CARING FOR PEOPLE WITH DEMENTIA EXPERIENCING BEHAVIOURAL & PSYCHOLOGICAL SYMPTOMS

CONTENTS

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Chapter Author(s): Dimity Pond, Jill Phillips, Jenny Day and Karen McNeil

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1. Key Messages

- Brain changes during dementia can lead to expression of behavioural and psychological symptoms of dementia (BPSD). These symptoms are an expression of the person's dementia rather than the person themselves and vary with dementia type and stage of the condition.
- BPSD affects most people with dementia at some time during their condition and can present in a multitude of ways. The severity and nature of BPSD varies.
- BPSD is independently associated with poor outcomes, including institutionalisation, reduction in patient and carer quality of life and carer burnout.

Assessing BPSD

- Multiple BPSD aetiologies commonly co-exist, leading to interrelated/mixed expressions of BPSD.
- Immediate and ongoing risks to the person, carer or others from BPSD should be assessed without delay, considering medical and psychosocial/environmental factors and the potential impact of abuse/neglect.
- To exclude clinical causes for BPSD the person should be initially assessed for clinical conditions, including history, physical examination and medications. Physical causes should also be excluded (e.g. hunger, thirst, fatigue).
- Changed behaviours, triggers, precipitating contexts and ensuing consequences should be identified. Analysis of behaviours informs the GP's understand the person's expression of BPSD and identifies target symptoms for management strategies.
- BPSD should be systematically re-assessed to inform ongoing symptom and impact management: for the person with dementia, carers/family and health care team.

- Specialist BPSD assessment/advice should be utilised when symptoms remain poorly managed/beyond the capacity of management strategies in primary care.

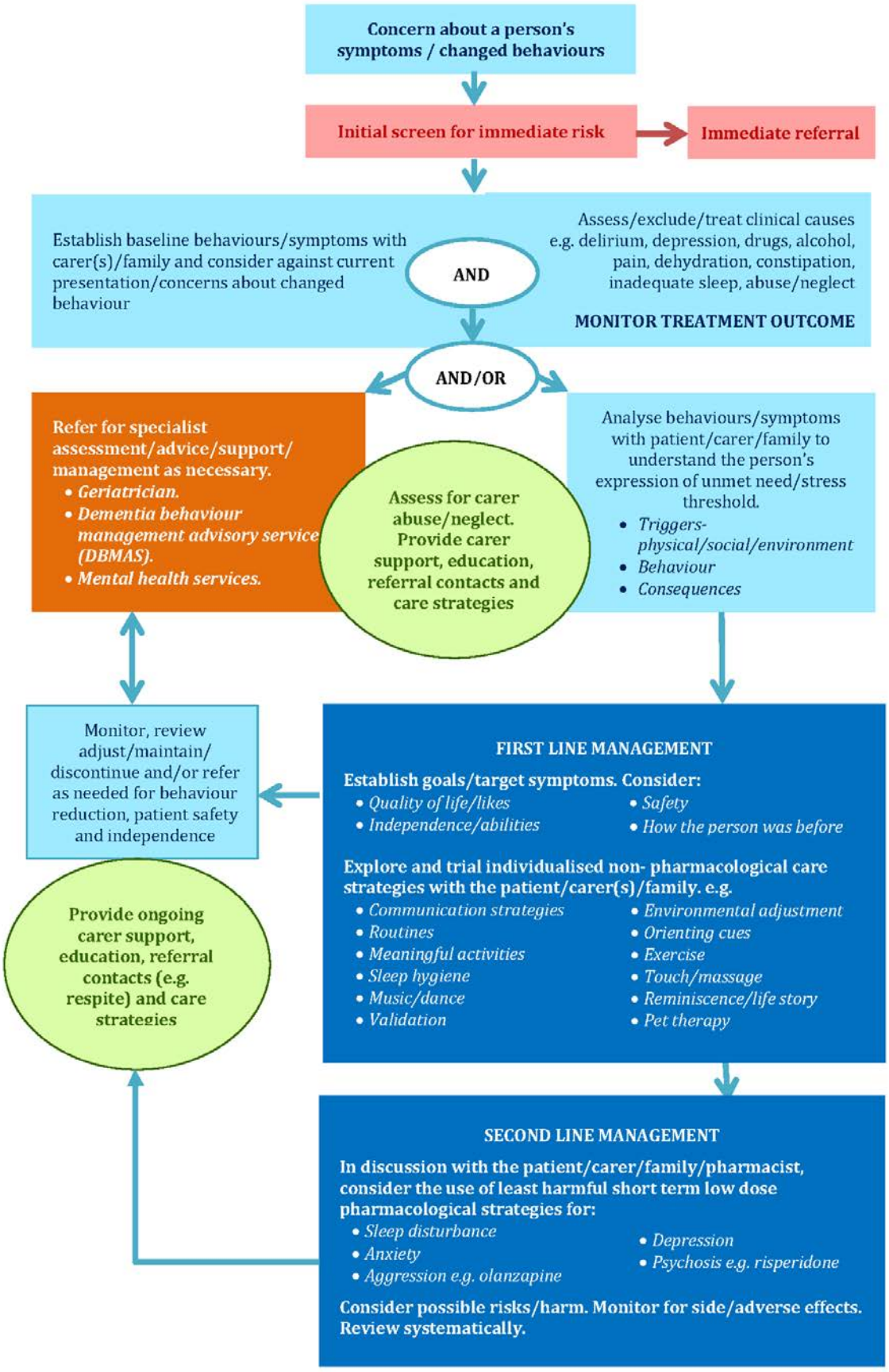
Managing BPSD

- The rights of the person with dementia should be recognised, respected and protected. Where the person with dementia is unable to engage in decision-making an appropriate alternative decision maker should be identified for decisions concerning BPSD management (see Advance Care Planning information and literature review available at https://cdpc.sydney.edu.au/research/care-service-pathways/primary-care-consensus-guide/).
- Underlying causative clinical/physical conditions should be treated as a priority. Treatment outcomes should be monitored, and treatments revised as required.
- Urgent and/or ongoing mental health conditions should be managed or referred to appropriate mental health services.
- After addressing immediate risks, BPSD care strategies should be identified in collaboration with carers/health care team members. Initially, practical non-pharmacological strategies that respond to the needs expressed by the behaviour and complement the retained abilities of the person with dementia should be negotiated with care providers.
- Strategies should target identified behaviours/triggers and maximise the person's quality of life, balanced against risks and safety concerns. Environmental modification/simplification should be considered.
- Carer education in BPSD and care strategies/optimising the environment should be provided. Resources, referral and support should also be provided to match individual circumstances. Carer respite should be considered and offered as indicated.
- Pharmacological strategies should be considered after unsuccessful trial/inappropriateness of non-pharmacological management. The use of medications for BPSD should be consistent with evidence-based guidelines

and occur in consultation with the person and their carer. The least harmful medication and the lowest dose should be used for the shortest period of time. Medication use must be systematically and regularly reviewed. Where no efficacy is observed, medications must be discontinued.

- BPSD management should be systematically followed-up with the person, carers and care team members and adjusted as BPSD change. Care strategies may need to be tailored as any one strategy may work to different degrees in different circumstances. Carer distress and coping should also be monitored and addressed.

2. Caring for patients with BPSD flowchart



3. Practice Points - What Can I Do?

a) Underlying principles of care of people expressing BPSD

- Recognise and protect the rights of people with dementia expressing BPSD.
- Aim to maximise the quality of life and safety of the person with dementia within the least restrictive environment.
- Recognise that behavioural symptoms may be a form of communication and due to a range of perceptual and cognitive issues.
- Recognise the impact of BPSD on the person with dementia and their carer(s).
- Collaborate with those affected by the expression of BPSD to manage BPSD, using a person centred approach.[3]
- Communicate with the person, carers/family and community members about BPSD using the terms 'changed behaviours' and 'expression of unmet needs' (see the Dementia Australia Language Guidelines at https://www.dementia.org.au/resources/dementia-language-guidelines). Use of these terms promotes inclusive, respectful, appropriate and non-stigmatising language.[4]
- Systematically follow-up BPSD management with the person, carers and care team members and adjust as symptoms change. Carer distress and coping should be monitored.
- Minimise the emergence of BPSD by providing assistance to identify the contributing factors to the behaviours that impact on the quality of life for the person with dementia, and their care (for example, referral to Dementia Support Australia (DBMAS) https://dementia.com.au/services/overview, Dementia Australia https://www.dementia.org.au, local specialist services and/or Allied Health Professionals). Assistance should include:
    - delivering tailored behavioural therapies and regimes which involve events the person with dementia finds pleasant;
    - problem-solving BPSD; and
    - optimising the environment of the person with dementia.[5]

b) Assessing the person's BPSD

Assess for immediate and potential risks posed by BPSD

- Assess degree of risk considering biological and psychosocial/environmental factors, such as:
    - acute health/medical deterioration (see Assess the person clinically);
    - physical changes (e.g. self-injury as a result of physical aggression);
    - risks to carer and others (psychological/physical); or [3].
    - mental health issues (e.g. depression, suicidal ideation, anxiety, psychotic symptoms).
- Consider pharmacological management if a high physical risk situation is evident. See Appendix 1 for guidance in the required process. Ensure your own/carer safety and that of others around. Avoid arguing or attempting to reason with the person expressing BPSD.[3]
- Urgently refer to a psychogeriatrician/psychiatric emergency/crisis team or hospital emergency department when the person with dementia is placed at risk due to suicidal thoughts, severe depression or is acting on delusions/hallucinations.
- Refer immediately to local geriatric services or the emergency department where management of symptoms is inappropriate/unmanageable in primary care.

Assess the person clinically

- Assess the person for clinical changes that may cause BPSD, particularly when the onset of symptoms has been abrupt or uncharacteristic for the person. Include:
    - physical health problems (e.g. infection, dehydration, constipation, delirium, pain, inadequate sleep, abuse/neglect);
    - medical comorbidities; and
    - medication review.

Assess the person's changed behaviours

- Assess BPSD symptoms and triggers. BPSD often includes disturbances or changes in mood or emotion, thinking, perception, motor movement and personality.[3, 5] Examples are listed below.

Symptoms	Triggers	
Psychological Anxiety Depression Psychosis	Delirium Physical illness Trauma Excessive noise/stimulation Constipation Medication Lighting (too light/bright) Dehydration Depression Confusion Hunger or thirst Fear Excessive demands	Hot or cold Anxiety Cultural or social issues Loneliness Grief Lack of structure/daily routine Boredom Pain Distressing behaviour of others Fatigue Behavioural response of others
Behavioural Aggression Apathy Agitation Disinhibition* Wandering Nocturnal disruption Vocal disruption		

Adapted from [3, 5, 6]

*Note: disinhibition may be due to a range of cognitive problems, for example poor memory and not remembering where the toilet is, apraxia and not being able to mobilise motor planning to get to the toilet, or agnosia and not recognising the toilet even when it is there.

