# THE USE OF RESTRAINTS AND PSYCHOTROPIC MEDICATIONS IN PEOPLE WITH DEMENTIA

# A REPORT FOR ALZHEIMER'S AUSTRALIA PAPER 38 MARCH 2014

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A full copy of the report including appendices and references can be found at www.fightdementia.org.au

## **FOREWORD**

Carers often face difficult and complex choices in the use of medications and restraints when caring for a person with dementia at home or seeking to ensure that the person they care for is receiving the appropriate care in residential aged care facilities.

These decisions can be made more difficult because of a lack of information about the effectiveness and potential consequences of these powerful medications, and a lack of awareness about alternative approaches. In some cases carers are not even being involved in the decision-making process. A study of Sydney nursing homes showed that only in 6.5% of cases was appropriate consent obtained (Rendina et al., 2009).

When it comes to the issue of physical restraints, family carers and aged care staff have a natural desire to want to keep the person they care for safe but often don't realise that restraining someone can increase the risk of falls and, in some cases, if restraints are not put in place carefully even put the person's life at risk.

The objective of this paper is to provide accessible information about the evidence on the current practice of physical restraints and the use of psychotropic medications. It looks at the physical and psychological consequences, the legal implications and the alternative approaches.

There are no simple answers. Clinical guidelines indicate that the first line of response to behavioural and psychological symptoms of dementia should be the use of psychosocial approaches (NSW Ministry of Health, 2013), but this paper also recognises that the use of restraints – whether physical or chemical – may be necessary in some circumstances. The concern is that in many cases physical and chemical restraints are often the first line of response to behavioural symptoms when, in most cases, other approaches should be tried first.

Family carers have the right to be properly informed about the potential consequences of psychotropic medications that can have dangerous side effects and the circumstances in which the use of medications and restraints may be appropriate.

There is a need to address the use of physical restraints and the cases of misuse of psychotropic medications for people with behavioural and psychological symptoms of dementia. Training and education for family carers and staff are a priority as is the availability of access to specialist advice through such organisations as the Dementia Behaviour Management Advisory Services. If we are to achieve the goal of care that respects the dignity and rights of people with dementia it is crucial that we achieve greater transparency in the use of restraints.

My thanks to Associate Professor Carmelle Peisah and Dr Ellen Skladzien for writing this publication and to our consumer networks and staff for their generous contributions.

Ita Buttrose AO, OBE National President Alzheimer's Australia

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## **DEFINITIONS**

#### **Antipsychotic Medications**

Antipsychotics (also known as neuroleptics) are medications that affect the action of a number of brain chemicals (neurotransmitters) and were initially developed to manage psychosis. Antipsychotics fall into two classes: typical and atypical. Typical antipsychotics were first developed in the 1950s to treat psychosis. They tend to be associated with more Parkinson's disease-like side effects (e.g. tremor, rigidity) and a syndrome of abnormal involuntary movements called tardive dyskinesia than the newer, atypical antipsychotics.

#### **Assault**

Assault is the application of force to a person, for example a hit, holding someone down or dragging them. It may also involve doing something that makes a person fear they are going to be assaulted, for example raising a fist.

## Behavioural & Psychological Symptoms of Dementia (BPSD)

Behavioural and psychological symptoms of dementia (BPSD) are symptoms of disturbed perception, thought content, mood and behaviour occurring in people with dementia (Burns et al., 2012). They include agitation, aggression, calling out/screaming, intrusive behaviours, disinhibition (sexual), wandering, night time disturbance, shadowing, swearing, depression, anxiety, apathy, delusions, hallucinations, irritability and elation/euphoria.

#### **Chemical Restraint**

Chemical restraint is the intentional sedation or control of an individual's behaviour through the use of medicines.

#### **Delirium**

Delirium is a disturbance of consciousness and a change in cognition that develops over a short period of time as a consequence of a general medical condition, substance intoxication or withdrawal, use of medication or toxin exposure that is not better accounted for by a pre-existing or evolving dementia. It differs from dementia because it comes on suddenly rather than gradually. It may complicate dementia and it often presents with an acute change in behaviour.

#### **Effect Size**

A statistical measure of the strength or magnitude of a phenomenon, including the effect of an intervention or treatment (e.g. drug or psychosocial treatment) often used when multiple studies are combined. A large effect size is 0.5, a medium effect size is 0.3 and a small effect size is 0.1.

#### **False Imprisonment**

False imprisonment is confining a person to a particular space, for example locking a person in a house.

#### **Physical Restraint**

Any device, material or equipment attached to or near a person's body and which cannot be controlled or easily removed by the person and which deliberately prevents or is deliberately intended to prevent a person's free body movement to a position of choice and/or a person's normal access to their body.

## **PURPOSE OF THIS PAPER**

The inappropriate use of chemical and physical restraint, particularly within residential care but relevant also in hospitals and community settings, is a significant concern for people with dementia and their families. Issues regarding inappropriate use have been raised in a number of consumer consultations and examples of misuse of restraint have recently been highlighted in media reports. There have been questions from both consumers and providers about what the facts are around the use of restraint and what the evidence is for alternative approaches to care such as psychosocial approaches.

The purpose of this paper is to provide the evidence of current practice, consequences, legal issues and alternative approaches. This paper is designed to be used by consumers, advocates as well as health care professionals.

This paper is written by Associate Professor Carmelle Peisah and Dr Ellen Skladzien, National Policy Manager at Alzheimer's Australia. Associate Professor Peisah is an Old Age Psychiatrist and a Conjoint Associate Professor at UNSW and Clinical Associate Professor at Sydney University. She is Clinical Director of Specialised Mental Health Services for Older People, Northern Sydney Local Health District. She has published and presented widely on a range of dementia-related topics, with special expertise in capacity and ethics, end-of-life issues, BPSD and family issues.

This paper was developed with input from Nick O'Neill, Alzheimer's Australia NSW Board member, former president of the NSW Guardianship Tribunal and human rights lawyer with expertise in medico-legal issues including decision-making, and Eesa Witt who is a Registered Nurse and Alzheimer's Australia NSW Board member who has extensive clinical experience in caring for people with dementia, delirium and BPSD.

