## Chapter 6

### The use of restraints in dementia care

A restraint free environment means no words, devices or actions will interfere with a resident's ability to make a decision or restrict their free movement...The use of restraint confronts a resident's rights and dignity and, in some cases, may subject the resident to an increased risk of physical harm. – *Decision-making tool: supporting a restraint free environment in residential aged care*, published by the Department of Health and Ageing  $[(Department)]^1$ 

I am increasingly concerned about the use of restraint in aged-care facilities as a means of responding to behaviours of concern. The use of restraint is a significant infringement on human rights and the lawful authority for the use of restraint in aged-care settings is ambiguous at best. – Office of the Public Advocate Queensland<sup>2</sup>

6.1 A key issue throughout this inquiry was the use of restraints in the management of dementia and Behavioural and Psychological Symptoms of Dementia (BPSD). Restraints can be divided into two categories: physical and chemical. Physical restraints include locked facilities<sup>3</sup>, the removal of mobility aids such as scooters<sup>4</sup>, binding patients to furniture<sup>5</sup>, and preventing patients from socialising with certain people.<sup>6</sup> Chemical restraints are typically medications that act to calm residents or prevent certain behaviours.<sup>7</sup> This chapter discusses the reasons and appropriateness of the use of restraints and monitoring and conditions placed on their use. The chapter concludes with the discussion of whether restraints are necessary in caring for people with dementia.

7 Ms Cook, Public Advocate, Office of the Public Advocate Queensland, *Committee Hansard*, 17 July 2013, p. 6.

<sup>1</sup> Department of Health and Ageing (Department), *Decision-making tool: supporting a restraint free environment in residential aged care*, 2012, p. 40.

<sup>2</sup> Ms Cook, Public Advocate, Office of the Public Advocate Queensland, *Committee Hansard*, 17 July 2013, p. 1.

<sup>3</sup> Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 36.

<sup>4</sup> Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, p. 7.

<sup>5</sup> Mrs Nicholl, Advocate, Elder Rights Advocacy, *Committee Hansard*, 16 December 2013, p. 24.

<sup>6</sup> Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, pp 7–8.

#### The rights of patients and considerations in using restraints

6.2 The committee heard that one of the impacts of a diagnosis of dementia in a residential aged care facility (RACF) was a seemingly automatic erosion of personal rights:

It is quite surprising and disappointing to see the number of staff members we train who do not understand that the people who live in the homes have rights. To me, what is lacking is a general rights based approach. That just not seem[s] to exist at all, and people do not understand that. They think, 'Well, they get to a certain age; they have a form of dementia, and that means we have to make decisions for them and don't have to take into consideration what they want.<sup>8</sup>

6.3 Extrapolating from the Universal Declaration of Human Rights, the United Nations Principles for Older Persons encourages governments to incorporate certain principles into their national programmes whenever possible, including:

Older persons should be able to utilise appropriate levels of institutional care providing protection, rehabilitation and social and mental stimulation in a humane and secure environment.<sup>9</sup>

6.4 In its submission to this inquiry, the Australian Medical Association (AMA) provided guidance on how and why restraints are used in an aged-care setting:

The need for physical or medical restraint is based on the medical practitioner's assessment of the issues. The medical practitioner has to determine the right balance between:

- A patient's right to self-determination;
- The need to protect the patient from harm; and
- The possibility of harm to others.

The decision to use restraint is not made in isolation. It involves a process of: request; assessment; team involvement; and consent within an ethical and legal framework.<sup>10</sup>

6.5 Some people derive great benefits from medication and need it to enable management of their condition.<sup>11</sup> The Royal Australian and New Zealand College of Psychiatrists (RANZCP) noted that 'the *appropriate* use of psychotropic medications is an essential element in improving the quality of life for some older people with mental illness'.<sup>12</sup> One of the experiences related to the committee highlights the

12 *Submission* 49, p. 12.

<sup>8</sup> Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, p. 4.

<sup>9</sup> See: <u>http://www.ohchr.org/EN/ProfessionalInterest/Pages/OlderPersons.aspx</u> (accessed: 26 March 2014).

<sup>10</sup> *Submission 39*, pp 2–3.