- Assess for psychosocial factors impacting on the person and their expression of BPSD, including:
    - the characteristics of the person with dementia (e.g. personal and psychological history, cultural background, migration and language);
    - the characteristics of the carer(s) and care relationship (e.g. how the relationship was prior to the diagnosis of dementia, roles, attitude to caring for the person with dementia, ability to provide care, including the risk of abuse); and
    - the care environment (e.g. physical, social, cultural).
- Identify target behaviours, the precipitating context/triggers and ensuing consequences to enable management strategies to be based on this analysis and care priorities.[6]

c) Management of the person's BPSD

Based on assessment and analysis of BPSD, the Antecedents-Behaviour-Consequences (A-B-C) approach suggests that it is helpful to identify and implement strategies that address target behaviours, the precipitating context/triggers and ensuing consequences.[3, 5, 7, 8] Strategies should be developed with the person and their carer/health care team and focus on the retained abilities of the person with dementia and quality of life.[3]

> The resident with dementia was wanting to attract the attention of the visiting guitar player, behaviour that was disruptive and prevented other residents from enjoying a guitar player's performance. To address the behaviour and meet the resident's needs, the RAC staff took the resident out into the garden, which she loved, about 15 minutes before the guitar player arrived. She was given a cup of tea and a biscuit and brought back in just in time for lunch, by which time the guitar player had finished for the day.
> **(BPSD analysis & strategy example from a GP consultation group member)**.

d) First Line Management

Trial non-pharmacological strategies initially

- Non-pharmacological approaches are favoured for sub-acute and long-term care of the BPSD. Where possible offer multicomponent interventions and individualised support for the person with dementia, preferably involving activities they enjoy.[9] Interventions that appear most beneficial include:
    - for depression and/or anxiety - music therapy, reminiscence therapy, support and psychotherapy;

> A pre-recorded playlist of a person's favourite music can be offered to the person when a carer, from experience, knows that the person becomes increasingly anxious/agitated or they identify that the person's mood has lowered. Listening to personally meaningful music has a positive impact on wellbeing.[1]
> **(Strategy Example – Personalised Playlist)**.

- for people experiencing agitation – therapies including massage, dancing, music or reminiscence, behavioural management intervention programs.[9]

> A Life Story book can be on hand and shared with the person when showing initial signs of agitation. Sharing the life story with the person helps them to reminisce and connect with who they are and the person reminiscing with them. A person who is becoming agitated from increased stimulation in their environment can be guide to a quiet place and asking them to tell you about an aspect of themselves from the book. The conversation follows the person's lead and focuses on them.
>
> Life stories are a collection of images and brief information about the person with dementia. It often starts with pictures of the person and a brief positive history of the person – one which avoids topics or images known to be distressing.[2]
> **(Strategy Example – Life Story Book and Reminiscence)**.

- Whilst exercise may not directly reduce expression of BPSD, a relationship has been shown between exercise and higher levels of independence in activities of daily living (see https://cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/). A regular simple exercise regime such as a 20-30-minute walk, five or more days a week, appears to benefit both the carer and the person living with dementia.[10]

Provide carer/family support - practical strategies and referral

- Provide the carer with practical strategies that will assist them in caring for a person expressing BSPD. For example:
    - Should the person with dementia begin to get agitated or upset, acknowledge their view rather than arguing a point. Walk away for a few minutes if safe to do so or divert attention to an enjoyed activity (e.g. having a cup of tea or walking in the garden together). However, always ensure personal safety and have a safety plan in place.
    - Use communication strategies (see Communication chapter) such as making one point at a time.

- Provide visual and other cues to assist the person with their daily routine.
- Keep the environment quiet, reducing background noise and avoid overstimulation.
- Provide care in a relaxed manner, while allowing the person to do simple things for themselves.
- Encourage the person to be involved in an activity that is meaningful and of interest to them, in terms of premorbid interests.
- Notice sudden changes in behaviour and look for a reason (e.g. pain, dehydration, constipation or infection).
- Consider utilising carer respite.

- Refer the carer to resources about BPSD and management strategies. Options include:
  - Dementia Support Australia (now incorporating the Dementia Behaviour Management Advisory Service (DBMAS)) provides clinical support to professionals and family carers of someone showing BPSD, including at home. Details about this support service and eligibility can be found at https://dementia.com.au/services/overview or by contacting the 24-hour helpline (1800 699 799).
  - A Guide for Family Carers: Dealing with Behaviours in People with Dementia (http://www.dementiaresearch.org.au/bpsdguide.html).[11]
- Reassess the person's BPSD and management strategies with the person and carer/health care team regularly and adjust as BPSD changes. In residential care, GP contribution to the care plan for the person may be beneficial (e.g. by suggesting urinalysis if behaviour is unusual).

e) Second Line Management

Pharmacological strategies

- Pharmacological strategies should be provided after unsuccessful trial/inappropriateness of non-pharmacological management.

- The introduction of medications for BPSD should occur in consultation with the person and their carer/health care team.[9]
- The least harmful medication should be used for the shortest period of time. Ensure that the lowest dose is used.[5, 12](Refer to Appendix 1 for evidence-based guidance).
- People with dementia experiencing agitation should have a trial of specific serotonin reuptake inhibitors (SSRIs) with the strongest evidence being for citalopram.[9]
- Because of increased risk of cerebrovascular events, antipsychotic medications should be used with caution and monitored for adverse effects. In addition, the antipsychotic use risks severe untoward reactions in people who have Dementia with Lewy Bodies.[9]
- Medication use must be systematically and regularly reviewed. Where no efficacy is observed, medications should be discontinued, and a new management plan developed and monitored in collaboration with the person and the carer/health care team.

f) Resources for GPs

- Utilise dementia and BPSD resources to enhance GP understanding, assessment and management of BPSD. Options include:
    - Behaviour Management: A Guide to Good Practice – available through the Dementia Centre for Research Collaboration (DCRC)[3] (http://www.dementia.unsw.edu.au/researchers.html?view=dcrc&layout=project&pid=258.).
    - A Clinician's Field Guide to Good Practice: Managing BPSD[13] (http://dementiakt.com.au/resource/bpsd-guide-clinician/).
    - The Australian Government's Better Access to Mental Health Care initiative is available to patients with dementia living in the community who have an additional clinically diagnosable mental disorder, such as depression, anxiety disorder, panic disorder or alcohol use disorder. This initiative is NOT available to people with dementia or delirium alone, and no other mental disorder. The full list of disorders covered

by this initiative can be found at this site https://www.psychology.org.au/for-the-public/Medicare-rebates-psychological-services/Medicare-FAQs-for-the-public. Services covered by this program include assessment and therapy provided by eligible psychologists, social workers and occupational therapists.[14]

- Credentialed mental health nurses can provide services, under a chronic disease management plan.
- From 2019, mental health services can be provided in residential aged care. The Residential Aged Care initiative is accessed through Primary Health Networks (PHNs). Further information is available from local PHNs and from https://www.health.gov.au/internet/main/publishing.nsf/Content/2126B045A8DA90FDCA257F6500018260/$File/11PHN%20Guidance%20-%20Psychological%20treatment%20services%20in%20Residential%20Aged%20Care.pdfthis Department of Health document.
- Severe Behaviour Response Teams https://dementia.com.au/services/overview GPs can make referrals to this service which is for people living in residential care, where there is evidence of risk, and behaviours are defined as severe.

4. Literature Review

Behavioural and psychological symptoms of dementia (BPSD) are an important and major group of non-cognitive dementia symptoms [15] which are experienced by most people with dementia at some stage, including prior to diagnosis.[5] Estimates indicate that up to 97% of all people with dementia are affected by BPSD at some point, contributing to reduced quality of life of patients and carers, carer burnout and institutionalization of the person with dementia.[5]

As the term BPSD denotes, behavioural and psychological symptoms of dementia are expressions of the condition rather than the person.[6] As well as being caused by the brain changes associated with dementia, these symptoms may occur because of physical health issues, or because the person with dementia is unable to communicate needs in other ways. Environmental factors may also be contributors.[5, 6] Hence the person should not be labelled through use of terms such as 'wanderer' 'wetter' or 'screamer'.[4] In addition, although BPSD remains an accepted term in clinical contexts, when communicating with patients, carers/family and community members the terms 'changed behaviours' and 'expression of unmet needs' are recommended by the Dementia Australia Language Guidelines (https://www.dementia.org.au/resources/dementia-language-guidelines).[4] These alternative terms promote inclusive, respectful, appropriate and non-stigmatising language.[4] Other terms for BPSD include responsive behaviours, behaviours of concern, challenging or difficult behaviours and non-cognitive or neuropsychiatric symptoms of dementia.[3]

a) BPSD types

BPSD can present in a multitude of ways but often includes disturbances or changes in mood or emotion, thinking, perception, motor movement and personality. Behaviours may include: depression, anxiety, apathy, agitation, aggression, hoarding, disinhibited behaviours, nocturnal disruption, wandering, sleep or appetite changes and vocally disruptive behaviours. It can have different degrees of severity within stages of disease progression.[3, 5]

BPSD can be grouped into four main subtypes: physical aggression (e.g. hitting, kicking, biting); physical non-aggression (e.g. pacing or inappropriately handling

objects, apathy, depression); verbal aggression (e.g. yelling, cursing or screaming); and verbal non-aggression (e.g. constant repetition or requests).[7]

b) Pathogenesis and aetiology

Whilst a clear pathogenesis for BPSD is yet to be described, it is thought to be multi-factorial (psychological, social, biological). The role of neurochemical, neuropathological, and genetic factors have been considered in recent studies.[15]

Several types of theoretical models have been proposed to aid understanding of the aetiology of BPSD and guide management: those referring to unmet physical or psychological needs; models based on behaviour, reinforcement and learning; and those that assume that changed behaviours arise from a lowered threshold to stress and a heightened sensitivity to environmental stimuli.[5, 7]

Each model is described below (see Non-pharmacological and psychosocial care strategies).

c) Principles of care

Knowing as much about the person with dementia as possible (e.g. collecting a social history) is vital, as health and life experiences may contribute to behaviour.[3] In addition, Robinson and colleagues note that "caring for people with dementia in primary care requires the same systematic approach as used for the management of other long-term conditions".[16(p657)]

In primary care, each of the following principles should apply to managing the care of people expressing behavioural symptoms.

