considering the use of antipsychotic medication when undertaking a thematic national review into the quality of care in residential care for people in 2019/20. Additionally, from 2019 CIW plans to ask care homes to report on the frequency of medication reviews and the use of antipsychotic medication in the annual on-line self-assessments which are completed by care homes. "This will enable inspectors to be sighted on those where usage is particularly high".<sup>81</sup>

**92.** The Royal Pharmaceutical Society and Community Pharmacy Wales both emphasised the need for all pharmacists directly involved in patient care (with the patient's consent) to have full read and write access to the patient health record

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<sup>78</sup> RoP, 5 October 2017, paragraph 332

<sup>79</sup> Written evidence, APS 08

<sup>80</sup> RoP, 19 October 2017, paragraph 184

<sup>81</sup> Written evidence, APS AI 03

in the interest of high quality, safe and effective patient care.<sup>82</sup> Sam Fisher, Community Pharmacy Wales, told us:

“So, whilst we currently will start to have access to what we call the GP record, which would just be a list of medication, for these to be really effective, we need to understand what’s going on behind that—so, what conditions. You can’t really say whether something is appropriately prescribed until you understand what condition the patient has and the background.”<sup>83</sup>

## Our view

**93.** We have heard evidence to suggest that increasingly antipsychotic medication is being routinely administered in response to challenging behaviour, in place of staff working to identify the root cause of the behaviour. A person living with dementia presenting challenging behaviour often has an unmet need which they may be unable to communicate. As such, we believe it is vitally important to look at the person as a whole in order to understand what may be causing a particular behaviour. The evidence given to us suggests that there are various good practice checklists that could be used by staff in care homes to identify the possible causes behind an individual’s behaviour.

**94.** We note the Cabinet Secretary has acknowledged that there is evidence that antipsychotic medicines are being used for the management of behavioural and psychological symptoms in dementia, and that particular challenges have arisen in parts of the care home sector. We believe cultural and systemic changes are needed to ensure antipsychotic medications are prescribed appropriately, and as a very last resort, not as a default first option.

**Recommendation 3.** The Welsh Government should ensure that every person with dementia presenting challenging behaviour receives a comprehensive person-centred care assessment of their needs. It should work with relevant health professionals to develop a standardised checklist tool to be used by health and social care staff to identify and address/rule out possible causes of challenging behaviour, including unmet physical or emotional needs. It must include a requirement for consultation with the individual and their carer or family. The checklist should be available within six months and must record the action taken to demonstrate that all other options have been considered before antipsychotics are prescribed for people with dementia.

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<sup>82</sup> Written evidence, APS 09

<sup>83</sup> RoP, 5 October 2017, paragraph 340

**95.** Given the harmful effects antipsychotic medications can have, we believe it is unacceptable that medication reviews for people living with dementia are not happening frequently. We are also concerned that, once medication is prescribed, it is often added to prescriptions which are dispensed on a repeat cycle without effective monitoring.

**96.** We believe the evidence we have received sets out robust arguments for mandatory regular (at least every three months) medication reviews. We also note and agree with witnesses that the multi-disciplinary team has an important role to play in undertaking these reviews, and further support the suggestion that an enhanced role for pharmacists is needed.

**97.** We welcome the Cabinet Secretary's confirmation that the new directed enhanced service concentrates on improving the quality of care that people receive in care homes. However we are not convinced that this goes far enough. We believe that it is not appropriate for repeat prescriptions for antipsychotics to roll on for an extended period and agree with witnesses that regular medicines reviews are vital for older people prescribed this potentially harmful medication.

**Recommendation 4.** We recommend the introduction of mandatory three monthly medication reviews for people with dementia who have been prescribed antipsychotic medication, with a view to reducing or stopping the medication following the first review where possible.

**Recommendation 5.** The Welsh Government should explore ways in which the repeat prescription system could trigger the need for a medication review at the three month point.

**98.** We welcome the fact that CIW has already reviewed its inspection frameworks in light of the feedback from the Committee and will be updating those frameworks to make specific reference to the timeliness of medication reviews and the use of antipsychotic medication as areas inspectors must consider on inspection. However, we agree with witnesses that this should be a mandatory part of the inspection regime for care homes.

**Recommendation 6.** We recommend that medicines monitoring should be a key part of care homes inspection, and that Care Inspectorate Wales mandates documented evidence of medicines' monitoring for older people prescribed antipsychotic medication in patient records.