## THE KEY POINTS AT A GLANCE

#### **Physical Restraint**

- The prevalence of physical restraint in aged care facilities varies and evidence suggests prevalence ranges from 12–49% (Evans et al.,1997, Feng et al., 2009; Retsas 1997, 1998; Hamers, Gulpers & Strik, 2004; Retsas & Crabbe 1997, 1998).
- Physical restraints can have a range of adverse psychological and physical effects. Research has shown that overall physical restraints do not prevent falls and may in some cases cause death (Enberg, Castle & McCaffrey, 2008; Tang, Chow & Koh, 2012; Evan et al., 2003; Karger et al., 2008; Rakhmatullina et al., 2013; Barnett et al., 2012).
- There are some situations in which it may be appropriate to use physical restraint for a short period of time, but clinical guidelines indicate that physical restraints should always be an intervention of last resort (Burns et al., 2012; Gastmans & Milisen, 2009).
- There are a wide range of environmental, strength-promoting, surveillance and activity-based alternatives to using restraints (Burns et al., 2012).
- It is best practice to ensure that consultation takes place with the carer and/or legal representative prior to the decision to apply restraint. In an emergency situation this may not be possible immediately but should be done as soon as possible. Jurisdictional variations in guardianship legislation govern the roles of proxy decision-makers in giving consent to restraint on behalf of people unable to give informed consent themselves (Department of Health and Ageing, 2012).

#### **Psychotropic Medications**

- About half of people in residential aged care facilities and up to 80% of those with dementia are
  receiving psychotropic medications, although this varies between facilities. There is evidence to suggest
  that in some cases these medications have been prescribed inappropriately (Hosia-Randell & Pitkälä,
  2005; National Prescribing Service, 2013).
- Behavioural and psychological symptoms of dementia (BPSD), although variable in severity are common and affect almost all people with dementia sometime during their illness (Selbaek et al., 2014; Brodaty et al., 2001).
- BPSD have a range of physical, environmental and psychosocial causes (Chenoweth et al., 2009; Brodaty et al., 2003).
- The evidence supporting the effectiveness of psychotropic medications in treating BPSD is modest at best, with some support for atypical antipsychotics. International data suggests that up to 20% of people with dementia who receive antipsychotic medications derive some benefit from the treatment (Chenoweth et al., 2009; Brodaty et al., 2003).
- Psychotropics have a range of serious side effects and are associated with increased mortality for people with dementia (Hien et al., 2005; Katz et al., 2004; Hedges et al., 2003; Byerly et al., 2001; Schneider et al., 2006; Ballard, 2009b; Brodaty et al., 2003).
- Psychotropics are best used where there is severe and complex risk of harm, when symptoms are
  psychotic in nature, when psychosocial interventions have been exhausted or when there are comorbid
  pre-existing mental health conditions (Alexopoulos et al., 2005; Burns et al., 2012; NSW Ministry of
  Health, 2013).
- Clinical guidelines suggest that psychotropic medications should be used according to the principle of
  the START LOW, GO SLOW strategy, and trials need to be sequential and systematic, preferably trialling
  one drug at a time with side effects monitored regularly, and the drug ceased immediately if significant
  adverse side effects emerge. Experts recommend that they be used for a limited period only, with
  regular review regarding possible discontinuation at least three-monthly (NSW Ministry of Health, 2013).
- Expert consensus guidelines recommend the use of multidisciplinary, individualised psychosocial approaches as a first line approach to behavioural symptoms of dementia. There are a range of psychosocial and caregiver interventions that have evidence-based support. Best practice for BPSD treatment is comprehensive, individualised assessment in order to provide person-centred care, with family and professional caregiver education and support (Burns et al., 2012; O'Connor et al., 2009; Livingston et al., 2005; Cohen-Mansfield, 2005; Brooker, 2004, 2005).
- Informed consent for use of psychotropic medications should be obtained from the person themselves where possible. Alternatively, if the person is unable to give informed consent, then consent should be obtained from a substitute decision-maker (O'Neill & Peisah, 2011).

## KEY RECOMMENDATIONS

Alzheimer's Australia recommends that the Commonwealth Government develop a multifaceted strategy to reduce chemical and physical restraint as part of its action to build on the 2012 Aged Care Reforms. This strategy could in part be funded through the repurposing of the \$1.1 billion wage supplement. Such a strategy would need to incorporate the following elements:

- 1. Training and education for the aged care workforce on person-centred care, BPSD and non-pharmacological interventions as well as information on when and how to access specialists such as DBMAS and psychiatrists when needed. Alzheimer's Australia, the Dementia Training Resource Study Centres (DTSCs) as well as DBMAS all have a role to play in ensuring access to regular, consistent, high quality training and education.
- **2.** A review of staffing arrangements within aged care facilities to ensure that facilities caring for people with BPSD have sufficient staff and an appropriate skills mix to provide the level of care required.
- **3.** Targeted information for consumers about their legal rights within the health and aged care sector including on issues relating to consent to physical restraint and the use of psychotropic medications. This information could be distributed through consumer groups such as Alzheimer's Australia, Carers Australia and CoTA.
- **4.** Information on BPSD to be incorporated into education for carers including the role of unmet needs and non-pharmacological mechanisms to respond to BPSD. This information is already available through Alzheimer's Australia but there is a need to promote and ensure access to this information.
- **5.** Support to assist physicians and residential aged care facilities to ensure that they are following clinical guidelines and using an evidence-based approach to prescribing psychotropic medications which should be used as a last resort, where symptoms are psychotic in nature, in cases with severe and complex risk of harm or psychosis or for pre-existing psychiatric illnesses. The use of these medications should be time-limited, reviewed regularly, and used with appropriate consent and multidisciplinary input from pharmacists, behaviour management experts, general practitioners and psychiatrists where possible.
- **6.** Changes to aged care regulation and accreditation including:
  - Public reporting for the rate of use of psychotropic medications and physical restraints in residential facilities on the MyAgedCare website. This must be done carefully to ensure that facilities are not discouraged from accepting people with higher care needs. It should be noted that many providers are already collecting this data but it is not currently accessible by consumers.
  - Ensuring that complaints around the use of physical and chemical restraints are facilitated and handled quickly through the Aged Care Complaints Scheme.
  - Regulation through the Australian Aged Care Quality Agency to ensure that care practices and care culture genuinely foster person-centred care and that appropriate consent procedures are in place for the use of psychotropic medications and physical restraints. The reasons for use of restraint and psychotropic medications should be well documented and reviewed regularly.
  - Reporting of adverse outcomes.
- 7. Review of the dementia and behaviour supplement in residential aged care to ensure that it is resulting in higher quality care for people with BPSD and provides sufficient funding to cover the costs of the high level of care required. Consideration should be given to how financial incentives could be used to encourage aged care organisations to develop specific expertise and skills in caring for people with severe BPSD (including use of psychosocial strategies, identification of a person within the facility as the behaviour program coordinator, and a regular review and audit of the care provided to people with BPSD).

## **BACKGROUND**

As a result of consumer concern and recent media attention a number of key initiatives to address the use of physical and chemical restraints are underway. These include the gradual implementation of quality indicators in the 2012 Aged Care Reforms; the expansion of the Dementia Behaviour Management Advisory Service (DBMAS); a 2012 Ministerial Roundtable on the use of antipsychotic medications;

new guidelines for psychotropic use in residential aged care; a 2013 Senate Inquiry into care and support for people with Behavioural and Psychological Symptoms of Dementia (BPSD); several important research projects on de-prescribing; and a knowledge translation project on Montessori approaches to care for people with dementia and their carers. More information about these initiatives can be found in the Appendix.