- Recognise and protect the person's rights.[3]
- Aim to provide an optimal quality of life within the least restrictive environment, while maintaining safety.[3]
- Recognise that behavioural symptoms may be a form of communication and arise from a range of perceptual and cognitive issues.[3]
- Use a patient-centred/individualised care approach.[3] This holistic approach to management considers the individuality of the person with dementia, rather than focussing on the disease or the tasks involved in care. It emphasises the

perspectives, experiences and needs of the person with dementia, considers their retained abilities and highlights the importance of maintaining independence.[16, 17] It incorporates:

- person- and behaviour- specific strategies tailored to the individual situations as these tend to be the most effective.[3, 8] Without this personal perspective, care may be little more than guesswork and BPSD may continue [18];
- recognition of each person's uniqueness, values all human lives regardless of age or cognitive ability; takes the perspective of the person with dementia to understand their world as much as able; encourages a positive social environment where the person with dementia can experience relative well-being [18, 19];
- a relational aspect of care which preserves the person who has dementia's sense of self through day-to-day interactions with others which become increasingly important for them [18]; and,
- includes positive interactions between the person with dementia and their carer, as a common basis of many interventions.[8]

- Recognise the impact of BPSD on the person with dementia and their carer(s)/family.
- Collaborate with those affected by the expression of BPSD to manage BPSD.
- Aim to minimise the emergence and impact of BPSD through carer education by educating carers to:
  - deliver behavioural therapies and regimes involving events the person with dementia finds pleasant;
  - problem-solve; and
  - optimise the environment of the person with dementia [5]; and
- Use systematic follow-up of the person with dementia and their carer in to re-assess BPSD and management strategies.[16]

d) Non-pharmacological and psychosocial care strategies

The diverse aetiology of BPSD challenges generic approaches to managing and treating these symptoms. Further, it is common for multiple aetiologies to co-exist and hence interrelated/mixed expressions of BPSD to present simultaneously.[20] Hence, a therapy or intervention effective in one set of circumstances may not be effective in another. Consequently, psychosocial interventions have only been found to have a modest influence when applied as a generic treatment for BPSD.[3]

Non-pharmacological approaches are favoured for sub-acute and long-term management of BPSD.[5, 12] Gauthier and colleagues' review of the literature, consequent to an 'Expert Roundtable Meeting', indicates that broad approaches to management of BPSD include: psychosocial/psychological counselling, interpersonal management, and environmental management.[5] Psychological therapies to reduce BPSD include: relaxation training, learning theory approaches, reminiscence groups and massage therapy.[5] Educating carers to deliver behavioural therapies and regimes involving pleasant events or carer problem-solving has shown some benefits. The provision of carer education, suitable activities and optimising the environment of the person with dementia may avoid emergence of BPSD.[5]

To appreciate the rationales for different non-pharmacological and psychosocial interventions, an understanding of the broad theoretical frameworks applied to conceptualising BPSD is helpful. As noted previously, these models include the 'unmet needs model', 'an environmental vulnerability/reduced threshold model' and 'a behavioural/learning model'.[5, 7] The different models may be complementary but they are not mutually exclusive.[7]

Unmet needs model

This model argues that BPSD may emerge in people with dementia when they are unable to articulate their needs and, consequently, react to adverse situations (e.g. physical or emotional pain or discomfort) with behaviours disturbing to others.[5, 7] For instance, an impaired ability to self-soothe may be displayed as yelling, shouting, or cursing.[5, 7] Such changed behaviours arise from normal physical, emotional and social human needs which have gone unrecognised or unaddressed by carers.[7, 8] It is important to consider neurological, psychosocial, and cognitive background factors, and the impact of the environment on behaviour.[3] Accordingly, providing

activities, sensory stimulation, social contacts, and appropriate treatment for pain are common strategies suggested.[7]

Environmental vulnerability model

The 'environmental vulnerability/reduced threshold' model suggests that BPSD is a response to lowered stress or stimuli thresholds resulting in changed behaviour.[5, 8] For example, reactions of overwhelming anxiety or frustration can be triggered by routine activities such as getting dressed or paying bills.[5] This approach considers that as coping abilities are lost, the environment becomes increasingly stressful for the person with dementia. The management approach is to create an environment of reduced stimulation and relaxation to reduce stress and decrease the expression of BPSD.[7] When analysing assessment information, consider stressors such as external/internal demands that exceed functional capability, change of environment or routine, level of fatigue, affective response to perceived loss – including anger or depression, acute illness, reactions to medications, pain or discomfort.[3]

Behavioural model

The 'behavioural/learning' model considers that environmental triggers and feedback from others, influences and impacts on behaviour. This has led to the Antecedents-Behaviour-Consequences (A-B-C) approach [3, 5, 7, 8] to management, which involves identifying antecedent contributors to the expression of the changed behaviour, and reviewing the consequences, which may inadvertently reward the person (e.g. with attention). From this perspective, an approach to BPSD would be to minimise antecedent triggers (e.g. loneliness, boredom), provide regular positive social attention when the person is not exhibiting changed behaviours and, if possible, ignore changed behaviours when expressed.[5, 7]

Triggers linked to BPSD are diverse. Environmental triggers may include: complex daily routines, low lighting levels, too much noise or stimulation, distressing behaviour of other, confusing surroundings, excessive demands, loneliness or boredom.[5] Aside from health triggers (which may include: hunger, thirst, hot or cold, boredom and tiredness), other factors that may contribute to the expression of BPSD include cultural or social issues (e.g. language, habits, rituals), personal history (e.g. trauma, education, pre-migration and settlement experiences), and the behaviour and response of others.[6]

Addressing anxiety and depression

Symptoms of anxiety and depression are common in people with dementia.[21] In a Cochrane review examining the best way to deliver psychological treatment, psychological interventions based on established models (e.g. cognitive behaviour therapy, interpersonal psychodynamic therapy) and counselling were reviewed.[21] The authors of the Cochrane review found it difficult to draw significant conclusions on optimum treatment delivery because of the small number of studies and high variations in type and duration of treatments. They conclude that psychological treatments added to usual care can reduce anxiety and depressive symptoms in people with dementia.[21] A review by Regan and Varanelli [22] similarly found treatment of depression in older adults with early dementia using problem-solving therapy (e.g. teaching skills to deal with everyday life and handle stressful situations) and modified cognitive behaviour therapy approaches (e.g. an emphasis on behaviour rather than cognitive interventions, such as use of visual cues such as reminder cards) suitably tailored for the person with dementia, may provide opportunities to alleviate depression and adjustment to the condition.[22]

e) Guidelines to manage BPSD

Assessment of the immediate and potential risk posed by the person's BPSD

Burns and colleagues recommend that the degree of risk associated with BPSD be assessed without delay. The risk assessment needs to consider:

- type and severity of the presenting behaviour(s);
- context of the behaviour(s); and
- the resources available within the home/context to manage the situation.[3]

The risk assessment should include identification and assessment of possible biological and psychosocial/environmental causes and influences, such as:

- environmental (e.g. carer's capability; noisy crowded or boring environment);
- medical/mental health issues/comorbidity (e.g. delirium secondary to infection or other cause, constipation, polypharmacy, mental illness). Delirium, physical danger to self and others, and profound mental illness should all be considered a serious risk.[6] Where the person with dementia is suicidal,

severely depressed or acting on delusions/hallucinations in a way that places them or others at risk, urgent referral to a psychogeriatrician/psychiatric emergency/crisis team or hospital emergency department is indicated; and

- physical (e.g. potential physical harm to the person with dementia due to their lack of awareness of exposure to danger; injury to self or others as a result of physical aggression directed at another or at inanimate objects). Where there is a high risk of physical harm/injury, further escalation of behaviours needs to be avoided and all involved protected. Therefore, avoid arguing or attempting to reason with the person with dementia.

Clinical assessment and the person's BPSD presentation

In assessing the expression of BPSD, a broad clinical evaluation is essential prior to specific therapies or care strategies being considered.[20] This is because physical health problems such as infection, dehydration or pain often precipitate BPSD, as described above.[20] The assessment should use a person-centred approach. It should include a medication review to identify medications, such as anticholinergic medications or psychotropics, which may be contributing to symptoms.[23] If there has been an abrupt and significant behavioural change, an underlying medical problem, such as delirium, needs to be excluded.[6]

Psychological causes must also be assessed. Factors that may contribute to expression of BPSD include: depression, fear, anxiety, grief, post-traumatic stress disorder, hallucinations and delusions.[6] Currently in Australia, the GP could consider a Mental Health Plan if the person with dementia has a mental health diagnosis such as depression or anxiety and the person lives in the community. (See section Provide carer/family support).

f) First line management

Trial non-pharmacological approaches initially

Non-pharmacological management strategies for BPSD are widely recommended in guidelines, including the Australian Clinical Practice Guidelines and Principles of Care for People with Dementia which can be found at https://cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/.[9] Although it is acknowledged that the evidence basis is low, these guidelines indicate that:

- music therapy, reminiscence therapy, support and psychotherapy should be considered for depression and/or anxiety;
- interventions for agitation such as massage, dancing, music, reminiscence therapy, behavioural management interventions should be considered; and
- multicomponent interventions involving activities that are enjoyable for the person along with individualised support where possible.

Interventions tailored to the abilities and preferences of the person with dementia appear most beneficial for the well-being of the person with dementia.[9]

Whilst exercise may not directly reduce expression of BPSD, exercise programs have been associated with higher levels of independence in activities of daily living (see Guideline Adaptation Committee [9]). A regular simple exercise regime such as a 20-30-minute walk, five or more days a week appears to benefit both carer and the person living with dementia.[10]

Ideally, non-pharmacological management of BPSD in clinical settings occurs in multidisciplinary teams including occupational therapists.[24] Fraker and colleagues reviewed the role of occupational therapy in dementia care discussing the DICE approach (Describe, Investigate, Create and Evaluate), a clinical reasoning approach to management of BPSD that puts the needs of the person with dementia and their carer first.[24] The role of the occupational therapist was described as "supporting the best functioning of the person with dementia, and providing education and skills training (e.g. communicating effectively, simplifying activities) and support to caregivers".[24(p6)] Areas where occupational therapy could be applied with people with dementia were identified as: "1) activities of daily living (ADLs; e.g., eating, hygiene, dressing, mobility and sexual activity); 2) instrumental activities of daily living (IADLs; e.g., care of others, household management, safety maintenance); 3) rest and sleep"; along with leisure and social participation.[24(p6)] However, an Australian survey of occupational therapists working with people with dementia (included therapists in hospital, community, and residential care) revealed occupational therapist caseloads including only a small number of people with dementia and their carers.[25] Further, 53% of participants were not at all confident, or only a little confident about their current knowledge of occupational therapy in dementia care. Participants indicated most common referrals were for environmental

modification, home assessment for prevention of falls, and functional assessments of daily living.[25] The key finding of their study was that interventions are limited by both organisational factors and logistics, and the time available to devote to care of people with dementia.[25]

Occupational therapy interventions reviewed in the Clinical Practice Guidelines and Principles of Care for People with Dementia[9] included studies which ranged from one to ten consultations. Community occupational therapy programs varied, though common elements included: "carer education and skills training, environmental modification, engagement of the person with dementia in meaningful activities, individualised problem solving and task simplification".[9(p36)]

Provide carer/family support - practical strategies and referral

When people express BPSD, carer stress is increased and the person with dementia is more likely to be admitted to a residential aged-care facility.[26] Dementia Support Australia (incorporating DBMAS) provides practical information to assist carers with management of BPSD, along with a library of varied resources for information and assistance including comprehensive and quick reference guides, resources for Aboriginal & Torres Strait Islanders in remote communities, and psychosocial approaches for responding to BPSD. These resources can be accessed online here http://dbmas.org.au/resources/library/.

BPSD referral and resource options for carers and family members include:

- Dementia Support Australia (https://dementia.com.au/services/overview) (incorporating DBMAS) – this national free service is funded by the Australian Government [27] and provides clinical support for people caring for someone with dementia expressing BPSD which impacts upon their care, including at home. The GP can refer the carer for support via a 24-hour helpline: 1800 699 799.