<sup>11</sup> Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 36.

positive impact appropriately used psychotropic medication can have on a sufferer of dementia:

I know everybody has been talking about how bad the drugs have been, but mum was only ever on one drug: Aricept. It really helped her a lot for the first nine months. We kept it up because we did not know how bad she would be without it, and it did help her. Before she was diagnosed she was all tearful and stopped doing her artwork, but after two weeks on Aricept she was back to painting again. It lasted for about nine months, and then the disease progressed.<sup>13</sup>

6.6 Alzheimer's Australia, a staunch advocate for those people living with dementia, also recognised that 'from time to time there are emergencies and we do accept that these drugs have a role'.<sup>14</sup> The committee similarly heard that while it was important to prevent the inappropriate use of medication, it was important that those who did need medication still received it. As Professor Draper noted:

[Whatever] consideration we give to how we in some way try to minimise the inappropriate use of these drugs, we need to also make sure we do not capture in that people who are appropriately being treated for serious mental disorders like schizophrenia or serious mood disorders like depression, manic depressive disorders, bipolar disorders.<sup>15</sup>

6.7 Unfortunately, the committee also heard allegations that restraints were used for the convenience and protection of the facility, rather than the clinical needs of the patient.<sup>16</sup>

#### **Chemical Restraints**

6.8 The evidence received by the committee points to a troubling trend in which there is an increased use of restraints as a management tool for BPSD, often used in the absence of guidelines about their appropriate use and management.<sup>17</sup> The committee heard that:

...anecdotally we are getting and seeing increasing reports of the use of restraints, particularly chemical restraints in aged-care settings. That is and of itself, particularly the use of antipsychotic medications, is of particular concern to me.<sup>18</sup>

- 17 Ms Cook, Public Advocate, Office of the Public Advocate Queensland, *Committee Hansard*, 17 July 2013, p. 6.
- 18 Ms Cook, Public Advocate, Office of the Public Advocate Queensland, *Committee Hansard*, 17 July 2013, p. 6.

<sup>13</sup> Dr Smith, Private Capacity, *Committee Hansard*, 17 December 2013, p. 22.

Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, p. 34.

<sup>15</sup> Professor Draper, private capacity, Committee Hansard, 17 July 2013, p. 50.

<sup>16</sup> Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, pp 5–7; Ms Cook, Public Advocate, Office of the Public Advocate Queensland, *Committee Hansard*, 17 July 2013, pp 5–7.

6.9 Alzheimer's Australia estimated that only one-in-five dementia sufferers currently on antipsychotics currently need to be on them.<sup>19</sup> One nurse contended however that:

Chemical restraints I believe are only prescribed by a doctor and given when all else has failed in managing the person's behaviour, for their safety. It is not just given out because it can [be].<sup>20</sup>

6.10 The committee heard that the over prescription of antipsychotic medication can present more risks to the health of a person than the behaviour that the medication was introduced to control.<sup>21</sup> As one witness related:

She was a risk of falls, because of the over-medication; she was drowsy and really unable to do any of the personal care and so forth, so required a lot more support from us...Sometimes medication that is over-prescribed can have a huge detrimental effect on the person and create more concerns for that person than they would if they had the behaviour.<sup>22</sup>

6.11 Morbidities that may come with these medications include cardiac deaths, strokes, falls and other injuries.<sup>23</sup> The committee also heard of cases where patients were given combinations of medication to control behaviours resulting in hospitalisations as a consequence of adverse reactions to those medications.<sup>24</sup>

6.12 HammondCare emphasised that there remains a grey area between the risks posed by restraints and the risks posed by a patient's behaviours:

One of the things HammondCare is passionate about is balancing people's knowledge about the risk of restraint versus what risk a person may pose to themselves or others without restraint. I think the grey area there has to be acknowledged, and that grey area is only managed with the right expertise at a medical level.<sup>25</sup>

6.13 The committee received evidence from stakeholders that restraints are being used too readily in aged-care to cover staff and resourcing constraints.<sup>26</sup> Some argued