## SCOPE

This paper takes a broad approach to the issues of restraint and use of psychotropic medication (medicines that act on the central nervous system to affect perception, mood, consciousness, cognition and behaviour). The paper is divided into two sections, with the first focusing on physical restraint and the second focusing on the use of psychotropic medications including antipsychotics.

The focus of this paper is on care practice within the residential aged care setting, but these issues are also relevant to consumers living at home and those being cared for in the acute hospital setting.

This document seeks to elucidate the best practice use of psychotropics and physical restraint in people with dementia as well as to outline alternative approaches.

Human rights frameworks, such as the Convention on the Rights of Persons with a Disability (CORPD) ratified by Australia in 2008, uphold several key human rights principles at stake here, including the right to human dignity and personhood, the right to autonomy and personal freedom, and the right to protection from abuse. Equally important are ethical principles of justice and equitable access to care (Katona et al., 2009), specifically the right to individualised, needsdriven, person-centred care.

## PHYSICAL RESTRAINT

#### What is Physical Restraint?

There are several different types of restraint including bed boundary markers, chairs with deep seats or rockers and recliners, lap belts, hand mitts and seat belts. Bed rails and removing mobility aids are considered "high-risk restraints" whereas seclusion, leg, wrist or ankle restraints are considered "extreme restraints". "Environmental restraint" is the restriction of movement of the client without the client's explicit and informed consent (eg. locked units, fenced areas) (Department of Health and Ageing, 2012; Todd, Ruhl & Gross, 1997).

#### **How Common is Their Use?**

Studies of the prevalence of physical restraint use in residential care have indicated diverse estimates of restraint use, ranging from 12% to 49% (Evans et al., 1997, Feng et al., 2009; Retsas 1997, 1998; Hamers, Gulpers & Strik, 2004; Retsas & Crabbe 1997, 1998). An international systematic review estimated that the proportion of residents in residential aged care facilities who were physically restrained ranged from 12% to a maximum of 47% (a mean of 27%). The range in duration was from 1 day to 350 days (during a one-year follow-up period) and 32% of residents were restrained for at least 20 days each month (Evans et al., 2002). The review also found that between 3.4% and 21% (a mean of 10%) of acute care patients were subject to some form of physical restraint during their period of hospitalisation (Evans et al., 2002).

The prevalence of physical restraint in aged care facilities varies and evidence suggests prevalence ranges from 12–49% (Evans et al., 1997, Feng et al., 2009; Retsas 1997, 1998; Hamers, Gulpers & Strik, 2004; Retsas & Crabbe 1997, 1998).

#### Why do Health Care Workers Use Restraint?

Physical restraints are most often used with the intent of minimising risk of harm to the person. Professional and family carers may perceive this as the only way to minimise falls, control inappropriate behaviours or reduce the risk of absconding from an aged care facility. In some cases restraint may be used to reduce the risk of harm to other residents when the person has severe behavioural symptoms in a facility. Research conducted in Victoria suggests that some of the barriers to reducing the use of restraint within aged care facilities includes fear of resident injury, staff and resource limitations, lack of education and information about alternatives to restraints, environmental constraints, policy and management issues, beliefs and expectations (of staff, family and residents), inadequate review practices and communication barriers (Moore & Haralambous, 2007).

## What are the Consequences of Using Physical Restraints?

Research suggests that the use of restraints can lead to a number of negative physical and psychological effects (Enberg, Castle & McCaffrey, 2008).

The negative consequences of restraint are related to:

- **1.** the physical effects of a device in contact with the body (e.g. bruises, skin tears).
- 2. the physical effects of being immobilised such as: decubitus ulcers (ulcers due to position such as prolonged sitting or lying); respiratory complications; urinary incontinence and constipation; under-nutrition; increased dependence in activities of daily living; impaired muscle strength and balance; and decreased cardiovascular endurance.

- **3.** the psychological effects of being trapped (such as increased agitation, depression, fear, discomfort and anxiety) (Castle, 2006).
- 4. the risks associated with escape (increased risk of mortality caused by strangulation or entrapment or serious injuries resulting from falls - for example, fracture or head trauma) (Department of Health and Ageing, 2012; Gastmans & Milisen, 2006).

A systematic review of the effectiveness of use of physical restraints in reducing falls in acute care and nursing homes found that overall physical restraints are not effective in reducing the risk of falls (Tang, Chow & Koh, 2012). As stated in guidelines developed by Department of Health (2012):

"The use of restraint is known to increase the risk of a person falling and incurring harm from that fall."

There have been a number of cases reported where physical restraint has led to severe injury or death (Evans, Wood & Lambert, 2003; Karger, Fracasso & Pfeiffer, 2008; Rakhmatullina, Taub & Jacob, 2013; Barnett, Stirling & Pandyan, 2012).

Physical restraints can have a range of adverse psychological and physical effects. Research has shown that overall physical restraints do not prevent falls and may in some cases cause death. (Enberg, Castle & McCaffrey, 2008; Tang, Chow & Koh, 2012; Evan et al., 2003; Karger et al., 2008; Rakhmatullina et al., 2013; Barnett et al., 2012)

#### When Should Restraint be Used?

Clinical guidelines indicate that physical restraints should be an intervention of last resort (Burns et al., 2012). Physical restraint should only be used if the benefits outweigh the shortcomings and should be considered only if the person's health, integrity, or living and caring environment would be seriously damaged by not using them, and if there are no alternatives or all alternatives have been exhausted (Gastmans & Milisen, 2006). The least restrictive methods should always be tried first and the person's freedom should not be restricted any longer, or to any higher degree, than is strictly necessary. Starting from a position to avoid unnecessary physical restraint, it has been suggested that restraint should be considered only when:

- specific benefits are envisioned
- there is a reasonable expectation that these benefits can be attained through physical restraint (effectiveness)
- there are no practical alternatives to physical restraint (as listed above)
- the application of physical restraint hinders the person as little as possible and the least restrictive form of restraint is used
- application is temporary (Gastmans & Milisen, 2006).

The choice to use or not to use physical restraint should be based on an individualised, comprehensive assessment – for example, cognitive, physical, mobility, and sensory state; drug therapy; past history; and environmental issues – and should involve consultation with family members or those who know the person well. If physical restraint is applied, then the reasons for use should be well documented and measures need to be taken to maximise respect for dignity and freedom/autonomy and to minimise harm. Such measures include:

- continuous monitoring of physical health status –
   e.g. skin integrity, colour, extremity movement, and personal needs such as toileting, food, and fluids
- maximum protection of privacy and optimisation of psychosocial comfort
- regular release of restraints
- regular review of the need for restraint
- clear concise documentation.