- The Dementia Centre for Research Collaboration (DCRC): A Guide for Family Carers: Dealing with Behaviours in People with Dementia[11] http://www.dementiaresearch.org.au/bpsdguide.html.

Care options for patients with a mental health condition and expressing BPSD include:

- The Australian Government's Better Access to Mental Health Care initiative is available to patients with dementia living in the community who have an additional clinically diagnosable mental disorder, such as depression, anxiety disorder, panic disorder or alcohol use disorder. Services covered by this program include assessment and therapy provided by eligible psychologists, social workers and occupational therapists.[14] This initiative is NOT available to people with dementia or delirium alone, and no other mental disorder. The full list of disorders covered by this initiative is available at this site https://www.psychology.org.au/for-the-public/Medicare-rebates-psychological-services.

- Credentialed mental health nurses can also provide services, under a chronic disease management plan.

g) Second line management

Consider pharmacological management of BPSD

There is consensus that the management of BPSD needs:

- careful symptom identification;
- identification of implications of the behaviour;
- non-pharmacological approaches trialled first; along with
- use of the least harmful medication for the shortest period of time.[20]

Azermai et al. recommends careful use of antipsychotics for BPSD, and Gauthier et al. recommends use of the least harmful medication for the shortest period of time.[5, 12] Refer to the extract from the Clinical Practice Guidelines and Principles of Care for People with Dementia[9] in Appendix 1 for further guidance.

h) GP resources for management of BPSD

- Behaviour Management: A Guide to Good Practice – available through the Dementia Centre for Research Collaboration (DCRC)[3] (http://www.dementia.unsw.edu.au/researchers.html?view=dcrc&layout=project&pid=258.).

- A Clinician's Field Guide to Good Practice: Managing BPSD[13] (http://dementiakt.com.au/resource/bpsd-guide-clinician/).

5. References

1. Long EM. The effect of a personalized music playlist on a patient with dementia and evening agitation. Annals of Long-Term Care: Clinical Care and Aging. 2016;24(11):31-3.
2. Alzheimer's WA. Creating a life story: A guide for family, friends and support staff. 2017.
3. Burns K, Jayasinha R, Tsang R, Brodaty H. Behavior management: a guide to good practice. Managing behavioural and psychological symptoms of dementia. Dementia Centre for Research Collaboration, University of NSW, Sydney 2012.
4. Dementia Australia. Dementia language guidelines n.d. [cited 2017 April 18]. Available from: https://www.dementia.org.au/resources/dementia-language-guidelines.
5. Gauthier S, Cummings J, Ballard C, Brodaty H, Grossberg G, Robert P, et al. Management of behavioral problems in Alzheimer's disease. Int Psychogeriatr. 2010;22(3):346-72.
6. Department of Health Victoria. Strengthening assessment and care planning: Dementia practice guidelines for HACC assessment services. Melbourne: Victorian Government; 2012.
7. Cohen-Mansfield J. Nonpharmacologic interventions for inappropriate behaviors in dementia: A review, summary, and critique. The American Journal of Geriatric Psychiatry. 2001;9(4):361-81.
8. O'Connor DW, Ames D, Gardner B, King M. Psychosocial treatments of behavior symptoms in dementia: a systematic review of reports meeting quality standards. Int Psychogeriatr. 2009;21(2):225-40.
9. Guideline Adaptation Committee. Clinical practice guidelines and principles of care for people with dementia. NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People; 2016.
10. Lowery D, Cerga-Pashoja A, Iliffe S, Thune-Boyle I, Griffin M, Lee J, et al. The effect of exercise on behavioural and psychological symptoms of dementia: the EVIDEM-E randomised controlled clinical trial. Int J Geriatr Psychiatry. 2014;29(8):819-27.
11. Burns K, Eyers K, Brodaty H. Dealing with behaviours in people with dementia – a guide for family carers. Dementia Centre for Research Collaboration, University of NSW, Sydney; 2014.
12. Azermai M, Petrovic M, Elseviers MM, Bourgeois J, Van Bortel LM, Vander Stichele RH. Systematic appraisal of dementia guidelines for the management of behavioural and psychological symptoms. Ageing Research Reviews. 2012;11(1):78-86.
13. Burns K, Jayasinha R, Brodaty H. A clinician's field guide to good practice: managing behavioural and psychological symptoms of dementia. Dementia Centre for Research Collaboration, University of NSW, Sydney; 2014.
14. Australian Government. Better access to mental health care: Fact sheet for patients: Department of Health; 2012 [cited 2017 May 31]. Available from: http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-ba-fact-pat.
15. Cerejeira J, Lagarto L, Mukaetova-Ladinska EB. Behavioral and psychological symptoms of dementia. Front Neurol. 2012;3:73-.
16. Robinson L, Iliffe S, Brayne C, Goodman C, Rait G, Manthorpe J, et al. Primary care and dementia: 2. Long-term care at home: psychosocial interventions, information provision, carer support and case management. Int J Geriatr Psychiatry. 2010;25(7):657-64.

17. Edwards R, Voss S, Iliffe S. Education about dementia in primary care: is person-centredness the key? Dementia. 2014;13(1):111-9.
18. Brooker D. What is person-centred care in dementia? Rev Clin Gerontol. 2003;13(3):215-22.
19. Rosvik J, Brooker D, Mjorud M, Kirkevold O. What is person-centred care in dementia? Clinical reviews into practice: the development of the VIPS practice model. Rev Clin Gerontol. 2013;23(2):155-63.
20. Ballard C, Corbett A, Chitramohan R, Aarsland D. Management of agitation and aggression associated with Alzheimer's disease: controversies and possible solutions. Current Opinion in Psychiatry. 2009;22(6):532-40.
21. Orgeta V, Qazi A, Spector AE, Orrell M. Psychological treatments for depression and anxiety in dementia and mild cognitive impairment. Cochrane Database of Systematic Reviews. 2014;1:CD009125.
22. Regan B, Varanelli L. Adjustment, depression, and anxiety in mild cognitive impairment and early dementia: a systematic review of psychological intervention studies. Int Psychogeriatr. 2013;25(12):1963-84.
23. Ballard C, Corbett A. Agitation and aggression in people with Alzheimer's disease. Current Opinion in Psychiatry. 2013;26(3):252-8.
24. Fraker J, Kales HC, Blazek M, Kavanagh J, Gitlin LN. The role of the occupational therapist in the management of neuropsychiatric symptoms of dementia in clinical settings. Occup Ther Health Care. 2014;28(1):4-20.
25. Bennett S, Shand S, Liddle J. Occupational therapy practice in Australia with people with dementia: a profile in need of change. Aust Occup Ther J. 2011;58(3):155-63.
26. Hungerford C, Jones T, Cleary M. Pharmacological versus non-pharmacological approaches to managing challenging behaviours for people with dementia. Br J Community Nurs. 2014;19(2):72-7.
27. DBMAS. Dementia Behaviour Advisory Service n.d. [cited 2017 April 12]. Available from: http://dbmas.org.au/.

Appendix 1 – Extract from NHMRC guidelines

The following recommendations for strategies to manage BPSD and evidence strength/quality definitions have been extracted from the Clinical Practice Guidelines and Principles of Care for People with Dementia.[9, (ppXIII-XVI)]

Recommendations

Number	Detailed Recommendation
77 PP	Health and aged care staff and carers and family should identify, monitor and address environmental, physical health and psychosocial factors that may increase the likelihood of the person with dementia experiencing distressing behavioural and psychological symptoms. These factors include: • unmet needs (e.g., pain, hunger, need to eliminate, lack of privacy, lack of meaningful activities, communication) • lowered stress threshold (e.g., conflicts or poor communication within the family or between staff, carer stress).
78 PP	People with dementia who develop behavioural and psychological symptoms should be offered a comprehensive assessment at an early opportunity by a professional skilled in symptom assessment and management. This should involve their carer(s) and families as appropriate and include; • analysis of the behaviours (e.g., antecedent [triggers], behaviour description and consequence [ABC approach]), frequency, timing and presentation • assessment of the person with dementia's physical and mental health • their level of pain or discomfort • whether they are experiencing side effects of medication • the influence of religious and spiritual beliefs and cultural norms • physical environmental and interpersonal factors • an assessment of carer(s) health and communication style when interacting with the person with dementia should also be undertaken • understanding the behaviour as a form of communication.
79 PP	People with dementia who develop behavioural and psychological symptoms of dementia should usually be treated using non-pharmacological approaches in the first instance. Pharmacological intervention should usually only be offered first if the person, their carer(s) or family is severely distressed, pain is the suspected cause, or there is an immediate risk of harm to the person with dementia or others (i.e., very severe symptoms). If pharmacological management is used, this should complement, not replace, non-pharmacological approaches.
80 PP	The objective measurement of behavioural and psychological symptoms of dementia should be undertaken using tools with strong psychometric properties and used to monitor the type and patterns of behaviours.

Number	Detailed Recommendation
81 EBR Low	If a person with dementia is suspected to be in pain due to their distress or behaviour, as indicated by responses on an observational pain assessment tool, analgesic medication should be trialled using a stepped approach. The trial should be for a defined time period, particularly if opioids are used.
82 EBR Low	Health and aged care staff should attempt to minimise the impact of behavioural and psychological symptoms of dementia by providing person-centred care (care that is consistent with the 10 Principles of Dignity in Care).
83 PP	Health and aged care staff should be trained to develop individual care plans (in partnership with the person with dementia's carer(s) and family) that provide a clear crises plan to anticipate severe behavioural and psychological symptoms of dementia and how to manage violence, aggression and extreme agitation, including de-escalation techniques.
84 EBR Very low to Low	For people with dementia who also have depression and/or anxiety or agitation, interventions should be tailored to the person's preferences, skills and abilities. The response to each modality should be monitored and the care plan adapted accordingly. Multicomponent interventions that involve engagement in activities that are enjoyable for the person with dementia plus individualised support should be offered where available. Where multicomponent interventions are not available, the following individual therapies should be considered: For depression and or/anxiety: • therapeutic use of music and/or dancing • support and counselling • reminiscence therapy. For agitation: • behavioural management interventions • therapeutic use of music and/or dancing • massage • reminiscence therapy.
85 EBR Low	To assist the carer(s) and family help the person with dementia who is experiencing behavioural and psychological symptoms of dementia, carer(s) and family should be offered interventions which involve: • carer skills training in managing symptoms and communicating effectively with the person with dementia • meaningful activity planning • environmental redesign and modification to improve safety and enjoyment • problem solving and management planning.
86 EBR Moderate	People with dementia who experience agitation should be offered a trial of selective serotonin reuptake inhibitor (SSRI) antidepressants (the strongest evidence for effectiveness exists for citalopram) if non-pharmacological treatments are inappropriate or have failed. Review with evaluation of efficacy and consideration of de-prescribing should occur after two months. The need for adherence, time to onset of action and risk of withdrawal effects and possible side effects should be explained at the start of treatment.