**99.** We were impressed with the evidence provided to us on the many examples of relatively simple, inexpensive non-pharmacological interventions that are available. These interventions, such as dance or music therapy, the use of calming

lights, reminiscence therapy and pet therapy, warrant further attention and investigation. We also heard about the benefits of intergenerational contact as a non-pharmacological intervention; this is something that was previously highlighted to us during our inquiry into tackling loneliness and isolation. We are aware that there are good localised applications of these types of therapy, and the development of non-pharmacological action plans, but without the sharing of good practice these positive steps are not being taken on a large scale.

**100.** During our evidence gathering we heard of the benefits allied health professionals can bring to the care and treatment of people living with dementia in care homes, particularly with regards to improving outcomes for the individual and reducing incidences of challenging behaviour. We are therefore concerned that the evidence suggests there are currently barriers in place which are preventing those individuals from accessing the services of professionals including occupational therapists, physiotherapists, speech therapists, dieticians and chiropodists. We are particularly alarmed by the evidence which suggests that the services provided by allied health professionals, whilst being available to an individual living in the community, stop once that individual enters residential care.

**101.** We welcome the creation of an allied health professional dementia consultant post in order to drive service improvement and hope that part of this role will be to work with care homes to improve access to allied health professionals for care home residents.

**Recommendation 7.** We recommend that the role of the allied health professional dementia consultant includes a requirement to work with care homes to improve access to allied health professionals for care home residents.

**Recommendation 8.** The Welsh Government should take action to address the shortage of speech and language therapists, given their value in improving outcomes for people with dementia, and report its progress to this Committee within 12 months.

## 5. Staffing

### Recruitment and retention

**102.** Evidence from Social Care Wales suggested that the social care sector is currently under pressure in terms of recruitment and turnover. Gerry Evans, Director of Regulation and Intelligence, told us:

“Recruitment of staff is difficult. Recruitment of managers for care homes is difficult. And staff turnover is also high, as we know—there has been mention of a 30 per cent turnover per year in some places. So, in that situation, it is going to be difficult to ensure that staff understand clearly the importance of having a full grasp of this area and understanding the effects of the medications they provide.”<sup>84</sup>

**103.** He drew attention to the issue of terms and conditions of employment, saying one of the problems facing the sector is that once staff have been trained they often move to the health sector, where the pay and conditions of employment are better.

**104.** He also suggested there was a need to boost the profile of the sector to make people aware that it is possible to have a very worthwhile and positive career working in social care.

**105.** Rhiannon Davies of Public Health Wales highlighted the importance of recruiting the right staff to work in care homes. She told us about work she had been involved in, led by David Sheard, which suggested that:

“not everyone can be a carer, [...]. Yet, the way that posts are often advertised is such that it appears as though anyone could come in. And, of course, the pay is not high either. So, really, it’s making sure that the questions that are asked when you recruit people are the appropriate questions that actually really draw out, ‘Is this person a caring, understanding person?’”<sup>85</sup>

**106.** Steven Ford of Care Forum Wales agreed. He told us:

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<sup>84</sup> RoP, 25 October 2017, paragraph 9

<sup>85</sup> RoP, 5 October 2017, paragraph 55

“...it’s about, first of all, the quality of the staff that’s providing the care [ ] not everybody’s cut out for this. You’ve got to have empathy to begin with. Without empathy, I think people are going to struggle.”<sup>86</sup>

**107.** Sue Phelps of Alzheimer’s Society Cymru also told us that there is a huge problem with retention of care home staff. She believes that if people feel more able to provide person-centred care, to have a reciprocal relationship with the person they are caring for, and really understand their issues, they will be more confident and possibly stay in their caring roles.<sup>87</sup>

## Staffing levels

**108.** Evidence from the Royal College of Nursing (RCN) stated that patients with dementia have specific and complex needs, and those with dementia in a care home are likely to require greater levels of care than other patients. It therefore believes this should be reflected in the calculation of nurse staffing levels.

**109.** The RCN argued that just as there is an evidence base to inform the nurse staffing levels in acute, general and surgical settings, one is needed for care homes, as the residents have really complex needs.