- 21 Mrs Edwards, Service Development and Improvement Advisor, BlueCare, *Committee Hansard*, 17 July 2013, p. 11.
- 22 Ms Astete, Senior Manager Day and Respite Programs, Brotherhood of St Laurence, *Committee Hansard*, 16 December 2013, p. 13.
- 23 Dr Cleary, Geriatrician, Dementia Behaviour and Management Advisory Service, *Committee Hansard*, 10 July 2013, p. 23.
- 24 Mrs Potter, *Submission 20*, p. [7].
- 25 Ms Raguz, General Manager Residential Care, HammondCare, *Committee Hansard*, 17 July 2013, p. 14.
- 26 Ms Raguz, General Manager Residential Care, HammondCare, Committee Hansard, 17 July 2013, p. 14; Mrs Edwards, Service Development and Improvement Advisor, BlueCare, Committee Hansard, 17 July 2013, p. 14.

Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, p. 34.

<sup>20</sup> NSW Nurses and Midwives' Association, *Submission 55*, p. 2.

that there is an overreliance on medication to manage the behaviour of residents that could be dealt with without resorting to chemical restraints.<sup>27</sup> The Australian Psychological Society (APS) argued that there is a pharmacological 'knee-jerk response' to many conditions associated with dementia—especially BPSD—rather than managing those conditions through non-medical pathways.<sup>28</sup> This position was echoed by the Young People in Nursing Homes National Alliance (YPINH) who stated:

What we have often seen is that the use of drugs becomes a response of first resort, not last resort, because of escalation of behaviour or because other residents may be being endangered, or even just because noise levels are unbearable.<sup>29</sup>

6.14 Elder Rights Advocacy (ERA) argued that General Practitioners (GPs) are prescribing drugs at the behest of facilities who are insufficiently staffed to deal with people with dementia:

As staffing pressures appear to mount – that is the message from the industry – they are using it as a soft restraint, it would seem to me. It is not that soft but you do not see it and that is the only difference in it. Mostly GPs are doing it, we believe at the behest of aged care facilities saying, 'we don't have an option. We can't cope with the person.'<sup>30</sup>

6.15 The AMA seemed to implicitly argue that the use of restraints is often a reflection of resourcing limitations rather than clinical need, noting:

In the environment of an under resourced residential aged care facility, with limited qualified nursing staff and sufficient numbers of carers, the need for restraint is an unfortunate reality.<sup>31</sup>

6.16 The committee heard that the use of restraints in residential care was often poorly managed with people placed on a restraint long-term, rather than using restraints as an intervention with start and finishing dates. Alzheimer's Australia explained to the committee how drugs can be undermanaged:

What tends to happen is that once somebody is on a drug they tend to stay on it. A lot of these drugs are recommended for regular review and they are not. Some of the prescribing practices seem to be learnt in hospitals, so the person comes back from acute care having been restrained by one

<sup>27</sup> Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, pp 35–6; Mr Stokes, Principal Advisory, Australian Psychological Society, *Committee Hansard*, 16 December 2013, p. 21.

<sup>28</sup> Mr Stokes, Principal Advisory, Australian Psychological Society, *Committee Hansard*, 16 December 2013, p. 16.

<sup>29</sup> Dr Morkham, National Director, Young People in Nursing Homes National Alliance, *Committee Hansard*, 17 July 2013, p. 34.

<sup>30</sup> Ms Lyttle, Chief Executive Officer, Elder Rights Advocacy, *Committee Hansard*, 16 December 2013, p. 25.

<sup>31</sup> *Submission 39*, p. 3.

antipsychotic or another and it is maintained in the residential care facility and not questioned.  $^{\rm 32}$ 

6.17 HammondCare suggested that:

In my view, an antipsychotic should be viewed in the same way that an antibiotic is. It should have a start time, a review time and a finish time. It is treatment for a particular intervention and is not something that should be used long term.<sup>33</sup>

6.18 The use of mandatory reviews of antipsychotic medication was another suggestion put to the committee to improve the management of medication. It was reported that the Australian Geriatric Society recommend that there should be a revision within three to six months.<sup>34</sup> The committee heard that:

Three months is what we tend to think is a time frame at which, if a drug is appropriately prescribed in the first place and seems to be assisting the situation, it is worth trying to stop the drug. And research suggests that up to 50 per cent or so can be stopped successfully.<sup>35</sup>

#### **Recommendation 12**

6.19 The committee recommends that the use of antipsychotic medication should be reviewed by the prescribing doctor after the first three months to assess the ongoing need.