Number	Detailed Recommendation
87 PP	Antidepressant medications with anticholinergic effects (e.g., tricyclic antidepressants) should be avoided because they may adversely affect cognition.
88 EBR Moderate	The role of antidepressants in the treatment of depression in people with dementia is uncertain. Larger trials conducted in people with dementia have not shown benefit (in group data) for antidepressants for treatment of depression per se. Nevertheless, it is considered that those with a pre-existing history of major depression (prior to developing dementia) who develop a co-morbid major depression should be treated in the usual way.
89 EBR Moderate	People with Alzheimer's disease, vascular dementia or mixed dementias with mild-to-moderate behavioural and psychological symptoms of dementia should not usually be prescribed antipsychotic medications because of the increased risk of cerebrovascular adverse events and death.
90 PP	As far as possible, antipsychotics should be avoided in people with Dementia with Lewy Bodies due to the risk of severe untoward reactions, particularly extrapyramidal side effects. Acetylcholinesterase inhibitors could be considered. If antipsychotics are used for severe behavioural and psychological symptoms of dementia, atypical or second-generation antipsychotics with low propensity to cause extrapyramidal side effects should be used; quetiapine and olanzapine are considered to have the best tolerability[5]. Healthcare professionals should use low dosage and closely monitor for adverse effects.

Number	Detailed Recommendation
91 EBR Moderate	People with dementia and severe behavioural and psychological symptoms of dementia (i.e., psychosis and/or agitation/aggression) causing significant distress to themselves or others, may be offered treatment with an antipsychotic medication. Risperidone has the strongest evidence for treating psychosis. Risperidone and olanzapine have the strongest evidence for treating agitation/aggression, with weaker evidence for aripiprazole[5]. The following conditions should also be met: There should be a full discussion with the person with dementia and their carers and family about the possible benefits and risks of treatment. In particular, cerebrovascular risk factors should be assessed and the possible increased risk of stroke/transient ischaemic attack and possible adverse effects on cognition discussed. Target symptoms should be identified, quantified and documented. The effect of comorbid conditions, such as depression, should be considered. The choice of antipsychotic should be made after an individual risk–benefit analysis. The dose should be initially low and titrated upwards if necessary. Monitoring for adverse effects including the metabolic syndrome should occur. If there is no efficacy observed within a relatively short timeframe (usually one to two weeks), treatment should be discontinued. Treatment should be reviewed every four to 12 weeks, considering the need for antipsychotics and possible cessation of medication. Review should include regular assessment and recording of changes in cognition and target symptoms. [5] The only antipsychotic that is currently listed for BPSD on the Pharmaceutical Benefits Scheme is risperidone.
92 PP	Where people with dementia have moderate to severe behavioural and psychological symptoms that puts themselves or others at risk, referral to a specialist service for the management of behavioural and psychological symptoms should occur.
93 PP	Health professionals who use medication in the management of violence, aggression and extreme agitation in people with dementia should: • be trained in the correct use of medications for behavioural control • be able to assess the risks associated with pharmacological control of violence, aggression and extreme agitation, particularly in people who may be dehydrated or physically ill • understand the cardiorespiratory effects of the acute administration of any medications used and the need to titrate dosage to effect • recognise the importance of positioning people who have received these medications in the recovery position and of monitoring vital signs • be familiar with and trained in the use of resuscitation equipment • undertake annual retraining in resuscitation techniques • understand the importance of maintaining a clear airway • be knowledgeable about the laws for informed consent in their jurisdiction.

Number	Detailed Recommendation
94 PP	If medications are necessary for the control of violence, aggression and extreme agitation in people with dementia, oral medication should be offered before parenteral medication.
95 PP	There is a paucity of evidence regarding the efficacy and safety of parenteral medication in behavioural emergencies. However, in certain rare situations, parenteral medication may be required for the management of people with dementia with extreme behavioural and psychological symptoms of dementia. Because circumstances vary from setting to setting, local evidence-based guidelines should be developed to provide clinicians guidance about the appropriate use of parenteral medication in these situations for that setting (e.g., the Handbook for NSW Health Clinicians addressing assessment and management of behavioural and psychological symptoms of dementia [BPSD]).
96 PP	If parenteral treatment is necessary for the control of violence, aggression and extreme agitation, intramuscular administration is preferable because it is safer than intravenous administration. Intravenous administration should be used only in exceptional circumstances. Vital signs should be monitored after parenteral treatment. Health professionals should be aware that loss of consciousness can be mistaken for sleep. If the person appears to be or is asleep, more intensive monitoring is required because of the risk of loss of consciousness.
97 CBR	If parenteral medication is necessary for the control of violence, aggression and extreme agitation in people with dementia, olanzapine or lorazepam are preferred. Wherever possible, a single agent should be used in preference to a combination.
98 PP	People with dementia who have received involuntary sedation should be offered the opportunity, along with their carer(s) and family, to discuss their experiences and be provided with a clear explanation of the decision to use urgent sedation. This should be documented in their notes.

Definitions of types of recommendations

Evidence-based recommendation (EBR) - Recommendation formulated after a systematic review of the evidence, with supporting references provided.

Consensus based recommendation (CBR) - Recommendation formulated in the absence of quality evidence, when a systematic review of the evidence has failed to identify any quality studies meeting the inclusion criteria for that clinical question.

Practice point (PP) - A recommendation that is outside the scope of the search strategy for the systematic evidence review and is based on expert opinion.

Definitions of GRADE ratings of the quality of the evidence

High - Further research is very unlikely to change our confidence in the estimate of effect.

Moderate - Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate.

Low - Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate.

Very Low - Any estimate of effect is very uncertain.[9(pp.IV)]

Appendix 2 – Evidence summary for chapter

Evidence summary for literature reviews

Reference Country	Study design/ Level of evidence	Sample characteristics (n=)	Intervention	Comparison	Results/findings	Quality appraisal*^
Azermai et al. (2012) **Belgium**	Systematic appraisal of dementia guidelines for BPSD management	Clinical practice guidelines on the management of dementia with attention to BPSD (n=15)	Clinical practice guidelines assessed using the AGREE instrument. Five clinical practice guidelines appraised as high quality were used to extract specific recommendations. It was noted that the AGREE instrument judges the overall quality of the guideline focusing on the development process; not the quality of the guideline's recommendations.	NA	From the 5 guidelines, specific practice recommendations (n=18) were extracted and compared to their level of evidence and strength. No agreement found for most of specific practice recommendations re non-pharmacological interventions, though these recommended as first-line of treatment. Pharmacological practice recommendations, second-line treatment, agreed for the use of a selection of antipsychotics based on supporting evidence, but with guidance for timely discontinuation. Nine key practice recommendations were identified.	1. Y 2. Y 3. Y 4. Y 5.N 6.Y 7. Y 8. Y 9.CA 10.Y 11. N
Ballard & Corbett (2013) **UK**	Non-systematic literature review of the current evidence for pharmacological & nonpharmacologic-al approaches to the treatment of agitation and aggression in people with dementias.	NA	NA	NA	There is a growing body of literature supporting the use of nonpharmacological approaches plus the treatment of pain as a first-line management strategy before psychopharmacotherapy. The best approach to manage these symptoms is within a framework that promotes prevention, monitoring and the use of nonpharmacological alternatives, with judicious short-term use of antipsychotics, when appropriate.	1. NA 2. CA 3. CA 4.N 5.NA 6. N 7.NA 8.NA 9.NA 10.NA 11.Y

Reference Country	Study design/ Level of evidence	Sample characteristics (n=)	Intervention	Comparison	Results/findings	Quality appraisal*^
Ballard et al. (2009) **UK**	Non-systematic literature review describing the current state of knowledge re management of BPSD, particularly agitation	Tabled randomised controlled trials (RCT) studies (n=6) for non-pharmacological treatment of agitation and aggression in people with dementia; and Tabled studies (n=25) for pharmacological treatment of agitation and aggression in people with dementia.	NA	NA	Reported: increasing evidence to support the value of simple psychological interventions and staff-training programs as first-line management for agitation prior to pharmacotherapy; atypical antipsychotics most widely prescribed pharmacological treatment with modest by significant benefit in short-term treatment of aggression, limited benefits in longer term therapy; increasing concerns re side-effects of pharmacological treatments. Large prospective randomised, placebo-controlled trials needed to establish the role of drugs other than neuroleptics as clinical therapies for the treatment of BPSD and for studies to evaluate BPSD treatments in non-Alzheimer dementias.	1. NA 2. CA 3. CA 4.N 5.NA 6. Y 7.CA 8.NA 9.NA 10.NA 11.N
Brooker, D. (2003)	Non-systematic literature review describing person-centred care in dementia	NA.	NA	NA	Described different elements of a model of person-centred care and the challenges to achieve this in practice.	1. N 2.NA 3.CA 4.Y 5.NA 6.NA 7.NA 8.NA 9.NA 10.NA 11. N

Reference Country	Study design/ Level of evidence	Sample characteristics (n=)	Intervention	Comparison	Results/findings	Quality appraisal*^
Cohen-Mansfield (2001) **USA**	Non-systematic literature review re non-pharmacological interventions for BPSD	Tabled studies (n=83) on the impact of non-pharmacological interventions. Search criteria: published in a scientific journal; participants aged ≥ 60 years with dementia or cognitive impairment; a measure of the behaviour or of change obtained. Studies were tabled by strategy (e.g. sensory enhancement/relaxation; social contact; behaviour therapy; structured activities)	NA	NA	Research suggests primary targets for interventions are: addressing pain, sensory limitations, sleep problems and limitations on autonomy; provision of social contact; provision of meaningful stimuli or activity; tailoring the intervention to the individual; reduction of stressful stimuli/increasing relaxation during care activities; staff training to improve care.	1.Y 2.NA 3.Y 4.N 5.NA 6.Y 7.Y 8. NA 9.NA 10.NA 11.N
Gauthier et al. (2010) Multinational	Non-systematic literature review re management of behavioural problems in Alzheimer's Disease	Evidence from clinical trials of both non-pharmacological and pharmacological treatments and from neurobiological studies. The Neuropsychiatric Inventory is discussed (utility, future developments, limitations and challenges encountered when quantifying behavioural responses in clinical trials).	NA	NA	No one therapy can address all behaviours; it is critical to understand the cause of the behaviour and utilise this information to formulate a treatment approach for most benefit. A range of management options tailored to individual needs with non-pharmacological interventions (e.g. psychological/psychosocial counselling, interpersonal and environmental management) attempted first. If necessary, follow this withthe least harmful medication for the shortest possible time.	1.Y 2.NA 3.Y 4.N 5.NA 6.NA 7.NA 8. CA 9.NA 10.NA 11.Y

