AGITATION
DECISION-MAKING
FRAMEWORK

for nurses and care staff caring for people with advanced dementia

SUPPORTING INFORMATION
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Acknowledgement

Dr John Bidewell, Professional Officer (Research), School of Nursing and Midwifery, College of Health & Science, University of Western Sydney developed this framework.
SECTION ONE: FRAMEWORK OVERVIEW

All health professionals must use their own professional judgement when using this framework and associated resources. Any decision to vary from this framework should be documented in the resident’s records to include the reason for the variance and the subsequent action taken.

1.1 Introduction to the agitation framework

Timely assessment and management of symptoms is a major component of a palliative approach to dementia care. This framework provides a process to adopt to assess and manage agitation in residents with advanced dementia, and is based on the best available evidence, or in the absence of evidence, expert opinion.

Use of this framework will assist nurses and care staff to improve their assessment and management of agitation; and improve the well-being of residents, per Guidelines 52-55 of the Guidelines for a Palliative Approach in Residential Aged Care (Enhanced Version, 2006).

It is recommended that in conjunction with the use of this framework, all nurses and care staff:

- refer to the sections relating to psychological support, family support, and end of life (terminal) care in the Guidelines for a Palliative Approach in Residential Aged Care;

- complete the Palliative Care Australia on-line End of Life (Terminal Care) Module, available to support the use of the Guidelines. This module contains information to assist with agitation in the last few days of life. Access the modules from this site: http://www.agedcare.pallcare.org.au. On the left-hand side there is a list of modules. Click onto the ‘Training Resources’ for the Guidelines;

- complete relevant sections relating to agitation within the Palliative Care Australia Competency unit: CHCPA01A Deliver care services using a palliative approach, available from Palliative Care Australia.

1.2 Competencies required

Categories of staff who should implement the framework are specified minimally, because staff classifications and skills will vary across institutions and responsibilities can be determined locally. Senior clinical staff and management should be well positioned to implement system-wide interventions, with trained, possibly subordinate, staff providing individual-level responses under senior supervision. Senior and expert staff may be deployed to individual therapy where the agitation is severe and intractable. The entire institution should be involved with system-wide initiatives. All categories of staff should be acquainted with the framework to ensure consistent and coordinated delivery.
All nurses and care staff have a responsibility to ensure they are competent to assess and manage agitation experienced by residents, within their scope of practice. Nurses and care staff who are concerned they do not have adequate levels of competency should discuss their concerns with their managers, so that additional training can be arranged for them.

1.3 Scope of this framework

The purpose of this framework is to provide best practice evidence, or in the absence of evidence, expert opinion, to enable nurses and care staff in residential aged care facilities to identify and manage agitation.

1.4 Using this framework

This framework provides a method of assessing agitation and managing it. Refer to the Guidelines for Nurses and Care Staff, and flowcharts, for additional information.

1. Assessing agitation

All residents with advanced dementia are at high risk of agitation and require:

- Screening for delirium, using a tool such as the Confusion Assessment Method (CAM) on admission and any time the resident’s behaviour indicates he/she may be delirious; and

- Assessment for agitation, using a tool such as the Brief Agitation Rating Scale (BARS) before and after interventions. Use a Behaviour Record Form, on which the triggers (Antecedents), Behaviours, and outcomes (Consequences) (ABC method) can be recorded.

2. Managing agitation

- Treat any reversible causes of agitation;
- Change systems and environmental conditions facility-wide whenever possible to reduce the chances of multiple residents being agitated at once;
- Provide training for staff so they are able to work with residents with irreversible causes of agitation without the need to resort to restraints.
SECTION TWO: AGITATION IN DEMENTIA

KEY POINTS

- agitation is a serious, unpredictable, persistent, diverse, and ill-defined state which resists straightforward remedies. It is a constellation of behaviours rather than a specific behavioural problem, and should be viewed as a form of maladaptive communication which is a clinical sign rather than a disorder of itself;

- there are a number of models of agitation, including biological models, unmet needs models, behavioural models and environmental models of agitation. The unmet needs model offers the most useful direction for management. The resident’s agitation can be interpreted as a clinical sign;