**Recommendation 13** 

6.20 The committee recommends that residential aged care facilities, as part of their existing Aged Care Standards and Accreditation Agency annual audit process, report:

- circumstances where an individual has been prescribed antipsychotic medication for more than six months, together with the reasons for and any steps taken to minimise that use; and
- general usage patterns of antipsychotic medications in each facility.

6.21 One of the reasons put forward to explain the under-management of medication was poor links within the care ecosystem. The committee heard that communication between doctors and different parts of the health system was, at times, poor, and meant that GPs working in residential facilities did not have sufficient information to cease a medication. As Professor Pond explains:

<sup>32</sup> Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, pp 33–34.

<sup>33</sup> Mr Cunningham, Director – The Dementia Centre, HammondCare, *Committee Hansard*, 17 July 2013, p. 18.

<sup>34</sup> Dr Cleary, Geriatrician, Dementia Behaviour and Management Advisory Service, *Committee Hansard*, 10 July 2013, p. 23.

<sup>35</sup> Professor Draper, private capacity, *Committee Hansard*, 17 July 2013, p. 51.

There is a gap when, as a new GP, I take over the care of someone in a nursing home. I often only have some written information about them and do not have any actual discussion or much detail from their former GP. [Discharge summaries] are often difficult to interpret for GPs, so we do not know why someone is on the medication. We really need a better way of gathering a history and improving that communication between acute and aged care. We as GPs might be reluctant to cease something when we are not quite sure what it is and when in a percentage of cases – around 20 per cent, I believe, from the literature – you will get a resurgence of behaviours if you stop the medication. That might be very difficult. I have certainly had a patient who ended up in a specialised unit having had her medication ceased. That is something that makes you very reluctant to follow that path again.<sup>36</sup>

6.22 The decision to start or cease a drug relies on the 'clinical professionalism of the doctor's prescribing behaviour and in the monitoring of the client over time'.<sup>37</sup> The committee also heard however, that doctors rely heavily on the facility to advise them on how the patient has reacted to medication, or for a history of that patient's past behaviour. As was explained to the committee:

[The] GPs often say that they feel powerless to do anything other than fulfil the nursing staff's requests, because the nursing staff are at their wits' end about how they can manage a situation that to them is causing huge problems in their facility, either with some form of aggression or agitation or other forms of disruption. So it becomes a bit of a chain even, if you like: there are the nursing staff, and maybe there are not enough of them, or not enough skills to deal with the problem; they hassle the doctors, and the doctors cannot think of much else to do, because the doctors themselves may not have many other skills beyond the prescription pad for this type of problem. And it continues on that way. Many doctors feel that if they do not prescribe then the patient will be sent by the facility to an emergency department because the facility cannot cope. These kinds of pressures happen.<sup>38</sup>

6.23 The committee was informed that GPs will see patients on medication at least every 12 weeks to write up medication charts.<sup>39</sup> It is not clear though, how doctors who only intermittently see dementia patients can accurately make the decision to start or cease a medication.

6.24 The Pharmaceutical Benefits Scheme (PBS) only records the number of medications dispensed, not necessarily to which patient, which has resulted in

<sup>36</sup> Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 35.

<sup>37</sup> Dr Towler, Principal Medical Adviser, Population Health Division, Department, *Committee Hansard*, 17 July 2013, p. 43.

<sup>38</sup> Professor Draper, private capacity, *Committee Hansard*, 17 July 2013, p. 52.