Reference Country	Study design/ Level of evidence	Sample characteristics (n=)	Intervention	Comparison	Results/findings	Quality appraisal*^
O'Conner et al. (2009) **Australia**	Systematic review of experimental studies of psychosocial treatments derived from learning theory, unmet needs and altered stress thresholds paradigms.	Studies (n=25); inclusion criteria: participants had both dementia and significant behavioural symptoms, or seemed likely to have them by virtue of residing in a dementia specific unit or psychogeriatric ward; a treatment was compared to another treatment and/or an 'attention control' condition; random allocation in studies with distinct treatment and control arms; sufficient information for study replication; participant nos. ≥10 (*m*=46.2; range 13 -136); use of cognitive and behavioural measures; some statistical analysis; behavioural measures collected by persons blinded to either the treatment allocation or the study's aims (or, when this was impractical, behaviour measures were generated by a single individual, or multiple individuals with high inter-rater reliability, or through the use of mechanical or electronic counters). Included RCT, randomised cross-over trials and repeated measure designs.	Papers graded using a quality checklist and potentially eligible papers were coded on 9 key selection criteria by a second blinded reviewer (agreement rates 92.6%).	NA	Aromatherapy, bed baths, person-centred bathing, one-to-one social interaction, preferred music, simulated family presence and muscle relaxation therapy all reduced behavioural symptoms better than control conditions. Effects were mostly small to moderate with a short duration of action. Most effective interventions were tailored to individuals' preferences.	1.Y 2.Y 3.CA 4.NA 5.N 6.Y 7.Y 8.Y 9.Y 10.CA 11.Y

Reference Country	Study design/ Level of evidence	Sample characteristics (n=)	Intervention	Comparison	Results/findings	Quality appraisal*^
Orgeta et al. (2014) **UK**	Systematic review of the evidence of the effectiveness of psychological treatments in reducing anxiety and depression in people with dementia and mild cognitive impairment (MCI)	RCTs (n=6), including cluster randomised trials, which included a control group (usual care) or a comparison group receiving no specific psychological intervention; and provided adequate information about study design and results as well as separate data on participants with dementia and MCI if the study was of a mixed population (e.g. also including older adults with normal cognition). Inclusion criteria: older adults diagnosed with dementia, Alzheimer's disease, organic brain syndrome, etc. according to the DSM-IV, International Classification of Diseases-10 (ICD-10), or comparable, and participants with a diagnosis of MCI in any setting (e.g. home, community, institution). Ongoing studies were identified though not included in the meta-analysis.	Psychological interventions designed to reduce anxiety and depression or improve adaptive functioning, or both; were based on a psychological theory (e.g. learning theory); involved a structured interaction between a facilitator and a participant that incorporated psychological methods (e.g. behavioural, cognitive behavioural, family systems). Interventions were facilitated by psychologists, therapists in training, and other trained professionals.	RCTs compared a psychological intervention with usual care or a placebo intervention (social contact control) in people with dementia or MCI.	No studies of participants with MCI were found; studies included people with dementia living in the community or in aged care facilities. Meta-analysis showed a positive effect of psychological treatments on depression (6 trials, n=439, standardised mean difference (SMD) -0.22; 95% confidence interval (CI) -0.41 to -0.03, moderate quality evidence) and on clinician-rated anxiety (2 trials, n= 65, mean difference (MD) -4.57; 95% CI -7.81 to -1.32, low quality evidence), but not on self-rated anxiety (2 trials, SMD 0.05; 95% CI -0.44 to 0.54) or carer-rated anxiety (1 trial, MD -2.40; 95% CI -4.96 to 0.16). Psychological interventions added to usual care can reduce symptoms of clinician-rated anxiety and depression for people with dementia and psychological interventions may improve patient well-being.	1.Y 2.Y 3.Y 4.Y 5.Y 6.Y 7.Y 8.Y 9.Y 10.Y 11. Y

Reference Country	Study design/ Level of evidence	Sample characteristics (n=)	Intervention	Comparison	Results/findings	Quality appraisal*^
Regan & Varanelli (2013) **Australia**	Systematic review of psychological intervention studies	Studies (n=16) of which included seven RCTs and eight pre-post studies. Inclusion criteria: participants met MCI criteria, or mild to moderate dementia, or with cognitive impairment $\geq$ 1 *SD* than normative samples in at least one domain or had been diagnosed with mild-moderate dementia (e.g. Clinical Dementia rating scale < 2). Studies used psychological and social interventions designed to improve mood, or adjustment and quality of life for participants diagnosed with dementia or MCI; described interventions that were predominantly psychological in content or social support with a clear description of the methods used and theoretical approach; included experimental, quasi-experimental, and before-and-after studies published from 1998 onward. Participants were living in the community.	Studies included or excluded using a priori criteria, and upon inclusion the quality of studies was evaluated using pre-set criteria	NA	Of the 16 studies, 15 were considered of adequate quality. Findings suggest individual psychotherapy can lead to small improvements in mood in people with mild-moderate dementia and co-morbid depression – no studies found that focused on MCI.	1.Y 2.Y 3.Y 4.CA 5.N 6.Y 7.Y 8.Y 9.CA 10.CA 11. Y
Robinson et al. (2010) **UK**	Narrative review on the role of the GP in the long-term care of people with dementia living at home considering psychosocial interventions, BPSD, provision of information and carer support and case management	NA. The systematic review done for the NICE/SCIE Guidelines was updated from Jan 2006; Cochrane Reviews identified, and other publications found by consultation with experts.	Papers only included when consensus about their implications for the review themes was attained	NA	Caring for persons with dementia at home requires the same systematic approach as the management of other long term condition and can be structured around: reframing dementia with a focus on a social model of disability; management of BPSD; supporting carers; active use of information sources and a structured case management approach.	1.NA 2.Y 3.CA 4.CA 5.N 6.NA 7.NA 8.CA 9.NA 10.NA 11.Y

Reference Country	Study design/ Level of evidence	Sample characteristics (n=)	Intervention	Comparison	Results/findings	Quality appraisal*^
Rosvik et al. (2013) **Norway**	Non-systematic review investigating person-centred care in dementia	NA	NA	NA	Described the VIPS framework as a four-part definition of person-centred care for people with dementia which was operationalised into a practice model and the use of the model in practice discussed. (VIPS: Value base which asserts the value of all human lives regardless of age or cognitive ability; Individualised approach recognising the uniqueness of the person with dementia; understanding the world from the person with dementia's Perspective; and positive Social psychology in which the person with dementia can experience relative well-being)	1. N 2.NA 3.CA 4.Y 5.NA 6.NA 7.NA 8.NA 9.NA 10.NA 11. Y

Note: * Appraisal criteria from the AMSTAR measurement tool which is a measurement tool to assess multiple systematic reviews (see Shea BJ, Grimshaw JM, Wells GA, Boers M, Andersson N, Hamel C, et al. Development of AMSTAR: a measurement tool to assess the methodological quality of systematic reviews. BMC Med Res Methodol. 2007;7(1):10.). As such, appraising non-systematic literature reviews with this instrument is offered with caution with consideration to the differences between them.
^ Where the above evidence summaries are not systematic literature reviews, the appraisals of these using this instrument were done to give some indication of the evidence reviewed. Later, the JBI Critical Appraisal Checklist for Text and Opinion Papers became available and replaced using the AMSTAR tool this way.
Appraisal items:
1, 'A priori' design provided; 2, duplicate study selection and data extraction; 3, comprehensive literature search performed; 4, the status of publication (i.e. grey literature) used as an inclusion criterion; 5, a list of studies (included and excluded) provided; 6, characteristics of the included studies provided; 7, scientific quality of the included studies assessed and documented; 8, scientific quality of the included studies used appropriately in formulating conclusions; 9, methods used to combine the findings of studies appropriate; 10, likelihood of publication bias assessed; 11, conflict of interest stated.
Ratings:
Yes (Y); No (N); Can't answer (CA); Not applicable (NA)

Evidence summary for text and opinion papers

Reference Country	Objective	Results/findings	Quality appraisal*
Fraker et al (2014) **USA**	Described the role of the occupational therapy (OT) in using the 'DICE' (Describe, Investigate, Create, and Evaluate) approach for BPSD management.	Medications may not impact some of the most common BPSD that are distressing to families and may trigger hospitalisations or residential care placement. Nonpharmacological techniques are currently under-utilized in standard care, but occupational therapists are well-positioned to find the best or just-right fit between the environmental and task demands, and the cognitive ability of the person with BPSD. DICE presents a clinical reasoning approach through which providers may more effectively and efficiently select optimal treatment plans.	1.Y 2. Y 3. Y 4.Y 5.Y (39refs) 6. NA
Hungerford, Jones & Cleary (2014) **Australia**	Described the non- pharmacological approaches taken by a multi-disciplinary team of a Dementia Behaviour Management Advisory Service to support people with dementia who have BPSD.	Improvement in the care and services provided to community-dwelling people with dementia and their carers may be met by teams reflecting together on their practice; appropriate support may reduce the likelihood of early admission to a residential care facility and reduce carer stress; non-pharmacological approaches are suggested; and the risk of adverse side-effects related to antipsychotic medications used to manage BPSD mentioned.	1.Y 2. Y 3. Y 4.Y 5.Y (58 refs) 6. NA

Notes: * Appraisal criteria from the JBI Critical Appraisal Checklist for Text and Opinion Papers – McArthur A, Klugárová J, Yan H, Florescu S. Innovations in the systematic review of text and opinion. International Journal of Evidence-Based Healthcare. 2015;13(3):188-95..

Appraisal items:

1. Is the source of the opinion clearly identified? 2. Does the source of opinion have standing in the field of expertise? 3. Are the interests of the relevant population the central focus of the opinion? 4. Is the stated position the result of an analytical process, and is there logic in the opinion expressed? 5. Is there reference to the extant literature? 6. Is any incongruence with the literature/sources logically defended?

Ratings: Yes (Y); No (N); Unclear (U); Not applicable (NA)

Evidence summary for qualitative studies

Reference Country	Objective	Participants (n=)	Method	Findings	QATSDD score*	Paper No.*
Edwards et al (2014) **UK**	Development of an educational intervention for primary care promoting person-centred responses to people with cognitive decline and dementia.	User and care group: people with dementia (n=3) and carers (n=4) from the Kingshill Research Centre User and Carer Research Group. Health professionals group (n=10): a GP, a RN, a Community Psychiatric Nurse, an OT, an OT technician, a consultant in old-age psychiatry, a drama therapist, a speech and language therapist, a dietician and a research assistant	Two parallel focus groups met three times to develop the content of the intervention and the materials used to deliver it. Data collected was recorded, transcribed and thematic analyses conducted.	Findings were discussed in the context of their contribution to challenge attitudes to dementia in primary care and the positive aspects of person-centred primary care for dementia. Themes identified: Reframing dementia as cognitive decline (Individual level) addressed the stigma that surrounds a dementia diagnosis; triggers for the recognition of dementia (Practitioner level) found memory loss continues to be the commonly recognised symptom and likely the main trigger for GPs to think diagnostically about dementia; engaging the whole primary care team (Practice level) – both focus groups identified that other members of the primary care team other than the GP were well-placed to identify cognitive decline; and the relationship between primary and secondary care (Service level) indicated that health professionals considered GPs would benefit from understanding more about services available and the effects of good secondary care on patients and carers lives.	76%	1

Note: * Appraisal criteria from Sirriyeh R, Lawton R, Gardner P, Armitage G. Reviewing studies with diverse designs: the development and evaluation of a new tool. J Eval Clin Pract. 2012;18(4):746-52.
See QATSDD scoring of qualitative studies overleaf for details

Quality Assessment Tool for Studies with Diverse Designs (QATSDD) scoring of qualitative studies

		Paper No:	1
No.	**Criteria (Scored 0-3)**		
1	Explicit theoretical framework		3
2	Statement of aims/objectives in main body of report		3
3	Clear description of research setting		2
4	Evidence of sample size considered in terms of analysis		1
5	Representative sample of target group of a reasonable size		3
6	Description of procedure for data collection		2
7	Rationale for choice of data collection tool(s)		2
8	Detailed recruitment data		3
9	Fit between stated research question and format and content of data collection tool e.g. interview schedule (**Qualitative only**)		3
10	Fit between research question and method of analysis		3
11	Good justification for analytic method selected		2
12	Assessment of reliability of analytic process (**Qualitative only**)		2
13	Evidence of user involvement in design		3
14	Strengths and limitations critically discussed		0
Total score (max 42):			32
Percentage:			76%

Note: * Appraisal criteria from Sirriyeh R, Lawton R, Gardner P, Armitage G. Reviewing studies with diverse designs: the development and evaluation of a new tool. J Eval Clin Pract. 2012;18(4):746-52.