There are some situations in which it may be appropriate to use physical restraint for a short period of time, but clinical guidelines indicate that physical restraints should always be an intervention of last resort (Burns et al., 2012; Gastmans & Milisen, 2009).

#### What are Some Alternatives to Restraint?

Restraint-free options can be classified into physical, social/environmental, psychosocial, care and physiological strategies. Table 1 provides an overview of the different strategies that can be used as alternatives to the use of physical or chemical restraint (Burns et al., 2012, pg. 67).

Please see page 18 for further discussion of alternative approaches to responding to BPSD.

Common to most successful restraint-minimising approaches are programs of multiple activities with restraint minimisation education for staff and expert clinical consultation (Evans et al., 2002). Alternatives to restraint can be found below in Table 1.

There is a wide range of environmental, psychosocial, care and physiological based alternatives to using physical restraints (Burns et al., 2012).

**Table 1:** Alternatives to Restraint Table adapted from (Burns et al., 2012, pg. 67)

Physical Environmental	<ul> <li>Measures to reduce the risk of falls including:</li> <li>lowered bed height to suit individual needs (or mattress placed on the floor. Ensure appropriate mobility aids are available</li> <li>non-slip flooring and footwear</li> <li>clutter-free and reduced-glare corridors</li> <li>appropriate seating</li> <li>hip protectors or helmets</li> <li>Measures to reduce agitation and confusion including:</li> <li>provide familiar objects from the person's home (photos, furniture etc)</li> <li>appropriate signage and visual reminders to aid orientation</li> <li>provide safe areas for residents to wander</li> <li>provide quiet areas and where possible, reduce over stimulation due to environmental noise and bright lighting</li> <li>increase ease of access to safe and protected outdoor area</li> </ul>
Social and Emotional Environment	<ul> <li>engage familiar staff</li> <li>relaxation activities such as therapeutic touch and massage</li> <li>reality orientation</li> <li>sensory aids and appropriate stimulation</li> <li>decreased sensory overload</li> </ul>
Activities	<ul> <li>rehabilitation and/or exercise</li> <li>physical, occupational and recreational therapies</li> <li>night-time activities</li> <li>individual and small-group social activities</li> <li>activities for promoting success through use of overlearned skills (e.g. gardening, folding laundry)</li> <li>activity boxes</li> </ul>
Care Approach	<ul> <li>person-centred care</li> <li>individualised and structured routines</li> <li>communication strategies</li> <li>increased supervision and observation by staff</li> <li>identification of behaviour triggers</li> <li>appropriate staffing levels and skills mix</li> <li>regular evaluation and monitoring of conditions that may alter behaviour</li> <li>strategic placement of residents</li> <li>falls prevention programs</li> <li>continence programs</li> </ul>
Physiological Assessment and Care	<ul> <li>comprehensive medical examinations and reviews</li> <li>nutrition and hydration management</li> <li>treating infections</li> <li>pain management</li> </ul>

## What are the Legal Issues to be Considered When Using Restraint?

The inappropriate use of restraint can become a legal concern. According to Department of Health guidelines (Department of Health and Ageing, 2012) prior to the decision to use restraint. "Consultation should take place with the resident or their legal representative. In an emergency situation this consultation may not be possible immediately but should be done as soon as possible."

A person capable of giving consent to their own restraint should be given the opportunity to do so. In some cases people may feel more comfortable with certain devices in place (e.g. bed boundary devices) and may have been familiar with their use at home.

Legislation dealing with those unable to give consent varies in different states and territories. In some jurisdictions a family member may need a relevant guardianship order or enduring power of attorney to give consent, while in other jurisdictions consent may need to be obtained from the Guardianship Tribunal or equivalent, particularly if the person is objecting to the restraint.

Regardless of the jurisdictional requirements, it is prudent and best practice to ensure that consultation takes place with the carer and/or legal representative prior to a decision to apply restraint. A discussion should be had about what situations the restraint will be used and what protections are being put in place to limit negative consequences of the use of restraint. If appropriate consent has not been obtained and there is not an urgent need for the use of restraint to protect a person from serious harm, restrictive practices can be considered assault, false imprisonment or detinue (withholding a person's possessions).

Assault, false imprisonment and detinue are unlawful unless one of the following legal defences exists:

- informed consent by the person with a full understanding and comprehension of the situation
- consent by a guardian with a restrictive practices function
- self-defence where the person believed on reasonable grounds that it was necessary selfdefence to restrain the other person. For example, holding the arms of a person who is about to hit you or someone else, but not if there is a clear opportunity to get away
- necessity where it was believed on reasonable grounds that it was necessary to do what was done to avoid death or serious harm. For example, grabbing someone who is about to walk in front of a car

It is best practice to ensure that consultation takes place with the carer and/or legal representative prior to the decision to apply restraint. In an emergency situation this may not be possible immediately but should be done as soon as possible. Jurisdictional variations in guardianship legislation govern the roles of proxy decision-makers in giving consent to restraint on behalf of people unable to give informed consent themselves (Department of Health and Ageing, 2012).

## **PSYCHOTROPIC MEDICATIONS**

#### What are Psychotropic Medications?

Psychotropic medications are medicines that cross the blood brain barrier and act on the central nervous system to affect perception, mood, consciousness, cognition and behaviour. Psychotropic medications include antidepressants, antipsychotics ('typical' and 'atypical'), sedatives, anticonvulsants and sex hormones. For the purposes of this review it will exclude cholinesterase inhibitors.

#### **How Common is Their Use?**

The reliance on medication to treat BPSD is common. A study of psychotropic medication use in Sydney nursing homes in 2009 found that 47.5% of residents were being prescribed psychotropic medications, including 28% who were receiving antipsychotic medications. Importantly, compared to an earlier audit by the same group in 2003, regular use of antipsychotic medication had increased by about 19%, although at a lower mean dosage than previously (Snowdon, Galanos & Vaswani, 2011). Of residents with dementia, up to 80% are regularly taking psychotropic medication (Hosia-Randell and Pitkälä, 2005). It is notable that there is wide variability in rates of antipsychotic medication use between facilities (Rochon et al., 2007; Hyojeong & Whall, 2006) attesting to the environmental and psychosocial contributions to the causes of BPSD and the suggestion that the use of psychotropic medications is neither inevitable, nor necessary in many cases.

The National Prescribing Service (NPS), an independent organisation funded by the Department of Health to promote quality use of medications, has noted:

"Analysis of PBS [Pharmaceutical Benefits Scheme] prescription data suggests a high level of inappropriate prescribing of antipsychotics in older people...there is a growing concern that antipsychotics and similar medicines are being overprescribed to people with dementia first line as a means of behaviour control." (National Prescribing Service, 2013).