**110.** Alison Davies, representing the RCN told us:

“We’ve got no national tool or measurement that helps us understand that. We need that to understand what level and type of staff we need to care for people there. That’ll help us inform meeting people’s needs, providing quality of care and workforce planning for the future.”<sup>88</sup>

**111.** Dr Jean White, Chief Nursing Officer, told us that one of the duties, under the nurse staffing levels legislation which came into force in April 2017, is about having sufficient nurses to care for patients sensitively:

“... that means, when the health boards commission placements in care homes, there is a duty on them to ensure that the commissioned place actually has enough nurses to look after the patients. We are starting to look forward to the integrated medium-term plans that will come out shortly, which is the planning process for the health boards, and they will need to demonstrate to us, sensitively, how they have taken this first

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<sup>86</sup> RoP, 19 October 2017, paragraph 139

<sup>87</sup> RoP, 21 September 2017, paragraph 88

<sup>88</sup> RoP, 5 October 2017, paragraph 198

duty on board, and how they're going to use it in their commissioning arrangements.”<sup>89</sup>

## Training

### Dementia awareness

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**112.** The need to improve health and social care staff training on dementia awareness and understanding and practical methods for dealing with challenging behaviour was a clear theme to emerge from evidence.

**113.** In its written evidence, the Care Inspectorate Wales (CIW) stated that “we believe the staff in all care homes for older people should be trained and competent in the care of people with dementia”.<sup>90</sup>

**114.** Sue Stephens of Hywel Dda UHB suggested that consideration should be given to making dementia-care training for care home staff a mandatory requirement.<sup>91</sup>

**115.** Evidence from the Royal College of Occupational Therapists stated that:

“the majority of care homes have not specifically been designed to provide care for people with the complex needs of those with severe/late stages of dementia. This means that residents with dementia often have multiple unmet needs such as: involvement in everyday activities, isolation and anxiety and depression. These unmet needs can lead to decreased quality of life and increased costs of care due to managing the resulting symptoms of behavioural and psychological symptoms of dementia.”<sup>92</sup>

**116.** Written evidence from CIW suggests that a significant proportion of care homes in Wales carry historical “EMI” or “dementia” registration classifications, and state in their Statement of Purpose brochures that they care for people with dementia, but in a number of instances they find that neither the staff nor the manager have had any specialist training in dementia.

**117.** David Francis, Assistant Chief Inspector, told us:

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<sup>89</sup> RoP, 17 January 2018, paragraph 71

<sup>90</sup> Written evidence, APS 18

<sup>91</sup> RoP, 19 October 2017, paragraph 490

<sup>92</sup> Written evidence, APS 04



“... about four years ago we made a very strong move to get rid of all those classifications, and we pushed very hard. The trouble is that there were legacy holder registrations that took place in 2002 when the Care Standards Act 2000 came in, and there was a legal pushback against us. So, we’re using the new Act [Regulation and Inspection of Social Care (Wales) Act 2016] as an opportunity to actually take away those classifications, and we are driving down now on our expectations that services set out very clearly in their statements of purpose who they’re providing care for and how they do it, and we’re going to be policing that.”<sup>93</sup>

### Person-centred approach to care

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**118.** In its written evidence, Social Care Wales says “it is vital that each care home is staffed by people who are sufficiently skilled to provide person centred and preventative approach to care”<sup>94</sup> and to support this aim has produced a range of training materials.

**119.** Alzheimer’s Society Cymru also talked of the need for staff to have a greater understanding of dementia and what causes particular behaviours and the importance of a person-centred approach to providing care for someone with dementia. Sue Phelps highlighted work that had been undertaken in Cwm Taf UHB:

“So, for example, I know that Cwm Taf Local Health Board have got a care home intervention team. So, they’ve been concentrating a lot on upskilling the knowledge and skills of their care home staff to take that more person-centred approach.”<sup>95</sup>

**120.** She went on to say that although there are pockets of good practice across Wales it is not consistent, and certainly not as good as she would like to see.

**121.** The Alzheimer’s Society “This is Me” toolkit<sup>96</sup> was highlighted as a useful resource for staff to understand more about individual residents and the things that are important to them.