<sup>39</sup> Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 35.

difficulty in monitoring drug use across Australia. It was not clear how many individuals were receiving treatment as one person may have been on several drugs concurrently.<sup>40</sup>

6.25 Evidence received from the Department appears to confirm the suspicions of a number of submitters to this inquiry: that the use of drugs in dementia is higher than would be expected on clinical grounds alone. The committee heard:

The drug utilisation subcommittee has become concerned about the use of antipsychotic medication in comparison with the prevalence of depression or schizophrenia at the population level. They undertook a comparison at the end of last year and at the beginning of this year. The reports show that the use of PBS-listed antipsychotics is growing at a higher than expected rate. It is growing at a higher rate in the elderly...In February 2013 it found that there is a high and inappropriate utilisation of antipsychotics in the elderly, especially in the case of two drugs: quetiapine and olanzapine, which are prescribed at a rate inconsistent with the age-specific prevalence of bipolar disease.<sup>41</sup>

6.26 Dr Towler went on to say:

There is no doubt that some of these medications that we suspect, because of the data that do not line up here, are being used inappropriately in terms of their funded indications on the PBS.<sup>42</sup>

6.27 Although the Department's submission argues that:

The Government has in place a range of initiatives to help ensure that antipsychotic medicines are used only as a last resort and that the prescription of anti-psychotic medicines is closely regulated.<sup>43</sup>

6.28 The evidence indicates that more can be done to minimise the use of drugs in aged care and increase the efficacy of the oversight regime.

6.29 The Australian Institute of Health and Welfare (AIHW) reported to the committee that the 2014 edition of *Australia's Health* will provide greater granularity of dementia drug prescribing practices than has previously been available.<sup>44</sup>

6.30 Alzheimer's Australia called for the accreditation standards agency to take a leading role in improving the transparency of prescribing practices within aged care.<sup>45</sup>

<sup>40</sup> Mr Cooper-Stanbury, Head – Ageing and Aged Care Unit, Australian Institute of Health and Welfare, *Committee Hansard*, 16 December 2013, p. 32.

<sup>41</sup> Ms Platona, Assistant Secretary, Pharmaceutical Benefits Division, Department, *Committee Hansard*, 17 July 2013, pp 40–41.

<sup>42</sup> Dr Towler, Principle Medical Adviser, Population Health Division, Department, *Committee Hansard*, 17 July 2013, p. 41.

<sup>43</sup> Department, *Submission 56*, p. 8.

<sup>44</sup> Mr Cooper-Stanbury, Head – Ageing and Aged Care Unit, Australian Institute of Health and Welfare, *Committee Hansard*, 16 December 2013, p. 32.

#### **Recommendation 14**

6.31 The committee recommends that the Commonwealth develop, in consultation with dementia advocates and service providers, guidelines for the recording and reporting on the use of all forms of restraints in residential facilities.

#### **Recommendation 15**

#### 6.32 The committee recommends that the Commonwealth collect and report:

- the number of residents in aged care and acute care facilities with a diagnosis of dementia;
- the number of these residents who are taking, or have taken, antipsychotic medication;
- the number of instances where a patient has been prescribed multiple anti-psychotic medications;
- the reason the medication was prescribed; and
- the average duration of a course of prescribed antipsychotics.

#### **Physical restraints**

6.33 It was put to the committee that the use of restraints is often for the necessary protection of patients:

Many facilities have a locked dementia unit so people cannot actually get out, where the might be a busy road or something like that. For the night people may be put in a low bed that is a little bit difficult to get out of so that they cannot wander easily. It is not actually a restraint as such but it does provide a physical barrier to wandering. So there are some things like that that do not feel anything like being tied up but that do minimise behaviour that might cause that resident some harm.<sup>46</sup>

6.34 The committee received some particularly disturbing evidence from ERA detailing the use of physical restraints in some facilities:

His daughter contacted us when she went to visit dad – bearing in mind he is 93 years old – and she found him strapped into a wheelchair. This is in a psychiatric facility, so one we would expect to have a high ratio of staff. She was told that they did this to keep him safe, because he would not settle, and they felt that he was a high falls risk and it would be best to strap him into the wheelchair. When challenged on this by me they said, 'No, it's

<sup>45</sup> Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, p. 33.