- only attribute dementia as the cause of agitation as a last resort. Rule out all other causes first;

- agitation that threatens the comfort, safety or welfare of the resident or other residents, staff or visitors requires treatment. Ignore milder episodes of agitation whenever possible;

- there is no one treatment that will apply to all cases of agitation. A problem-solving approach is required, with continuous reassessment to uncover unmet needs;

- treatments such as multi-sensory rooms and relaxation therapy have some benefit. They are resource-intensive, and should not be used in place of high quality basic care;

- institution-wide interventions should be tried first. If they fail then individualised therapy is required;

- negative interventions such as restraint or medication should be used as a last resort after excluding all other possible causes first;

- monitoring of the resident’s behaviour and condition, the effects on others in the vicinity, and the outcomes of interventions should be continual.
2. Introduction

The aged care literature recognises agitation in dementia as a common and difficult problem in residential settings. Effects of agitation extend beyond the individual in whom the condition manifests. Hallberg and Norberg (1995) found agitation to correlate moderately highly with emotional exhaustion among nurses. Agitated residents can cause behaviour problems for lucid residents which, in turn, can aggravate the initial agitation. Kopecky, Kopecky, and Yudofsky (1998, p. 302) refer to the “immediacy, unpredictability, intermittence and destructiveness” of agitation, with attendant safety and management complications. The current paper proposes a framework for preventing and treating agitation from dementia in residential aged care.

2.1 Definition of agitation

The degree of challenge from agitation in aged care is well established. The challenge is both conceptual and practical. More than 20 years ago, Cohen-Mansfield and Billig (1986) argued that the concept and aetiology of agitation were unclear. Kopecky et al (1998) stated that there was “no consensus” (p. 303) on the conceptualisation or measurement of agitation. Poole and Mott (2003) reviewed 80 articles and found 47 behaviours classified as agitation. On the basis of Neugroschi (2002), agitation could include practically any aberrant behaviour associated with dementia. Kong’s (2005) review presents four definitions based on other writings:

1. Excessive, non-productive and repetitious motor activity associated with inner tension. Examples include inability to sit still, pacing, wringing of hands and pulling at clothes. “Tension” is here a nebulous, untestable cause.

2. Inappropriate verbal, vocal or motor activity not explained by needs or confusion. Behaviours include aimless wandering, pacing, cursing, screaming, biting and fighting. This definition bypasses causation; indeed, two potential causes are excluded.

3. Vocal or motor behaviour that is disruptive, unsafe, or interferes with the delivery of care. Included are vocalisation, motor disturbances, aggressiveness and resisting care. This definition refers to the effects of agitation on others. Cause is again unspecified.

4. Behaviours that communicate to others that the agitated person is experiencing an unpleasant state of excitement. The agitation remains after attempts to manage resistance, alleviate physical signs, or decrease sources of stress.

Whilst the above definitions summarise common manifestations of agitation, they offer no clues for prevention and treatment because none specify causes that can be readily controlled.

Other descriptions of agitation list such a range of behaviours as to confound any attempt at establishing a simple definition or a single cause. For example, the 15 most common problematic behaviours on Snowdon, Miller, and Vaughan’s (1996)
list compiled from residential aged care observation included: complaining, cursing and verbal aggression, general restlessness, repetitive sentences, negativism, constant calls for help, wandering and trying to escape, pacing, inappropriate dressing, strange noises, hoarding, repetitive mannerisms, screaming, strange movements and hiding things.

Agitation therefore presents as serious, unpredictable yet persistent, diverse, ill-defined, and resisting straightforward remedy. Any clinical framework for managing agitation must view it as a constellation of behaviours rather than specific behavioural problem. Nevertheless, some potentially controllable factors affecting agitation have been identified, and general approaches to managing behavioural problems in institutional settings offer worthwhile prospects.

### 2.2 Associated factors and suggested causes of agitation

Factors affecting agitation can be classified as background circumstances promoting agitation without directly causing it, instead amplifying more proximate causes; and immediate triggers sufficient to initiate agitation episodes. Some triggers may operate conditionally, that is, only when particular background conditions are in place. Some beneficial background circumstances, which institutional carers should be keen to identify, could neutralise a trigger, thereby preventing agitation.