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<sup>93</sup> RoP, 19 October 2017, paragraph 223

<sup>94</sup> Written evidence, APS 02

<sup>95</sup> RoP, 21 September 2017, paragraph 68

<sup>96</sup> **Alzheimer’s Society** – This is me – A support tool to enable person-centred care

### Case Study 2

A gentleman in a care home, he seemed very distressed, very agitated, very angry; he was banging his head against a glass door constantly. Nothing the staff seemed to do would calm him down. He was becoming a risk to himself and a risk to others. So, at this stage, you might start to think that maybe there is a role for antipsychotic drugs, but a canny member of staff began to question why it was the same door every single time—nowhere else; it was just this area where he became agitated. It turns out, when they spoke to his relatives, that this gentleman had been a keen gardener all his life. He had a greenhouse; it was the love of his life; it was the place, I suspect, he snuck off to when everything else was too much and too noisy. It was his safe place. So, he goes into a care home; he's frightened, he's distressed, he's anxious, and he sees through the door a greenhouse—the one place he's not allowed to go. So, instead of prescribing antipsychotics, they helped him go back out to the greenhouse, and it became his safe place in a world of turmoil and horror in no small part for him, and his behaviour changed completely.

**Sarah Rochira, Older People's Commissioner for Wales**

### Case Study 3

There was somebody who, in the hospital I work in, had developed dementia but was a pharmacist and kept wanting to go and see the drugs trolley, because, in their profession, that's what they would have done—to check the drugs. Obviously, it was seen as interfering, but, actually, in terms of that person, because they were going back to their earlier memories—. So, rather than actually using medication in situations like that, we actually gave them some bottles and Smarties and things so that they could label, so they could channel that energy in a positive way.

**Wendy Davies, Royal Pharmaceutical Society Wales**

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## De-escalation techniques

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**122.** Several witnesses talked about the benefits of de-escalation and safe restraint training and indeed the NICE guidelines state:

“Health and social care staff should be trained to anticipate behaviour that challenges and how to manage violence, aggression and extreme agitation, including de-escalation techniques and methods of physical restraint.”<sup>97</sup>

**123.** The British Psychological Society described the communication and interaction training they have developed, which incorporates customer care skills, and de-escalation techniques. Dr Ian James told us:

“... we’ve gone to Marks and Spencer, we’ve gone to John Lewis, and we’ve got their customer care skills [ ] then we’ve gone to the police. So, how do police de-escalate situations? People don’t want to get arrested. [ ] There’s a thing called ‘verbal judo’ they use, by George Thompson, and that’s got some instructions—things not to say when someone’s upset—and we’ve taken those and we’ve packaged those into a treatment called CAIT.”<sup>98</sup>

**124.** Gerry Evans told us that Social Care Wales had issued guidance and resource around promoting positive behaviour, which was developed from the learning disability sector but was also applicable in the care of people with dementia, particularly around challenging behaviour. He went on to say that while there are certain homes where staff are aware of de-escalation techniques, he did not know the extent and depth of knowledge that staff have of those techniques but it is an area that Social Care Wales would want to pursue.<sup>99</sup>

## The “Good Work” framework

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**125.** The Welsh Government’s written evidence drew attention to “Good Work” – A dementia learning and development framework<sup>100</sup> it launched in 2016 in collaboration with the then Care Council for Wales (now Social Care Wales), NHS Wales and Public Health Wales. The “Good Work” framework provides broad

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<sup>97</sup> **Dementia: supporting people with dementia and their carers in health and social care**, November 2006

<sup>98</sup> RoP, 5 October 2017, paragraph 434

<sup>99</sup> RoP, 25 October 2018, paragraph 49

<sup>100</sup> **“Good Work”**– A dementia learning and development framework for Wales, 2016

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principles for education and training based on best practice. According to Social Care Wales:

“The new resource aims to change the way in which dementia care is provided in Wales by creating a single, shared vision for health and social care workers to provide the best possible care and support for those living with dementia. The framework has people with dementia at its heart and recognises that people with dementia, their families and carers should all be central to the care and support they receive.”<sup>101</sup>

**126.** CIW described training in dementia care as “variable and a confusing landscape”. It says the new pathway [‘Good Work’] was helpful but in its experience, “awareness of the pathway is low and it has yet to be applied by many care homes”. CIW also observed that it is hard to assess competency as there are no commonly adopted standards, and there is a huge variation in training courses.<sup>102</sup>

**127.** When asked about CIW’s comments, the Cabinet Secretary told us:

“Well, it’s disappointing that there isn’t not just a greater awareness, but a greater take-up of ‘Good Work’. It’s been designed with the health and care sectors, the third sector and Social Care Wales. So, we want to see greater take-up of that, and the dementia plan will be an opportunity to reset some of this.”<sup>103</sup>

**128.** The Cabinet Secretary’s written evidence stated that further roll out of “Good Work” will be a requirement of the forthcoming dementia plan and its uptake will be monitored throughout. The Cabinet Secretary went on to say:

“I’m not going to prioritise every single part of the plan, but there will be an expectation that, actually, there’s not just greater awareness but a greater take-up of that training, which, as I said, is for everyone within the health and care sector, because we think that will improve the quality of care that people will receive. And actually, it will help staff to do a better job, and that’s likely to make staff feel better about the job that they do as well.”