<sup>46</sup> Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 36.

not restraint, because he can still move his feet and pull the chair along.' This is a psychiatric team who told me this.<sup>47</sup>

6.35 It was further reported that the same facility managed another patient by locking him into an isolated corridor area.<sup>48</sup>

6.36 As well as overt restraint, the committee heard of a number of situations that may be deemed a restraint in that they limit a person's rights to information and association. The committee was informed that residents were sometime restricted from engaging in sexual relationships at the request of their families.<sup>49</sup> The committee heard that there was a need to balance the rights of consenting adults with dementia to associate with whomever they please, and the wishes of the family who may find the relationship painful to observe:

Another scenario similar to that which I really want to highlight and which upsets a lot of people is where you have a person who has dementia who has forgotten who their living spouse is and forms a relationship with another person who might have dementia in the residential aged-care home. This is really, really difficult...What [providers] tend to do is separate the two.

•••

Even if you have dementia, even if this is hurting someone, you still have a right to choose who you have relationships with. This is a difficult issue. I sympathise with people who are caught up in that type of scenario, but the rights are still and there and they will never disappear.<sup>50</sup>

6.37 ERA recommended to the committee that Australia explore 'deprivation of liberty safeguards' such as those used in the United Kingdom.<sup>51</sup>

#### Committee view

6.38 While the committee is not in a position to verify the accuracy and currency of these claims of physical restraint, the committee takes these claims seriously. The committee believes that this case serves as a cautionary warning of the harm that can occur where dementia care practices do not focus on the patient.

<sup>47</sup> Mrs Nicholl, Advocate, Elder Rights Advocacy, *Committee Hansard*, 16 December 2013, p. 24.

<sup>48</sup> Mrs Nicholl, Advocate, Elder Rights Advocacy, *Committee Hansard*, 16 December 2013, p. 24.

<sup>49</sup> Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, pp 7–8.

<sup>50</sup> Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, pp 7–8.

<sup>51</sup> Mrs Nicholl, Advocate, Elder Rights Advocacy, *Committee Hansard*, 16 December 2013, p. 30.

#### **Guidelines for the use of restraints**

6.39 The Department reported that there are guidelines and advices provided by the authorities to RACFs:

For some years, staff in aged care homes have had access to a decisionmaking guide to help them make decisions about minimising the use of physical and chemical restraint in the care of older people with dementia.<sup>52</sup>

6.40 The official guidelines were updated and in 2012 two new decision-making tools were reportedly provided to all residential and community care services: *Responding to Issues of Restraint in Aged Care in residential care* and *Responding to Issues of Restraint in Aged Care in community care* (Guidelines).<sup>53</sup> The Guidelines replaced and updated the previous guidelines published in 2004. As the Department explains:

[The guidelines] emphasise that: a restraint-free environment is a basic human right for all care recipients and chemical restraint should not be implemented unless alternatives are explored; and a review of the use of chemical restraint should be carried out in consultation with the care recipient's medical practitioner and an accredited pharmacist.<sup>54</sup>

6.41 In addition, the National Prescribing Service has produced over ten publications on the management of behavioural problems related to dementia that include guidance on minimising the use of drugs, as well as conducted outreach education programs.<sup>55</sup>

6.42 A diversity of opinions was put to the committee regarding the current guidelines. One service provider 'strongly [recommended] more robust guidelines be written to prevent long-term use of antipsychotic medications'.<sup>56</sup> This view was not universal. Another provider posited that 'there are very good and solid guidelines', but these need to be properly implemented.<sup>57</sup> This position was echoed by Benetas which argued that the Guidelines 'provide an excellent model but again the problem is to have health professionals attend aged care facilities to undertake medication reviews.'<sup>58</sup>

6.43 Despite the availability of guidelines and official guidance on the use of restraints, different providers were reported to still have differing ideas of what constitutes a restraint:

- 53 Department, *Submission 56*, p. 7.
- 54 *Submission 56*, p. 8.
- 55 Department, *Submission 56*, p. 9.
- 56 Mrs Edwards, Service Development and Improvement Advisor, BlueCare, *Committee Hansard*, 17 July 2013, p. 11.
- 57 Mr Cunningham, Director The Dementia Centre, HammondCare, *Committee Hansard*, 17 July 2013, p. 18.
- 58 *Submission 21*, p. [4].

<sup>52</sup> *Submission* 56, p. 7.