Key to paper:

1. Edwards R, Voss S, Iliffe S. Education about dementia in primary care: is person-centredness the key? Dementia. 2014;13(1):111-9.

Evidence summary for quantitative studies

Reference Country	Objective	Participants (n=)	Method	Results/findings	QATSDD*	Paper No.*
Bennett et al. (2011) **Australia**	Described Australian OT practice with people with dementia.	Occupational therapists (convenience sample) identified by OT Australia as working in aged care; recruited through dementia-specific facilities in Australia; or through OT aged care list serves (n= 134).	Survey measure which asked about referrals received, assessments and interventions used, perceived educational needs, and perceived barriers to the delivery of interventions. Descriptive data analysis presented as frequencies and percentages.	Most referrals were for: environmental modification, home assessment or falls prevention, and for assessment of activities of daily living. OTs spent most time on assessment (brief cognitive and functional assessments used most frequently); environmental modification advice and prescription of assistive equipment were the most common interventions. The most commonly reported barrier to the delivery of interventions was lack of time. OTs identified concerns about staffing and role restrictions imposed by organisations, and also identified that further training would be useful.	88%	1

Note: * Appraisal criteria from Sirriyeh R, Lawton R, Gardner P, Armitage G. Reviewing studies with diverse designs: the development and evaluation of a new tool. J Eval Clin Pract. 2012;18(4):746-52. See QATSDD scoring of quantitative studies for details below.

QATSDD scoring of quantitative studies

		Paper No:	1
No.	**Criteria (Scored 0-3)**		
1	Explicit theoretical framework		3
2	Statement of aims/objectives in main body of report		3
3	Clear description of research setting		3
4	Evidence of sample size considered in terms of analysis		2
5	Representative sample of target group of a reasonable size		2
6	Description of procedure for data collection		3
7	Rationale for choice of data collection tool(s)		3
8	Detailed recruitment data		3
9	Statistical assessment of reliability and validity of measurement tool(s) (**Quantitative only**)		1
10	Fit between stated research question and method of data collection (**Quantitative only**)		3
11	Fit between research question and method of analysis		3
12	Good justification for analytic method selected		3
13	Evidence of user involvement in design		2
14	Strengths and limitations critically discussed		3
Total score (max 42):			37
Percentage:			88%

Note: * Appraisal criteria from Sirriyeh R, Lawton R, Gardner P, Armitage G. Reviewing studies with diverse designs: the development and evaluation of a new tool. J Eval Clin Pract. 2012;18(4):746-52

Key to paper:

1. Bennett S, Shand S, Liddle J. Occupational therapy practice in Australia with people with dementia: a profile in need of change. Aust Occup Ther J. 2011;58(3):155-63. (example)

Grey literature appraisal

Instrument: AACODS	Reference: Burns K, Jayasinha R, Tsang R, Brodaty H. Behavior management: a guide to good practice. Managing behavioural and psychological symptoms of dementia. University of New South Wales: Dementia Collaborative Research Centre - Assessment and Better Care 2012.	YES	NO	?
Authority	*Identifying who is responsible for the intellectual content.*			
	Individual author:			
	• Associated with a reputable organisation?			
	• Professional qualifications or considerable experience?			
	• Produced/published other work (grey/black) in the field?			
	• Recognised expert, identified in other sources?			
	• Cited by others? (use Google Scholar as a quick check)			
	• Higher degree student under “expert” supervision?			
	Organisation or group:			
	• Is the organisation reputable? (e.g. W.H.O)	x		
	• Is the organisation an authority in the field?	x		
	In all cases:			
	• Does the item have a detailed reference list or bibliography?			x
Accuracy	• Does the item have a clearly stated aim or brief?	x		
	• Is so, is this met?	x		
	• Does it have a stated methodology?			x
	• If so, is it adhered to?			x
	• Has it been peer-reviewed?	x		
	• Has it been edited by a reputable authority?	x		
	• Supported by authoritative, documented references or credible sources?	x		
	• Is it representative of work in the field?	x		
	• If No, is it a valid counterbalance?	x		
	• Is any data collection explicit and appropriate for the research?			
	• If item is secondary material (e.g. a policy brief of a technical report) refer to the original. Is it an accurate, unbiased interpretation or analysis?			
Coverage	*All items have parameters which define their content coverage. These limits might mean that a work refers to a particular population group, or that it excluded certain types of publication. A report could be designed to answer a particular question or be based on statistics from a particular survey.*			
	• Are any limits clearly stated?			x
Objectivity	It is important to identify bias, particularly if it is unstated or unacknowledged.			
	• Opinion, expert or otherwise, is still opinion: is the author’s standpoint clear?	x		
	• Does the work seem to be balanced in presentation?	x		
Date	*For the item to inform your research, it needs to have a date that confirms relevance*			
	• Does the item have a clearly stated date related to content? No easily discernible date is a strong concern.	x		
	• If no date is given, but can be closely ascertained, is there a valid reason for its absence?			
	• Check the bibliography: have key contemporary material been included?			
Significance	*This is a value judgment of the item, in the context of the relevant research area*			
	• Is the item meaningful? (this incorporates feasibility, utility and relevance)?	x		
	• Does it add context?	x		
	• Does it enrich or add something unique to the research?	x		
	• Does it strengthen or refute a current position?			
	• Would the research area be lesser without it?	x		
	• Is it integral, representative, typical?	x		
	• Does it have impact? (in the sense of influencing the work or behaviour of others)	x		

Appraisal instrument: Tyndall J. Authority, accuracy, coverage, objectivity, date and significance scale (AACODS) 2010 [Available from: https://dspace.flinders.edu.au/xmlui/bitstream/handle/2328/3326/AACODS_Checklist.pdf;jsessionid=2EB4A7A580B36D6D06FFD6428FB02920?sequence=4 .

Grey literature appraisal

Instrument: AACODS	Reference: Guideline Adaptation Committee. (2016). Clinical Practice Guidelines and Principles of Care for People with Dementia. Sydney: Guideline Adaptation Committee.	YES	NO	?
Authority	*Identifying who is responsible for the intellectual content.*			
	Individual author:			
	• Associated with a reputable organisation?			
	• Professional qualifications or considerable experience?			
	• Produced/published other work (grey/black) in the field?			
	• Recognised expert, identified in other sources?			
	• Cited by others? (use Google Scholar as a quick check)			
	• Higher degree student under "expert" supervision?			
	Organisation or group:			
	• Is the organisation reputable? (e.g. W.H.O)	x		
	• Is the organisation an authority in the field?	x		
	In all cases:			
	• Does the item have a detailed reference list or bibliography?	x		
Accuracy	• Does the item have a clearly stated aim or brief?	x		
	• Is so, is this met?	x		
	• Does it have a stated methodology?	x		
	• If so, is it adhered to?	x		
	• Has it been peer-reviewed?	x		
	• Has it been edited by a reputable authority?	x		
	• Supported by authoritative, documented references or credible sources?	x		
	• Is it representative of work in the field?	x		
	• If No, is it a valid counterbalance?			
	• Is any data collection explicit and appropriate for the research?	x		
	• If item is secondary material (e.g. a policy brief of a technical report) refer to the original. Is it an accurate, unbiased interpretation or analysis?			
Coverage	*All items have parameters which define their content coverage. These limits might mean that a work refers to a particular population group, or that it excluded certain types of publication. A report could be designed to answer a particular question or be based on statistics from a particular survey.*			
	• Are any limits clearly stated?	x		
Objectivity	It is important to identify bias, particularly if it is unstated or unacknowledged.			
	• Opinion, expert or otherwise, is still opinion: is the author's standpoint clear?	x		
	• Does the work seem to be balanced in presentation?	x		
Date	*For the item to inform your research, it needs to have a date that confirms relevance*			
	• Does the item have a clearly stated date related to content? No easily discernible date is a strong concern.	x		
	• If no date is given, but can be closely ascertained, is there a valid reason for its absence?	x		
	• Check the bibliography: have key contemporary material been included?	x		
Significance	*This is a value judgment of the item, in the context of the relevant research area*			
	• Is the item meaningful? (this incorporates feasibility, utility and relevance)?	x		
	• Does it add context?	x		
	• Does it enrich or add something unique to the research?	x		
	• Does it strengthen or refute a current position?	x		
	• Would the research area be lesser without it?	x		
	• Is it integral, representative, typical?	x		
	• Does it have impact? (in the sense of influencing the work or behaviour of others)	x		

Appraisal instrument: Tyndall J. Authority, accuracy, coverage, objectivity, date and significance scale (AACODS) 2010 [Available from: https://dspace.flinders.edu.au/xmlui/bitstream/handle/2328/3326/AACODS_Checklist.pdf;jsessionid=2EB4A7A580B36D6D06FFD6428FB02920?sequence=4

Grey literature appraisal

Instrument: AACODS	Reference: Department of Health Victoria. (2012). Strengthening assessment and care planning: Dementia practice guidelines for HACC assessment services. Melbourne: Victorian Government.	YES	NO	?
Authority	*Identifying who is responsible for the intellectual content.*			
	Individual author:			
	• Associated with a reputable organisation?			
	• Professional qualifications or considerable experience?			
	• Produced/published other work (grey/black) in the field?			
	• Recognised expert, identified in other sources?			
	• Cited by others? (use Google Scholar as a quick check)			
	• Higher degree student under “expert” supervision?			
	Organisation or group:			
	• Is the organisation reputable? (e.g. W.H.O)	x		
	• Is the organisation an authority in the field?	x		
	In all cases:			
	• Does the item have a detailed reference list or bibliography?	x		
Accuracy	• Does the item have a clearly stated aim or brief?	x		
	• Is so, is this met?			x
	• Does it have a stated methodology?		x	
	• If so, is it adhered to?			
	• Has it been peer-reviewed?	x		
	• Has it been edited by a reputable authority?	x		
	• Supported by authoritative, documented references or credible sources?	x		
	• Is it representative of work in the field?	x		
	• If No, is it a valid counterbalance?			
	• Is any data collection explicit and appropriate for the research?			
	• If item is secondary material (e.g. a policy brief of a technical report) refer to the original. Is it an accurate, unbiased interpretation or analysis?			
Coverage	*All items have parameters which define their content coverage. These limits might mean that a work refers to a particular population group, or that it excluded certain types of publication. A report could be designed to answer a particular question or be based on statistics from a particular survey.*			
	• Are any limits clearly stated?			x
Objectivity	It is important to identify bias, particularly if it is unstated or unacknowledged.			
	• Opinion, expert or otherwise, is still opinion: is the author’s standpoint clear?			
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Date	*For the item to inform your research, it needs to have a date that confirms relevance*			
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	• If no date is given, but can be closely ascertained, is there a valid reason for its absence?			
	• Check the bibliography: have key contemporary material been included?			
Significance	*This is a value judgment of the item, in the context of the relevant research area*			
	• Is the item meaningful? (this incorporates feasibility, utility and relevance)?	x		
	• Does it add context?	x		
	• Does it enrich or add something unique to the research?	x		
	• Does it strengthen or refute a current position?			
	• Would the research area be lesser without it?	x		
	• Is it integral, representative, typical?	x		
	• Does it have impact? (in the sense of influencing the work or behaviour of others)	x		