NB: The Welsh Government’s Dementia Action Plan was subsequently published in February 2018. The plan includes a key action to:

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<sup>101</sup> Written evidence, APS 02

<sup>102</sup> Written evidence, APS 18

<sup>103</sup> RoP, 17 January 2018, paragraph 68

- Ensure all NHS employed staff who come into contact with the public (including porters, receptionists and medical / support staff) receive an appropriate level of dementia care training (as specified in – “Good work – Dementia Learning and Development Framework”) (April 2018 and annual review thereafter).

**129.** The Action Plan goes on to say the target for this is “75% by end of 2019”.

**130.** A number of witnesses highlighted the importance of ensuring the right sort of training is provided and that care homes are supported throughout the process. Dr Ian James told us:

“... in Scotland, they threw a lot of money at training. NHS Education for Scotland put a programme together [ ] but people just attended. They didn’t get the supervision. They didn’t get the training around one-to-one skills.”<sup>104</sup>

**131.** Rhiannon Davies of Public Health Wales told us that she believed training was most effective when there is a closer relationship between the health board and the care home so that it can guide them with the sort of training that is needed. She said that one of the benefits of 1000 Lives Plus was that it had enabled the sharing of good practice and the development of models that really worked.<sup>105</sup>

**132.** Karin Orman representing the Royal College of Occupational Therapists also highlighted the role of the multi-disciplinary team in relation to training. She said:

“... we’ve got clear models in other areas. We’ve got liaison psychiatry teams in hospitals, which are often multidisciplinary, we can see how effective they are at delivering training and modelling and changing people’s attitudes. Why aren’t we applying that to care homes?”<sup>106</sup>

**133.** She went on to give an example where, in Cwm Taf UHB, the mental health liaison occupational therapists have been delivering training to nurses and nursing assistants, raising people’s understanding around dementia awareness.

“Again, it’s very applicable in the care home sector, and that service has been held up as an exemplar of best practice to be implemented

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<sup>104</sup> RoP, 5 October 2017, paragraph 433

<sup>105</sup> RoP, 5 October 2017, paragraph 51

<sup>106</sup> RoP, 19 October 2017, paragraph 37

across Wales. So, we don't have to look far at examples that we could actually apply in a care home setting."<sup>107</sup>

## National Standards

**134.** We were told that, while there are some good examples of training, none of it is accredited. Mair Davies of the Royal Pharmaceutical Society argued that:

"... we don't actually know whether it's the right training, whether it's the appropriate training or whether every carer, nurse or anybody working in these homes is having the same training. So, we would advocate for there to be some national standards for that training. We would also say that there needs to be uniformity across Wales— there shouldn't be different training in different places."<sup>108</sup>

**135.** This was supported by Kim Williams, Cwm Taf UHB, who was concerned that there are no minimum standards for training for staff in care homes. She told us that this puts staff in a very difficult position:

"... if they have no training in de-escalation or physical restraint, they're often in a situation where they have somebody who's at risk or who poses a risk to somebody else. They've got no training in physical intervention, so what they turn to is the medication. What we would want them to do is to say, 'Okay, that might work now, but we need very quickly to review that and to put an alternative in place', and there isn't a mechanism for doing that. I think if we had some minimum training standards for care staff in homes, as they do in some areas of England, we would be in a much better position across Wales."<sup>109</sup>

**136.** Sue Stephens, Hywel Dda UHB agreed, suggesting that national standards for dementia-care training should be developed to equip care home staff with the necessary skills and knowledge of risks and benefits of antipsychotic medication.<sup>110</sup>

## Qualifications

**137.** Social Care Wales is working with Qualifications Wales on a new set of qualifications for health and social care from 2019, which it says have a strong emphasis on person centred care, with a specific pathway for the skills needed to

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<sup>107</sup> RoP, 19 October 2017, paragraph 50