About half of people in residential aged care facilities and up to 80% of those with dementia are receiving psychotropics, although this varies between facilities. There is evidence to suggest that in some cases these medications are being prescribed inappropriately (Hosia-Randell & Pitkälä, 2005; NPS Health News and Evidence, 2013).

## What are the Symptoms That Psychotropic Medications Treat?

BPSD are symptoms of disturbed perception, thought content, mood and behaviour occurring in people with dementia (Burns et al., 2012). They include agitation, aggression, calling out/screaming, disinhibition (sexual), wandering, night time disturbance, shadowing, swearing, depression, anxiety, apathy, delusions, hallucinations, irritability and elation/euphoria.

Most people with dementia will experience BPSD at some time, with up to 97% of people experiencing BPSD of variable severity during the course of their illness. Symptoms can fluctuate over time with many behaviours occurring episodically and for limited time periods (Selbaek et al, 2014; Brodaty et al., 2001).

These symptoms cause distress to the person with dementia and caregiver alike and are associated initially with increased rates of institutionalisation, and subsequently, with threatened tenure in residential care facilities, higher rates of hospitalisation and complications in hospital, faster rate of decline and increased mortality.

There is often great pressure to "treat" and "cure" these behaviours. Residents in aged care facilities with BPSD are more likely to be physically restrained, receive antipsychotic medication, negatively influence other residents and increase nurse stress and burden (Maslow, 1994; Rodney, 2000; Draper et al., 2000).

BPSD, although variable in severity, are common and affect almost all people with dementia sometime during their illness (Selbaek et al., 2014; Brodaty et al., 2001).

#### What Causes These Behaviours?

Several paradigms have been used to explain BPSD invoking biological, sociological, psychological and environmental causes. These models can help us assess why the behaviour is occurring and how best to intervene.

Possible biological causes of BPSD include structural changes in the brain, depletion of key neurotransmitters and genetic factors. Sudden changes in behaviour can also be caused by delirium – acute changes of cognition as a result of medical illness. It is imperative that any delirium is identified and managed because while it is usually treatable and reversible, it is associated with increased mortality.

There are several psychosocial models used to understand the possible causes of BPSD. One model is based on learning theory and suggests that behaviours of people with dementia are linked to the responses and behaviours of their carers. This theory relies on the ABC model of Antecedents, Behaviour and Consequences and seeks to understand the triggers and reinforcers of behaviours. Alternatively, the Progressively Lowered Stress Threshold model attributes behaviours to a progressive inability to manage stress as dementia progresses, and seeks to facilitate the use of retained skills and a reduction of environmental triggers for behaviours.

The most commonly adhered to psychosocial model of BPSD is the Need-Driven Behaviour model, which proposes that BPSD is a manifestation of unmet needs that are unable to be understood or expressed by the person with dementia. These needs include loneliness, intimacy, hunger, thirst, fear, frustration, cold or discomfort. Physical causes such as pain, acute medical illness and constipation are also important factors that can cause the onset of BPSD, whether mediated through unmet needs or a superimposed delirium.

Environmental factors related to increased rates of BPSD include:

- lower staff-to-resident ratios
- more residents per room
- inadequate training of facility staff and engagement of management staff
- fewer activities to engage residents (Burns et al., 2012).

For people from CALD (Culturally And Linguistically Diverse) backgrounds, difficulty communicating their needs and getting access to translation services and culturally appropriate care may exacerbate behavioural symptoms. This may also make it difficult for care staff to understand the cause of the behaviour and to respond appropriately (Runci, Redman & O'Connor, 2005). For example, a person from a CALD background may become aggressive because they are frustrated that they are not able to communicate or are not understood by care staff.

There is strong evidence that both the care environment and carer expertise/training influences both the emergence and the management of these symptoms (Chenoweth et al., 2009; Brodaty et al., 2003).

BPSD have a range of physical, environmental and psychosocial causes. (Chenoweth et al., 2009; Brodaty et al., 2003)

## What is the Effectiveness of Psychotropics in Treating BPSD?

There have been an excess of 20 placebo controlled trials and several meta-analyses examining the efficacy of psychotropics to treat BPSD. These studies show a small effect size of 0.13 to 0.20 of antipsychotics in particular (Schneider, Dagerman & Insel, 2006; Ballard et al., 2009a). Notably this effect size is smaller than some non-pharmacological approaches to treatment of BPSD.

The only psychotropic listed by the PBS for treating BPSD is risperidone and this medication has the strongest evidence for its effectiveness (the recommended dose ranges from 0.25mg–2mg daily).

Other medications are at times prescribed for treatment of BPSD although they have not been listed by the PBS for this purpose. There are mixed and limited results supporting the use of atypical antipsychotics - such as olanzapine (dose range 5-10mg), quetiapine (dose range 25-150mg), and aripiprazole (5-10mg) and the antidepressant citalopram (dose range 10-20mg) – in patients with agitation and aggression, and some support for antiandrogen or oestrogen drugs and prazosin (a drug used for hypertension and benign prostatic hypertrophy). There is no evidence to support the use of sodium valproate and mixed results for carbamazepine. There is some mixed evidence supporting the use of cholinesterase inhibitors and memantine in particular, for certain BPSD symptoms, and particularly for Lewy Body Dementia (Burns et al., 2012).

These findings were summarised by Professor Subee Banerjee in a report to the Minister of State for Care Services in the UK in 2009:

"Reviewing the evidence, these drugs appear to have only a limited positive effect in treating these symptoms but can cause significant harm to people with dementia. Clearly, some people do benefit from these medications and there are groups (e.g. where there is severe and complex risk) where trials have not been completed but where there may be particular value in using these medications. 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."

Similarly, pharmacological intervention studies of antidepressants in dementia are limited in quality and number, and equivocal in terms of proving efficacy, with several early small studies showing moderate to strong efficacy of antidepressants (Alexopoulos et al., 2005), while more recent studies have shown either no efficacy over placebo or equal efficacy with "usual care" from specialist old-age psychiatry services (Macfarlane, McKay & Looi, 2012; Banerjee et al., 2011). Because these medications are associated with a range of adverse events, most notably sedation, lowered sodium levels, tremor and gastrointestinal and respiratory effects (Banerjee et al., 2011) the potential benefits must be weighed against the risks. Unless the depression is severe, patients with dementia and depression should receive psychosocial interventions in the first instance, followed by consideration of antidepressants if there is no response.

The evidence supporting the effectiveness of psychotropics in treating BPSD is modest at best, with most support for atypical antipsychotics. International data suggests that up to 20% of people with dementia who receive antipsychotic medications derive some benefit from the treatment (Schneider et al., 2006; Ballard et al., 2009a; Banerjee, 2009).