Appraisal instrument: Tyndall J. Authority, accuracy, coverage, objectivity, date and significance scale (AACODS) 2010 [Available from: https://dspace.flinders.edu.au/xmlui/bitstream/handle/2328/3326/AACODS_Checklist.pdf;jsessionid=2EB4A7A580B36D6D06FFD6428FB02920?sequence=4

Instrument: AACODS	Reference: Dementia Behaviour Management Advisory Service. 12 top tips in caring for a person with dementia. Retrieved 18th Dec 2014, from http://dbmas.org.au/uploads/resources/12_top_tips_for_family_carers.pdf	YES	NO	?
Authority	*Identifying who is responsible for the intellectual content.*			
	Individual author:			
	• Associated with a reputable organisation?			
	• Professional qualifications or considerable experience?			
	• Produced/published other work (grey/black) in the field?			
	• Recognised expert, identified in other sources?			
	• Cited by others? (use Google Scholar as a quick check)			
	• Higher degree student under “expert” supervision?			
	Organisation or group:			
	• Is the organisation reputable? (e.g. W.H.O)	x		
	• Is the organisation an authority in the field?	x		
	In all cases:			
	• Does the item have a detailed reference list or bibliography?		x	
Accuracy	• Does the item have a clearly stated aim or brief?	x		
	• Is so, is this met?			x
	• Does it have a stated methodology?		x	
	• If so, is it adhered to?			
	• Has it been peer-reviewed?			
	• Has it been edited by a reputable authority?	x		
	• Supported by authoritative, documented references or credible sources?	x		
	• Is it representative of work in the field?	x		
	• If No, is it a valid counterbalance?			
	• Is any data collection explicit and appropriate for the research?			
	• If item is secondary material (e.g. a policy brief of a technical report) refer to the original. Is it an accurate, unbiased interpretation or analysis?			
Coverage	*All items have parameters which define their content coverage. These limits might mean that a work refers to a particular population group, or that it excluded certain types of publication. A report could be designed to answer a particular question or be based on statistics from a particular survey.*			
	• Are any limits clearly stated?	x		
Objectivity	It is important to identify bias, particularly if it is unstated or unacknowledged.			
	• Opinion, expert or otherwise, is still opinion: is the author’s standpoint clear?			
	• Does the work seem to be balanced in presentation?	x		
Date	*For the item to inform your research, it needs to have a date that confirms relevance*			
	• Does the item have a clearly stated date related to content? No easily discernible date is a strong concern.		x	
	• If no date is given, but can be closely ascertained, is there a valid reason for its absence?			
	• Check the bibliography: have key contemporary material been included?			
Significance	*This is a value judgment of the item, in the context of the relevant research area*			
	• Is the item meaningful? (this incorporates feasibility, utility and relevance)?	x		
	• Does it add context?	x		
	• Does it enrich or add something unique to the research?			
	• Does it strengthen or refute a current position?			
	• Would the research area be lesser without it?			
	• Is it integral, representative, typical?	x		
	• Does it have impact? (in the sense of influencing the work or behaviour of others)	x		

Appraisal instrument: Tyndall J. Authority, accuracy, coverage, objectivity, date and significance scale (AACODS) 2010 [Available from: https://dspace.flinders.edu.au/xmlui/bitstream/handle/2328/3326/AACODS_Checklist.pdf;jsessionid=2EB4A7A580B36D6D06FFD6428FB02920?sequence=4

Evidence summary for randomised controlled trials^:

Reference Country	Study design/Level of evidence	N(n)	Participants	Intervention	Comparison	Main outcomes	Measure/s	Length of follow-up	Results/ Effect size
Lowery et al. (2014) **UK**	Two arm, pragmatic RCT, single blind, parallel-group of a dyadic exercise program to determine the effectiveness of incremental walking for treating BPSD compared with treatment as usual.	N= 131 Dyads. 89% of dyads completed the trial (N=116),	Community-dwellers with ICD-10 confirmed dementia and: clinically significant BPSD, a carer willing and able to co-participate in the exercise program, and no symptoms or physical conditions that would preclude exercise participation	Walking regimen tailored to individuals which was designed to become progressively intensive and last between 20 – 30min for at least five a week. Participants diarised activity over a 12-week period (exercise therapist progressively withdrew support after first 6 weeks.	Treatment as usual with walking regimen compared to treatment as usual.	Regular simple exercise does not appear to improve BPSD but seemed to attenuate carer burden.	The primary endpoint was a between-group difference of proportions of people with a decrease of three or more points on the composite NPI score on follow - up at 12 weeks. Secondary outcome measures were: mean differences in scores on the Neuropsychiatric Inventory (NPI), the General Health Questionnaire, DemQOL-Proxy, and Zarit Caregiver Burden Inventory. Carers used daily diaries and a rating of perceived exertion scale participants' level of exercise and compliance.	Opened for recruitment in Jan 2010 and final follow-up was Dec 2012. After the assessments at 6 and 12 weeks, further telephone contact occurred at 26 weeks to ass for adherence to exercise regimen, adverse events, mortality, change in domiciliary status.	There was no significant difference in BPSD measured by the NPI at week 12 between the group receiving the dyadic exercise regimen and those that did not (adjusted difference in means (intervention minus control) = 1.53, p = 0.6, 95% CI [7.37, 4.32]). A significant between-group difference in carer's burden as measured by the Zarit Caregiver Burden Inventory at week 12 (OR = 0.18, p = 0.01, CI [0.05, 0.69]) was found which favoured the exercise group.

Note: ^ See Evidence appraisal for randomised controlled trials for appraisal criteria on following page

Evidence appraisal for randomised controlled trials

RCT: Lowery D, Cerga-Pashoja A, Iliffe S, Thune-Boyle I, Griffin M, Lee J, et al. The effect of exercise on behavioural and psychological symptoms of dementia: the EVIDEM-E randomised controlled clinical trial. Int J Geriatr Psychiatry. 2014;29(8):819-27.		
1	eligibility criteria were specified	Yes
2	subjects were randomly allocated to groups (in a crossover study, subjects were randomly allocated an order in which treatments were received)	Yes
3	allocation was concealed	No*
4	the groups were similar at baseline regarding the most important prognostic indicators	Yes
5	there was blinding of all subjects	No
6	there was blinding of all therapists who administered the therapy	No
7	there was blinding of all assessors who measured at least one key outcome	Yes
8	measures of at least one key outcome were obtained from more than 85% of the subjects initially allocated to groups	Yes
9	all subjects for whom outcome measures were available received the treatment or control condition as allocated or, where this was not the case, data for at least one key outcome was analysed by “intention to treat”	Yes
10	the results of between-group statistical comparisons are reported for at least one key outcome	Yes
11	the study provides both point measures and measures of variability for at least one key outcome	Yes

*Note: States strategies were adopted to minimise de-blinding of research staff.

Appraisal instrument: PEDro Partnership. PEDro Scale 1999 [updated 21 June. Available from: https://www.pedro.org.au/wp-content/uploads/PEDro_scale.pdf.

Search strategy summary

Medline	PsycINFO	EMBASE
1. (manage* or treat*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] 2. symptom*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] 3. psycholog*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] 4. (behaviour* or behavior*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier] 5. (Alzheimer$ or Alzheimer or Alzheimer's or Alzheimers).mp. 6. dementia.mp. or Dementia, Vascular/ or Delirium, Dementia, Amnestic, Cognitive Disorders/ or Dementia/ or AIDS Dementia Complex/ or Frontotemporal Dementia/ or Dementia, Multi-Infarct/ 7. 5 or 6 8. 1 and 2 and 3 and 4 and 7 9. limit 8 to (abstracts and English language and humans and yr="2008 -Current")	1. (manage* or treat*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] 2. (behavior* or behaviour*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] 3. symptom*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] 4. psycholog*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] 5. (Alzheimer$ or Alzheimer or Alzheimer's or Alzheimers).mp. 6. Vascular Dementia/ or Dementia/ or Semantic Dementia/ or AIDS Dementia Complex/ or Presenile Dementia/ or dementia.mp. or Dementia with Lewy Bodies/ or Senile Dementia/ 7. exp Vascular Dementia/ or exp Dementia/ or exp Semantic Dementia/ or exp AIDS Dementia Complex/ or exp Presenile Dementia/ or dementia.mp. or exp Dementia with Lewy Bodies/ or exp Senile Dementia/ 8. dementia.mp. or Dementia, Vascular/ or Delirium, Dementia, Amnestic, Cognitive Disorders/ or Dementia/ or AIDS Dementia Complex/ or Frontotemporal Dementia/ or Dementia, Multi-Infarct/ 9. 5 or 6 or 7 or 8 10. 1 and 2 and 3 and 4 and 9 11. limit 10 to (human and english language and abstracts and yr="2008 -Current")	1. (manage* or treat*).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword] 2. (behavior* or behaviour*).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword] 3. symptom*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword] 4. psycholog*.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword] 5. (Alzheimer$ or Alzheimer or Alzheimer's or Alzheimers).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword] 6. Cornell Scale for Depression in Dementia/ or semantic dementia/ or multiinfarct dementia/ or frontal variant frontotemporal dementia/ or "mixed depression and dementia"/ or dementia.mp. or frontotemporal dementia/ or HIV associated dementia/ or Pick presenile dementia/ or dementia/ or Clinical Dementia Rating/ or presenile dementia/ or senile dementia/ 7. Dementia.mp. or Dementia, Vascular/ or Delirium, Dementia, Armestic, Cognitive Disorders/ or Dementia/ or AIDS Dementia Complex/ or Frontotemporal Dementia/ or Dementia, Multi-Infarct/ 8. 5 or 6 or 7 9. 1 and 2 and 3 and 4 and 8 10. limit 9 to (abstracts and human and english language and yr="2008 -Current") 11. limit 10 to exclude Medline journals
PHCRIS search strategy: Topic: General Practitioners; Keywords: BPSD and dementia or Alzheimer*; Publication date: last 10 years		