<sup>108</sup> RoP, 5 October 2017, paragraph 298

<sup>109</sup> RoP, 19 October 2017, paragraph 295

<sup>110</sup> RoP, 19 October 2017, paragraph 490

care for people with dementia. People who work in the care profession will be required to hold these qualifications.<sup>111</sup>

**138.** Gerry Evans told us that this work involved developing a whole new suite of qualifications for the care sector, which are joint health and social care qualifications. He went on to outline what the different modules would cover:

“[they] range from an initial induction for staff in health and social care, which covers things like medicines management and also dementia, albeit not at a hugely in-depth level, because we are talking about an induction for staff. Moving on from there, manager qualifications are being developed that provide more detail about what they need to be aware of in terms of managing medicines and, again, dementia, and there are specialist modules being developed for managers at the sort of post-initial qualifying level for homes that want to specialise in dementia care. So, those are coming on-stream in the near future.”<sup>112</sup>

**139.** He went on to say that:

“... we are looking at a range of modules for staff to develop their understanding and their skills in both areas of dementia and medicines management, including the use of antipsychotic drugs. So, the work is being developed, the qualifications are being developed, and they're now an awarding body that's looking to develop the detail of those qualifications. They will come into being in 2019, but there are already significant amounts of training and resources available.”<sup>113</sup>

## Training for GPs

**140.** As stated in Chapter 2, it is important to bear in mind that responsibility for prescribing antipsychotic medication lies with GPs and/or hospital psychiatrists or clinicians.

**141.** Wendy Davies of the Royal Pharmaceutical Society told us:

“We did an audit of GP prescribing of antipsychotics in Cardiff. It was part of the quality and outcomes framework a few years ago [ ] looking at what the prescribing of the antipsychotics was. Some were very good and some were not so good, but you can't just look at the prescribing.

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<sup>111</sup> Written evidence, APS 02

<sup>112</sup> RoP, 25 October 2017, paragraph 19

<sup>113</sup> RoP, 25 October 2017, paragraph 20

You've got to look at whether it's appropriate or inappropriate. So, I think there's a level of training and understanding for the GPs."<sup>114</sup>

**142.** Both Public Health Wales and the RCN also highlighted the need for GP training and “upskilling GPs in their knowledge and understanding, and also in perception and attitudes”.<sup>115</sup>

### Our view

**143.** We appreciate that the social care sector is currently under pressure in terms of recruitment and turnover of staff. We are also aware that, increasingly, trained social care sector staff are moving to the health sector because salaries and conditions of employment can be better. We agree with witnesses who told us that if people feel more able to provide person-centred care, they may be more inclined to remain in a caring role.

**144.** It is clear that people living with dementia have specific and complex needs and are likely to require greater levels of care than other care home residents. We note the evidence from the Royal College of Nursing (RCN) who believe this should be reflected in the calculation of nurse staffing levels. We agree with the RCN's point that there is now an evidence base to inform the nurse staffing levels in hospital settings, and there should be a similar mechanism developed for care homes, given the complexity of care home residents' needs.

**Recommendation 9.** The Welsh Government should develop a method for assessing the appropriate skills mix required for care home staff, and produce guidance on this to ensure that there are safe and appropriate staffing levels in every care home, and that staff have time to provide high quality care.

**145.** It is clear that there is a need to improve training provided to health and social care staff on dementia awareness and understanding, and practical methods for dealing with challenging behaviour. The evidence from the Royal College of Occupational Therapists, who told us that the majority of care homes are not designed to provide care for people with the complex needs of those with severe or later stage dementia, gives us cause for concern. We are also alarmed by the evidence from CIW with regards to care homes carrying historical “EMI” or “dementia” registration classifications without actually having staff who have had specialist training in dementia. We agree with Social Care Wales who told us it is

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<sup>114</sup> RoP, 5 October 2017, paragraph 317

<sup>115</sup> RoP, 5 October 2017, paragraph 65



vital that care homes are staffed by people who are sufficiently skilled to provide a person centred and preventative approach to care.

**146.** We are further concerned by CIW's description of training in dementia care as variable and confusing. Basic training for staff, particularly those working in facilities offering dementia care, is essential and there needs to be uniformity of training. We welcome the Cabinet Secretary's commitment to further roll out of "Good Work" in the dementia action plan. However we note that this commitment refers specifically to NHS employed staff and would highlight that the Committee heard evidence that social care staff also need better dementia training.