## What are Some of the Possible Consequences of Using Psychotropics?

Most psychotropics, by virtue of their action on the brain, are associated with an increased risk of sedation, falls, urinary tract infection or incontinence, and worsening cognition. Antipsychotic medications specifically are associated with sedation, exacerbation of existing cognitive impairment and confusion, fractures, falls, urinary tract infections, peripheral oedema, gait disturbances and extrapyramidal symptoms ("parkinsonism") and heart rhythm (ECG) abnormalities. The pattern of sideeffects is shaped by the class of antipsychotic drug, and some drugs have a greater or lesser potential to cause anticholinergic side effects, including delirium, constipation and urinary retention, and tardive dyskinesia (abnormal involuntary movements usually of the tongue or mouth). Serious side effects of antipsychotics include increased risk of fracture, stroke and related cerebrovascular events seizures, and hospitalisation (Hien et al., 2005; Katz et al., 2004; Hedges, Jeppson & Whitehead, 2003; Byerly et al., 2001; Schneider et al., 2006; Ballard, 2009b).

The most significant consequence of the use of antipsychotics is the increased risk of death. Deaths related to bronchopneumonia, thrombo-embolic events (including stroke and pulmonary embolism), and sudden cardiac arrhythmias are all significantly increased in people with dementia receiving antipsychotic treatment. An initial meta-analysis completed by the Food and Drug Administration, which has been confirmed by independent analyses, highlighted a 1.5 to 1.8-fold increase in mortality risk for people with Alzheimer's disease receiving antipsychotics, compared with placebo (Schneider et al., 2006; Ballard et al., 2011; Brodaty et al., 2003). A population-based cohort study of nursing homes in the United States found that users of haloperidol had an increased risk of mortality, although this is an association only with no causality proven (Huybrechts et al., 2012).

This data is summarised by Professor Subee Banerjee in his report to the UK Minister of State for Care Services in 2009:

"Summarising the risks and benefits, the data here suggest that treating 1,000 people with BPSD with an atypical antipsychotic drug for around 12 weeks would result in:

- an additional 91–200 patients with behaviour disturbance showing clinically significant improvement in these symptoms
- an additional 10 deaths
- an additional 18 cerebrovascular adverse events, around half of which may be severe
- an additional 58–94 patients with gait disturbance."

Two particular concerns regarding side effect prevention and management are that medications are often managed by care staff who have low knowledge of pharmacology and medication management and are less likely to be able to identify medication-related problems or adverse drug reactions experienced by residents. A second concern arises out of the poor partnerships with carers over consent issues (see below), particularly when decisions are needed to evaluate the risk—benefit ratio for use of these medications for individual residents.

The use of psychotropics is costly in dollar terms given their level of effectiveness. A conservative estimate of the public cost of antipsychotic medications for people with dementia is \$19.1 million per annum (Australian Institute of Health and Welfare, 2012).

Psychotropics have a range of serious side effects including their association with increased mortality for people with dementia and financial cost to the community (Hien et al., 2005; Katz et al., 2004; Hedges et al., 2003; Byerly et al., 2001; Schneider et al., 2006; Ballard, 2009b; Brodaty et al., 2003).

## When Should Psychotropic Medications be Used?

Where there is severe and complex risk of harm to the person and/or others around them, requiring an urgent response, and there is no obvious, easily remediable cause, expert consensus recommends atypical antipsychotics for physical aggression (Alexopoulos et al., 2005).

Pharmacological interventions are also recommended when symptoms are psychotic in nature, when the person with dementia is unresponsive to psychosocial interventions or where residual symptoms are problematic (Burns et al., 2012). Conversely, there are certain symptoms for which medication is not recommended at all. For example, medication is unlikely to be effective in treating wandering, or verbal aggression/screaming.

Psychotropic medications are also an important intervention for pre-existing comorbid psychiatric conditions, such as schizophrenia or bipolar disorder, that predated the onset of dementia.

Clinical guidelines suggest that when psychotropic medications are used, the START LOW, GO SLOW strategy should be used and that there is a need for systematic, sequential trialing one drug at a time with side effects monitored regularly, and the drug ceased immediately if adverse side effects are noted. Since the natural history of BPSD is variable, often intermittent and dependent on the symptomatology, it is recommended that the use of such agents is time-limited and reviewed for their potential discontinuation at least three-monthly (NSW Ministry of Health, 2013).

Discontinuation trials comparing continuous use of antipsychotics with discontinuation found no detrimental effects on behaviour, except for a small group of patients with more severe symptoms (Ballard & Corbett, 2010; Ballard et al., 2008; Devanand et al., 2012; Declercq et al., 2013).

The NPS (2013) makes the following recommendations around the use of antipsychotic medications for people with dementia:

"Manage underlying causes of behavioural and psychological symptoms of dementia and try behavioural interventions. Use an antipsychotic only if aggression, agitation or psychotic symptoms cause severe distress or an immediate risk of harm. Monitor closely when starting therapy to ensure the target behaviour improves and that adverse effects are tolerated. Review the need for continuing antipsychotic therapy within three months and regularly afterwards. Withdrawing antipsychotic treatment may not worsen behaviour."

Psychotropic medications are best used when symptoms are psychotic in nature, where there is severe and complex risk of harm, when psychosocial interventions have been exhausted or where there are comorbid pre-existing mental health conditions (Alexopoulos et al., 2005; Burns et al., 2012; NSW Ministry of Health, 2013).

Clinical guidelines suggest that psychotropics should be used according to the principle of the START LOW, GO SLOW strategy, and trials need to be sequential and systematic, trialling one drug at a time with side effects monitored regularly. Experts recommend that they be used for a limited period only with regular review regarding possible discontinuation, at least three-monthly (NSW Ministery of Health, 2013).

#### What are Some Alternatives to Psychotropics?

Expert consensus guidelines recommend the use of multidisciplinary, individualised care as a first line approach to behavioural symptoms of dementia (Burns et al., 2012; O'Connor et al., 2009; Livingston et al., 2005). See Table 1 (page 14) for an overview of some of the alternative strategies that can be used in responding to BPSD.

A person-centred approach to BPSD has been found to be an effective alternative to psychotropic medications. This approach conceptualises behaviour as a non-verbal communication of feelings, generated by the interplay of neuropathology, personality, life history, medical problems and the interpersonal and environmental context (Cohen-Mansfield 2005; Brooker, 2005; Brooker, 2004). The key to this approach is to identify unmet needs that may be contributing to behavioural symptoms.

For example, assessment and appropriate management of pain is perhaps one of the most crucial steps in treating BPSD. The acknowledged relationship between pain and abnormal behaviours such as restlessness, agitation, aggression and vocalisation, and the difficulties many people with dementia have in reporting pain, mandate a vigilant approach towards pain assessment and proactive prescribing of analgesia (McAuliffe et al., 2009). A randomised cluster trial of a stepped protocol of pain relief for patients with dementia and agitation in nursing homes showed significant reductions in both pain and agitation (Husebo et al., 2011).