**Biological model of agitation**

Cohen-Mansfield summarises four models for the causes of agitation, starting with the biological model, which attributes agitation to organic pathology, the dementia itself being the primary and largely untreatable cause. However, Wiener, Kiosses, Klimstra, Murphy, and Alexopoulos (2001) note that dementia co-morbidities such as responses to pharmaceutical drugs, hydration and electrolyte problems, under-nourishment, infections, endocrine, lung, liver, kidney and heart problems, all arguably biological, may contribute to agitation. Treatment for biologically based agitation would involve identifying and treating physiological causes additional to the dementia.

**Unmet needs model of agitation**

According to the unmet needs model, agitation is a response to a somatic, social or environmental (externally physical) problem. The unmet needs model obviously contradicts theories describing agitation as inappropriate verbal or motor activity not attributable to unmet needs. However, needs could simply be unapparent owing to communication or interpretation difficulties.

The biological and unmet needs models can intersect. Neglect in care, leading to hunger, dehydration, discomfort, problems with medication, hygiene or other personal maintenance can bring unmet needs. Uncontrolled pain can start agitation, so managing agitation may involve meeting an unmet need for pain relief. During
one study by Kovach et al (2004)\textsuperscript{25,26}, forty percent of participants (n=23) were found to have a physical cause for their behaviour, yet 70\% of these people received no treatment for the physical cause of their behaviour. This pattern of failing to provide the right treatment/intervention was found throughout the trial. The approach to treatment implied by the unmet needs model is to identify and remedy the unmet need, which must be inferred when direct communication is ineffective. Inferring the need may require close and insightful reading of the individual’s presentation.

**Behavioural model of agitation**

The *behavioural model* emphasises the environment because it argues that problem behaviours such as agitation are learned. They persist because they are rewarded. The environment supplies the rewards. Agitated residents may receive extra attention from staff, which reinforces their problematic behaviour. For the behavioural model, managing a person’s agitation entails preventing the environmental triggers for the behaviour and attentional rewards when the behaviour occurs. The behaviours will extinguish because they receive no encouragement.

Again there is potential for overlap between the unmet needs and behavioural models. For an institutionalised person, any attention may be better than none. Staff and other residents could be the only sources of attention, and challenging behaviour the best way to gain attention and meet that unmet need.

Behavioural treatments may clash with quality of care principles because ignoring a resident who seeks attention could be considered neglectful, especially as the attention-seeking may reflect deficient care or another unmet need. Anticipating and meeting the needs for social interaction before agitation occurs is preferable to limiting social contact in order to extinguish agitation.

The cognitive impairment from dementia presents a problem for the behavioural model\textsuperscript{27}. Impaired memory and adaptation will compromise a resident’s capacity to learn agitation from recent experience; and residents will likely forget how staff respond to their behaviour, compromising behavioural approaches to treatment.

**Environmental models of agitation**

*Environmental models* link agitation with factors external to the person. For example, a residential aged care facility may deprive residents of social and sensory stimulation. According to the so-called environmental vulnerability model, dementia renders a person excessively reactive to minor environmental stimuli that an unimpaired person would ignore. The challenge for treatment is to identify and eliminate stimuli that could trigger problem behaviour. Teri et al (1998)\textsuperscript{28} reveal how problem behaviours’ antecedents can be identified and targeted.

Excessive demand on the resident is another form of environmental vulnerability. Whereas dementia brings deteriorating abilities apparent to observers, the person
with dementia sees their environment as ever harder to manage, leading to frustration and consequent agitation. Agitation can therefore be reduced through simplifying tasks and reducing expectations. The challenge is to design tasks and environments that reduce stressful demand while meeting residents’ need for stimulation and involvement.

In summary, agitation should be considered the product of interactions between the individual (biological model) and their context (environmental) with both types of cause interpretable via the unmet needs model. Biological and environmental factors converge to produce an unmet need expressed through agitation.