**Recommendation 10.** We recommend that, within six months, national standards for dementia-care training be developed to equip care home staff with the necessary skills to deal with challenging behaviour. Dementia-care training and specific training to deal with challenging behaviour (as stated in NICE guidelines: including de-escalation techniques and physical restraint methods) should be mandatory requirements for all care home staff, and compliance with this should be scrutinised as part of CIW's inspection regime.

## 6. Use of antipsychotic medication in other settings

**147.** Although this inquiry has predominantly focused on the use of antipsychotic medication in care homes, their use is much wider than just the care home population.

**148.** It was noted in evidence received that the initial prescription of antipsychotic medication often takes place in hospital, and then continues in care homes after discharge (through repeat prescriptions).

**149.** According to the Bannerjee report:

“There needs to be attention to their use in all settings. This includes the community, where people with dementia may be living with a family carer or alone in their own household, in sheltered and other supported housing, in general hospitals, in mental health units and in NHS continuing care settings.”<sup>116</sup>

**150.** Evidence from the All Wales Therapeutics and Toxicology Centre stated that the appropriate monitoring and review of antipsychotic treatment in patients with dementia should apply to all patients no matter what the care setting. It went on to say:

“Feedback from one health board indicates that all of the above measures apply equally to other care settings and the audit of antipsychotic use in dementia will include patients in all care settings. A leaflet will be available in ward settings and offered to carers to raise awareness of the risks and benefits of using antipsychotics in dementia. The provision of this leaflet will be documented in patient records, and consideration given to ways of monitoring service user feedback.”<sup>117</sup>

**151.** Victoria Gimson of Cardiff and Vale UHB described work she had been involved in to develop an antipsychotic checklist for dementia patients in a hospital setting:

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<sup>116</sup> The use of antipsychotic medication for people with dementia, October 2009

<sup>117</sup> Written evidence, APS 15

“They fill this in, tick the target indication, tick who’s reviewing and tick what should be the arrangement on discharge. It’s a piece of paper at the moment, we’re trying to get it in an e-form, so it gets pinged electronically to the GP on discharge, but then you’ve got somewhere to start. You’ve got somewhere that, if you’re reviewing that patient, you know [ ] the reason why they were prescribed it and you know what behaviour to look for.”<sup>118</sup>

**152.** The Older People’s Commissioner suggested that there was a stronger focus on monitoring and review in the hospital sector than there is in the care home sector:

“I’m not saying it’s perfect, but when you can find a report, you can pretty much guarantee it’s talking about a hospital. When you can find data, you can pretty much guarantee it’s talking about hospital care as well.”<sup>119</sup>

**153.** Written evidence from the Cabinet Secretary cited studies conducted in the UK to evidence the levels of use of antipsychotic medicines in people with dementia in secondary care but stated “we are not aware of any study which has measured the prevalence of antipsychotic prescribing in mental health services in Wales”. The paper explained that:

“... secondary care prescribing data are not linked to patients’ age, gender, postcode or diagnosis. In some respects secondary care data is more limited since medicines may be supplied to wards/services either as items for specific patients or as stock items. In the case of the latter this means they might be administered to more than one patient. Medicines supplied in secondary care may be coded to directorates on the basis of the prescribing consultant or team or directly to wards. This means where a patient is prescribed a medicine, including an antipsychotic medicine, it will not necessarily relate to the ward or unit on which they are an inpatient.”<sup>120</sup>

**154.** We also heard that problems can occur when a patient is discharged from hospital to a care home. Dr Jane Fenton-May of the Royal College of GPs told us:

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<sup>118</sup> RoP, 19 October 2017, paragraph 343

<sup>119</sup> RoP, 21 September 2017, paragraph 56

<sup>120</sup> Health, Social Care & Sport Committee, 17 January 2018, Paper 1

#### Case Study 4

... after a number of days [ ] we noticed that mum's mental state seemed to be deteriorating, in that she was very, very drowsy, had very slurred speech, a very poor attention span, didn't seem to be able to connect with us in the way that she had been, even post-operatively, through the trauma and the pain, and certainly not in the way that she had been prior to her fall. She also had a fall on the ward, where she just fell forward out of a chair and hit her head on the table going down. Fortunately, it wasn't a serious fall, but there were a number of things that were going on like this, the kinds of experiences that I've just mentioned, that we were confused about. We didn't know why her mental state was deteriorating in this way. And it was only by accident, from my dad asking questions of the staff, I think, to do with some of her medication, that it was then disclosed to us that she had actually been on antipsychotic medication for 10 days without us being informed, without there being any discussion about that at the time. So, she was prescribed quetiapine and diazepam at the same time, and that was obviously why she was experiencing the drowsiness, the slurred speech, and I think that both of those things led to the fall that she had out of her chair.