I would even go so far as to say that I believe that there are differences in the definitions that different providers are using of what constitutes a restraint. In my travels over the years I have heard people saying, 'Oh, well, if you have got a person who has a diagnosis of dementia, you do not have to class it as a chemical restraint because the person has an antipsychotic.' That is where it starts to get problematic.<sup>59</sup>

6.44 This confusion should not exist. The Guidelines are clear regarding what constitutes a restraint and under what circumstances they may be used, and emphasises that restraints 'must not be implemented until alternatives are explored extensively through assessment'.<sup>60</sup> The committee, unsurprisingly, heard calls for greater publicity and training to be provided around the Guidelines and other advices.<sup>61</sup>

#### Committee view

6.45 The adequacy of the existing Guidelines is obviously a concern based on the evidence presented above. The committee was surprised that many people appear to be unaware that Guidelines exist, let alone what they contain. The Guidelines appear to be of a high quality and recommend various alternatives to the use of restraints. The committee notes however that there do not appear to be any penalties for the over use of medication, or incentives for providers to minimise the use of restraints.

6.46 Unfortunately the lack of granularity in the data limits the scope of these considerations. In the first instance, the committee considers it important that the use of medication that could be considered as a restraint is quantified and reported to enable a clearer picture of how restraints are being used.

6.47 The committee recognises that the government has produced a number of guides and advices, in addition to the Guidelines, regarding the use of restraints in managing dementia and other conditions. This information however does not seem to have percolated through the sector, especially to doctors who are responsible for prescribing and managing these drugs.

#### **Recommendation 16**

# 6.48 The committee recommends that the Commonwealth undertake an information program for doctors and residential aged care facilities regarding the guidelines *Responding to Issues of Restraint in Aged Care in Residential Care*.

#### Are restraints necessary?

6.49 A number of contributors argued that when the time was taken to understand the causes of BPSD the use restraints was typically unnecessary:

61 Benetas, *Submission 21*, p. [4].

<sup>59</sup> Ms Raguz, General Manager – Residential Care, HammondCare, *Committee Hansard*, 17 July 2013, p. 17.

<sup>60</sup> Department, *Decision-making tool: supporting a restraint free environment in residential aged care*, 2012, p. 26.

I think that knowing the person, working with them and understanding them is a much more effective way to go. Communicating with them and understanding what their behaviours are about is a much more effective way to go than using chemicals restraint.<sup>62</sup>

6.50 Alzheimer's Australia emphasised that when the causes, rather than just the behaviours, were considered it was easier to understand why the person is acting the way they do:

I think the secret to dementia care is actually very simple, and that is to look at the cause of a person's symptoms and not to respond to the symptoms themselves. If somebody is violent, they are not being violent because they are a nasty person. They are being violent because they are frustrated. They feel no purpose in life...They do not know where they are. They feel disorientated. They may feel very depressed. They may be suffering psychosis. They may be losing their words. They may not be able to communicate. You put all those things together and think of how you would react and then you can start to translate it into your own behaviours.<sup>63</sup>

6.51 A person's behaviour may also be as a result of their own personal history. Demonstrating the importance of understanding a person's background is well demonstrated in the following example:

I have a patient who is looking at nursing home care, and I know she was in Europe during World War II and was bombed, and she gets very upset when there is a low-flying aircraft and will probably exhibit behaviours in the nursing home that might be very difficult for people to understand unless they know that particular issue.<sup>64</sup>

6.52 The Brotherhood of St Laurence argued that with a sufficient understanding of the patient, most antipsychotic medications were unnecessary:

We very rarely have a need to use antipsychotic medication. There may be a use of anxiety-reducing medication, but generally that might be undertaken for a short period where you are getting the anxiety brought under control but you are looking at all those other things that we have just been speaking about, which was understanding the person.<sup>65</sup>

<sup>62</sup> Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, p. 6.

<sup>63</sup> Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, p. 31.

<sup>64</sup> Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 35.

<sup>65</sup> Ms Morka, General Manager, Retirement, Ageing and Financial Inclusion, Brotherhood of St Laurence, *Committee Hansard*, 16 December 2013, p. 12.