The CADRES (Caring for Aged Dementia Resident Study) was a landmark prospective randomised controlled trial comparing person-centred care and dementia care mapping (DCM) with usual care. This study showed a significant reduction in agitated behaviours associated with person-centred care and DCM (Chenoweth et al., 2009). Importantly, person-centred care can only be implemented in environments where there is organisational support for this type of care i.e. a culture conducive to meeting the individual needs of residents rather than being task and schedule-orientated. Nursing home cultures that are conducive to person-centred care promote empowerment and professional growth of staff, and encourage staff to have meaningful engagement with residents and to collaborate in decision-making in regards to patients (Weaver & Peisah, 2013). Residential aged care facility (RACF) managers must echo person-centred philosophies both in their leadership style and approach to resident care, which must be flexible and foster schedules that meet psycho-social needs of residents, rather than being rigidly task-orientated and risk-aversive (Cohen-Mansfield & Bester, 2006; Weaver & Peisah, 2013). An example might be significantly reducing shower frequency in someone who is distressed or frightened of being showered.

A range of other specific psychosocial and environmental interventions have been investigated for treating BPSD. While evidence is limited, there is some support for light massage and aromatherapy (particularly Lavender Oil, Melissa Oil and Lemon Balm), individualised music, animal assisted therapy, individual behaviour therapy, bright light therapy, Montessori activities and humour therapy (Brodaty & Arasaratnam, 2012). Additionally family caregiver interventions, including psychoeducation, can significantly reduce BPSD with effect sizes of 0.34 (Brodaty & Arasaratnam, 2012), which is a larger effect size than has been found with the use of psychotropics.

External experts in behavioural symptoms, including DBMAS can be important in supporting alternative approaches to care. The role of DBMAS clinicians is to provide information and advice on dementia and related behaviour, assessment and diagnosis support and clinical supervision and mentoring of carers and care staff (Burns et al., 2012). These services capitalise on the evidence regarding the positive effects of education provided to residential care staff on BPSD outcome (Livingston et al., 2005).

Expert consensus guidelines recommend the use of multidisciplinary, individualised psychosocial approaches as a first line approach to behavioural symptoms of dementia. There are a range of psychosocial and caregiver interventions that have evidence-based support. Best practice for BPSD treatment is comprehensive, individualised assessment in order to provide person-centred care, with family and professional caregiver education and support (Burns et al., 2012; O'Connor et al., 2009; Livingston et al., 2005; Cohen-Mansfield, 2005; Brooker, 2004, 2005).

## Why are Psychotropic Medications Used as the First Line Approach to Care of BPSD in Some Cases?

Many people with dementia enter residential aged care with a prescription for psychotropic medications already in place (O'Connor, Griffith & McSweeney, 2010). Physicians, nurses and families of older people with dementia are often reluctant to try to stop antipsychotics, fearing deterioration of symptoms. Yet, a recent Cochrane Review that examined the current literature on de-prescribing of antipsychotic medications for people with dementia found that many older people with BPSD can be withdrawn from chronic antipsychotic medication without detrimental effects on their behaviour (Declercq et al., 2013).

There are a range of other barriers that aged care professionals have identified to the use of alternative approaches to caring for a person with BPSD including staff and resource limitations, lack of education and information about alternatives, environmental constraints, policy and management issues, beliefs and expectations (of staff, family and residents), inadequate review practices and communication barriers (Moore & Haralambous, 2007). Lack of understanding about the potential side effects and consequences of use of these medications can also contribute to their use (Agens, 2010). Clinical leadership, adequate resources and staff with appropriate skills have all been found to be essential in the uptake of evidenced-based person-centred approaches to care in aged care facilities (Jeon, Meryln & Chenoweth, 2010).

Professor Brian Draper, Conjoint Professor, School of Psychiatry UNSW, in a recent submission to the Senate Inquiry into the Care and Support of People with BPSD said:

"I am firmly of the view that this long term overuse of psychotropic drugs in residential care is largely indicative of a combination of a number of factors – poor facility design, poorly trained staff, inadequate numbers of staff and lack of suitable activity programs for residents. The behaviours being treated by drugs are exacerbated or indeed at times caused by these issues. Psychotropic drugs are used because GPs and residential care staff can see no other solution."

## What Are Some of the Legal Issues Around Use of Psychotropic Medications?

Informed consent for any type of medical treatment including the use of psychotropics should always be obtained from the person themselves where possible when they are able to give informed consent (O'Neill & Peisah, 2011). If the person is not able to give consent, most jurisdictions require that a prescription of antipsychotics is consented to by a substitute decision maker. This requirement is rarely met (only 6.5% of cases according to a study in NSW) (Rendina et al., 2009). Crucial to the autonomous, dignified and individualised management of people with BPSD is joint decision making involving the prescriber and the person themselves when they can give informed consent, or with their proxy decision maker. The failure to consider issues of consent in using psychotropics in residential care facilities is a phenomenon noted overseas as well (Gurian et al., 1990).

Depending on the jurisdiction, it may be necessary to obtain consent from the tribunal with guardianship jurisdiction (e.g. in NSW the NSW Civil and Administrative Tribunal prior to prescribing hormonal therapy such as anti-androgens).

It should be noted that to date there have been two coronial inquiries in NSW and SA (the South Australian Coronial Enquiry of 2011 into the death of John Arthur Burns (Inquest Number 24/2010 (1389/2006)) which have investigated the relationship between the manner and cause of death of a nursing home resident and the use of psychotropic medications.

Informed consent for use of psychotropic medications should be obtained from the person themselves where possible. Alternatively, if the person is unable to give informed consent, then consent should be obtained from a substitute decision-maker (O'Neill & Peisah, 2011).



#### Recent initiatives to address use of restraint and antipsychotic medications

#### Ministerial Roundtables

Two Ministerial Roundtables of experts (e.g. clinicians, researchers, members of the Ministerial Dementia Advisory Group, aged care representatives, senior people from the Pharmaceutical Benefit Scheme and NPS, consumers, senior Departmental officials, and staff from the Minister's office) on the use of antipsychotic medications were convened by the then Minister for Mental Health and Ageing, Mark Butler MP in August and October 2012. These roundtables led to prioritisation of funding for research on deprescribing through the 2012 Aged Care Service Improvement and Healthy Ageing flexible fund.

#### **Senate Inquiry**

On 28 February 2013, the Senate Committee on Community Affairs commenced an inquiry into the care and management of younger and older people with behavioural and psychological symptoms of dementia. The terms of reference for this inquiry were as follows:

The care and management of younger and older Australians living with dementia and BPSD, including:

- **a.** the scope and adequacy of the different models of community, residential and acute care for Australians living with dementia and BPSD, with particular reference to:
  - 1. Commonwealth-provided support and services
  - 2. state- and territory-provided services
  - 3. services provided by the non-government sector.
- **b.** resourcing of those models of care
- **c.** the scope for improving the provision of care and management of Australians living with dementia and BPSD, such as:

- 1. access to appropriate respite care
- reduction in the use of both physical and chemical restraints.