When I became aware that she had been prescribed the antipsychotics, and I tried to make sense of what we were noticing in mum, I then started discussing that with the staff, raised my concerns with the staff, had a meeting with the sister on the unit and with the psychiatric registrar—no, sorry, not the psychiatric registrar, the orthopaedic registrar—who told me, "Well, this is how we do it here". That was the reason given for mum being prescribed antipsychotic medication. It wasn't clear at all if any record had been kept of the so-called target behaviours prior to the medication being started or even after it having been started.

So, there was no way of ascertaining whether the use of the medication, which had been prescribed to control her behaviour—because she was resisting personal care and she did become quite violent and aggressive towards staff when they tried to approach her and deliver the personal care—and it was because of that that she was apparently prescribed the antipsychotic medication, to basically sedate her and make her more manageable to the staff.

But, what I could see when I was there and witnessed staff interacting with her was that it was perhaps due to their ignorance, staffing levels, their lack of understanding about what the triggers for mum's behaviour might be—that there could have been some other ways of dealing with her that wouldn't have required her to be sedated in the way that she was.

**Suzanne Tarrant**

“[ ] they become a temporary patient of a local GP and the GP does not know that patient at all. They don’t get any information about that patient. They might get a discharge note if they’re lucky. So, all they have is what medication the patient came out of hospital with, they don’t have any indications about why the patient is on that medication, and this makes life very difficult for them. We are hoping that the electronic discharge letters will help improve that situation.”<sup>121</sup>

**155.** Sue Phelps of Alzheimer’s Society Cymru told us that she is aware of examples of inappropriate use of antipsychotics in hospital:

“... we’ve got a case study from somebody who was admitted to hospital and was difficult—difficult to manage. No account, really, was made of the fact that, actually, that person had gone into a very unfamiliar environment, didn’t know why they were in hospital, didn’t want to be there, very scared, frightened, and were prescribed an antipsychotic, which essentially rendered that person unable to feed themselves. They were immobile, became bed bound. When they did put that person in a chair, their carer went to visit [ ] and he was slumped in a chair, not able to speak, in her words, ‘Dribbling into his lap’, and he’d gone into hospital for a problem unrelated to his dementia. So, that is completely unacceptable and it does happen, because it was easier for the nurse to manage, I guess.”<sup>122</sup>

**156.** We heard a similar story from Suzanne Tarrant, who told us about her mother’s experience after she was admitted to hospital for emergency surgery on a fractured hip. See Case Study 4 opposite.

## Our view

**157.** While our evidence has largely focused on care homes, it is important to recognise that antipsychotic medication is increasingly prescribed outside of this setting.

**158.** It is therefore worrying that there is so little data available on the prescribing and monitoring of antipsychotic medication in secondary care. It is particularly concerning that someone may be admitted to hospital when they are in crisis and prescribed an antipsychotic without their, or their carer’s/family’s knowledge, as evidenced by Suzanne Tarrant. Without the appropriate monitoring and review

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<sup>121</sup> RoP, 5 October 2017, paragraph 93

<sup>122</sup> RoP, 21 September 2017, paragraph 126

this medication may continue as part of the repeat prescribing cycle, even when the crisis has passed and the patient has been discharged from hospital.

**159.** We believe it is essential that before antipsychotic medication is introduced, a discussion should take place with the person being prescribed the medication and their carer or family, so that they have a say in what is being prescribed, and, more importantly, an understanding of the effect it may have on them.

**160.** We note the evidence from the All Wales Therapeutics and Toxicology Centre about the provision of information in hospital wards to raise awareness among carers of the risks and benefits of using antipsychotics in dementia, and believe this is an inexpensive and easy to implement initiative that should be rolled out across all health boards.

**161.** We also note the evidence provided by Cardiff and Vale UHB on its development of an antipsychotic checklist for dementia patients that can be transferred with the patient on discharge from hospital and believe consideration should be given to extending this practice more widely.

**Recommendation 11.** The Welsh Government should commission a review of the levels and appropriateness of the use of antipsychotic medication in people with dementia in secondary care. The findings of this review should be published and reported back to this Committee.