6.53 Wintringham reported great success in transitioning patients off medication when the time was taken to understand the root cause of their behaviours.<sup>66</sup> Similarly, HammondCare reported that their dementia-specific facility 'with appropriate design principles and specially trained staff' has successfully implemented a no-restraint policy.<sup>67</sup> Rural Northwest Health reported large reductions in the number of patients on medication following their conversion to the Montessori method of care.<sup>68</sup>

6.54 Speaking from a medical perspective, Professor Pond agreed that there was scope for reducing the reliance on medication through additional staff training and resources:

I think it would be so much better if the nursing home staff had the training and resources to provide some simple distracting activities [for residents]. Some nursing homes are excellent at this, but all too often residents are left to their own devices for huge swags of the day and then they turn to pacing and rattling doors and wanting to go home, and calling out.<sup>69</sup>

6.55 This view was echoed by Professor Brian Draper:

I think there is clearly an overuse of drugs, and I think a lot of this relates to poor design of facilities and training of staff, inadequate numbers of staff and lack of suitable activity programs. I think that if a lot of that could be improved then the use of medications would be much less.<sup>70</sup>

6.56 Based on this evidence, it appears that the use of restraints can be significantly reduced from their current levels. Providing personalised care; ensuring staff members have the appropriate training; and that facilities are designed and managed with the needs of dementia in mind appear to be three of the foundations to build a better care model upon.

6.57 The RANZCP provides an important caveat to this viewpoint:

A recent systematic review into the ability to implement non pharmacological management of BPSD within residential aged care concluded that there are several non-pharmacological interventions that may be effective, but *most interventions required significant resources from* services outside of long term care or significant time commitments from long term care nursing staff for implementation.<sup>71</sup> (emphasis in original)

<sup>66</sup> Ms Small, General Manager of Operations, Wintringham Specialist Aged Care, *Committee Hansard*, 16 December 2013, p. 5.

<sup>67</sup> *Submission* 25, p. 4.

<sup>68</sup> Ms Walters, Innovation and Continuous Improvement Manager, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 5.

<sup>69</sup> Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 36.

<sup>70</sup> Professor Draper, private capacity, *Committee Hansard*, 17 July 2013, p. 50.

<sup>71</sup> *Submission 49*, p. 9.

6.58 It is possible to significantly reduce reliance on restraints provided that the resources in the form of training, time and facilities are available:

For the desirable goal of reduced use of restraint and pharmacological interventions in people with BPSD to be achieved, increased access to trained staff with adequate time and resources within residential aged care facilities will be required.<sup>72</sup>

#### **Committee view**

6.59 The evidence provided by the Department of Health and Ageing seems to confirm that there is significant overuse of psychotic medication in aged care to control BPSD. This overuse must not be allowed to continue. The existence of several providers who manage BPSD without reliance on chemical or physical restraints highlights what can be achieved with the current resources available.

6.60 This chapter, and those preceding it, have shown that aged care professions know how to reduce the impacts of BPSD. Chapters three and four highlighted the importance of appropriate facilities and environments and a person-centred focus in reducing unnecessary BPSD. Chapter five discussed the importance of adequate staff training in managing BPSD. This chapter brings together these tools—education, appropriate facilities, adequate staff numbers, partnerships with carers, and a person-centred focus—to demonstrate that some service providers are already managing dementia and BPSD without resorting to restraints unnecessarily.

6.61 The use of medication is a symptom of the aged care system not placing enough emphasis on staff training and providing a person-centred focus that engages the patient in meaningful activities. Reliance on restraints to manage dementia and BPSD is not an acceptable model of care, especially as more and more Australians are diagnosed with dementia. It is necessary to make the necessary investments in training and facilities to ensure that the rights of people with dementia are respected and they are free from unnecessary restraints.

6.62 The Commonwealth has recently made significant changes to the aged care system under the *Living Longer, Living Better* reforms. It is hoped that some of these reforms, such as the Dementia and Cognition Supplement, will improve the quality of life for people living with dementia. If the ratio of dementia patients on antipsychotics does not decrease, there will be a need for further government involvement.

<sup>72</sup> Royal Australian and New Zealand College of Psychiatrists, *Submission 49*, p. 12.