As of August 2013, the Committee had received 60 written submissions and held two public hearings. Recommendations from the Alzheimer's Australia submission included:

- **1.** The use of physical and chemical restraints in residential aged care should be carefully monitored and regulated through:
  - Public reporting of the rate of use of psychotropic medications and physical restraints in residential facilities on the proposed 'My Aged Care' website.
  - Regulation through the Aged Care Accreditation Agency to ensure appropriate consent procedures are in place for the use of psychotropic medications and physical restraint.
  - A streamlined process through the Aged Care Complaints Scheme for consumers who report the inappropriate use of medications in residential aged care such that a response is required by the 'Scheme' within 3 working days of a complaint being lodged.
- 2. As with the provisions for community care services, individuals with dementia should be eligible for a 10% dementia respite supplement. This additional funding should be used by providers to ensure appropriate care for individuals with BPSD.
- 3. Double the current financial resourcing for DBMAS over the next three years to ensure that the service can adequately support family carers, residential, primary and acute care.

- 4. Ensure that all health workers in the aged care sector have appropriate training in BPSD and non-pharmacological interventions. This should include training on psychosocial approaches to prevent and respond to BPSD in medical student, nursing and allied health academic programs and in all Aged Care Certificate 3 and 4 programs.
- 5. The dementia behaviour supplement in residential care should only be provided to aged care facilities that can document that they are able to provide high quality care for individuals with severe BPSD. This should include:
  - Identifying a person within the facility as the behaviour program coordinator. This person would be responsible for identifying staff training needs, ensuring access to appropriate materials and resources, coordinating access to specialist clinicians with expertise in behaviours and ensuring standards are met.
  - A commitment to using no physical restraint except in cases of immediate danger for self or others and document action taken and how soon the restraint has been removed.
  - Documentation of a comprehensive assessment to identify any untreated medical cause of behaviour and to identify any unmet needs and action taken to address those needs.

The Committee is due to report on 19 March 2014.

#### **Expansion of DBMAS**

The DBMAS aim to improve the quality of life of people with dementia and their carers where the behaviour of the person with dementia impacts on their care and wellbeing. This is achieved through building the capacity of health professionals and carers so they gain increased knowledge and confidence in understanding BPSD and person-centred care principles.

The DBMAS program is being expanded through increased scope and additional funding of \$12.5 million (over five years) under the 2012 Aged Care Reforms.

#### **Restraint Guidelines**

In 2012, the Government provided all residential and community care services with these two new decision-making guidelines: Responding to Issues of Restraint in Aged Care in residential care and Responding to Issues of Restraint in Aged Care in community care.

These guides are designed to help aged care staff to reduce, and ideally eliminate, the need to use restraint. They offer alternatives to using chemical and physical restraint in community and residential settings and emphasise that a restraint-free environment is a basic human right for all care recipients.

#### **National Prescribing Service (NPS)**

The NPS has conducted two targeted programs that address the use of antipsychotic medications in people with dementia. In 2008, more than 13,000 health professionals participated in the Treating the symptoms of dementia program. Similarly, in 2011 more than 13,500 health professionals participated in the Balancing the benefits and harms of antipsychotic therapy.

#### **Research Funding**

There have been three research projects recently funded to address the use of antipsychotic medications. Two focus specifically on antipsychotics and were funded through the second round of the Government's Aged Care Service Improvement and Healthy Ageing Grants Fund. The third looks at deprescribing more generally in residential aged care and is funded through the National Health and Medical Research Council (NHMRC). These projects are three-year projects, and it is unlikely that any results will be published until 2016:

- 1. The University of New South Wales will run a Halting Antipsychotic use in Long Term Care (HALT) project that aims to reduce the inappropriate use of antipsychotic medication in aged care. People in 12-18 high-level RACFs in Sydney will be screened for regular administration of antipsychotics. A liaison GP embedded within each Medicare Local will inform treating GPs of issues around antipsychotic use for older people, particularly increased risk of side effects and alternatives treatments. Relevant staff at RACFs will receive training on responding to behaviours from the project and DBMAS clinicians. Treating GPs will be given a schedule for reducing antipsychotic medication prepared by project pharmacists. The schedule for de-prescribing will vary by participant, but will take place over approximately three months. Data collection will take place before deprescribing (one month and one week prior) and during a twelve month follow-up (three months, six months and twelve months after the start of de-prescribing). The main outcome measure will be use of antipsychotic medications.
- 2. Dr Westbury from the University of Tasmania has received \$3 million from the Department of Health to deliver a program to reduce the use of sedatives in aged care facilities. This program is based on an intervention that was piloted in 25 aged care facilities in Tasmania and found to reduce the use of sedatives by approximately half. It is a multifaceted program that involves collaboration among nurses, carers, pharmacists and GPs. It includes training/information to raise awareness about sedatives, their uses and side effects and is followed by an audit. A list of people who have been on the medications for longer than recommended is developed and input provided to staff, family and the doctor regarding alternative approaches. The program will be rolled out to 150 aged care facilities across Australia (including some Bupa and Southern Cross Care facilities). The NPS is also involved in the program.
- 3. The third project on de-prescribing was funded through the NHMRC. A randomised controlled trial of de-prescribing to optimise medical therapy for frail older people: the Opti-Med study. This project led by A/Professor Christopher Eltherton-Beer will determine the safety and benefits of reducing the number of medications prescribed to frail older people in RACFs. Researchers will withdraw as many medications as possible from participants in the intervention group. The study will provide randomised controlled data on the safety and efficacy of ceasing medications in frail older people (including antipsychotic medications).

#### Alzheimer's Australia's Ongoing Work

Alzheimer's Australia has been working to raise awareness around the use of antipsychotic medications over the past several years including through:

- A Parliamentary Friends of Dementia Event in 2011 with Professor Gerard Byrne
- Hosting Professor Sube Banerjee to conduct a seminar series in 2012
- Involvement in the Ministerial Roundtable on the use of antipsychotic medications
- Raising the issue in submissions including the recent Senate Inquiry into BPSD
- Including it as an action item in the Alzheimer's Australia Fight Dementia Campaign – Election 2013 document
- Advocating for rates of antipsychotic medications to be included as a quality indicator for RACFs (through involvement on aged care implementation subgroups through the National Aged Care Alliance).

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National Consumer Summit Younger Onset Dementia Communique. February 2009

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Younger Onset Dementia: A New Horizon, National Consumer Summit March 2013

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