Agitation is in effect a form of maladaptive communication, that is, a clinical sign rather than a disorder in itself. Factors internal to the person and additional to dementia, such as pain, discomfort, dehydration, co-morbidities, or medication that may cause agitation are treatable, and should be addressed through everyday care. The resident’s environment might also be modified to advantage.

There is little choice but to work at such an abstract level of biological and environmental factors and unmet needs because only at that level can we accommodate all likely causes. Cause and treatments for agitation will vary across individuals, ruling out formulaic “one size fits all” approaches to prevention and therapy. Identifying and meeting each person’s needs provides the strongest overall rationale for agitation management, and reflects contemporary health care principles.

Despite the above argument, attributing a person’s agitation solely to their dementia will occasionally be necessary because even the most diligent assessment may reveal no alternative cause. Attributing agitation to the dementia itself should be the inference of last resort, applicable only when all other conceivable causes have been ruled out.
2.3 Agitation associated with delirium

A particular, very important, type of agitation, which falls within the biological model, is delirium. Delirium is an acute, potentially reversible disorder of attention and cognition that is extremely common in people with dementia. The Australian delirium guidelines (2008) indicate that over half (52.6%) of older people hospitalised from long-term care institutions experience delirium. In the United States of America, 40.5% of residents screened in one study in an aged care facility were found to be delirious. The most common cause was insufficient fluid intake. People with dementia were found to be at high risk of delirium. Residents with delirium and dementia will have worse outcomes than residents with dementia and no delirium. They are more likely to have an increased rate of cognitive decline, more likely to need repeat hospitalisation, and are more likely to die.

It can be difficult to distinguish between the symptoms of dementia and those of delirium. However, delirium starts abruptly, while dementia is a slow process. Agitation, frequently associated with visual hallucinations, may be present. Other symptoms include either heightened or reduced attention in residents with dementia; altered psychomotor activity; speech pattern changes eg slurred, slowed or rapid speech; and tremor. Residents with dementia may be more likely to have a ‘quiet’ form of delirium, where they are hypoactive, that is, less active than usual. They are often overlooked and therefore undiagnosed with delirium.

Causes of delirium are numerous, and include not drinking enough, pain, infections, taking multiple medications, and electrolyte abnormalities. People with vision impairment, who are undernourished, have a urinary catheter, or have more than 3 new medications added at once are vulnerable to delirium.

The Australian delirium guidelines recommend that every health setting, including every residential aged care facility, should have a structured process for screening for delirium, with staff trained in the use of the screening tools. A copy of the Confusion Assessment Method (CAM) is attached to this document. The annotated bibliography contains information to assist you to audit delirium screening within residential aged care.

Prevention strategies include:

- environmental strategies: appropriate lighting for the time of day; quiet environment especially at rest times; clearly visible clock and calendar; encourage family / carer involvement in care; encourage family/carer to bring in familiar objects; avoid room changes;

- clinical practice strategies: assist with eating & drinking to ensure adequate intake; if the resident has spectacles and hearing aids make sure they are used; avoid constipation; encourage regular mobilisation; encourage independence in activities of daily living; review medications; promote relaxation and sleep; manage pain; provide orienting information; minimise use of indwelling urinary catheters; avoid use of physical restraints; avoid psychoactive drugs; use interpreters and other communication aids; use Aboriginal liaison officers if available.
Seek immediate medical attention for any resident thought to have delirium.

2.4 ‘Terminal’ agitation

Terminal agitation, also called terminal restlessness, or agitated delirium, appears to be a type of delirium associated with the final days of life. The resident may appear to have similar signs and symptoms to those experienced when he/she had an infection, pain, or adverse drug reaction which caused delirium in the past. The resident may be physically agitated, thrash about, fidget, toss or turn in the bed, yell or moan.

Wilden & Wright (2002) reviewed the records of 23 patients with vascular dementia admitted to a behaviour stabilisation unit in a one-year period. They found that many who were admitted with a range of increased behaviours of concern, including agitation, died within a short time of admission. Wilden & Wright suspect that terminal agitation is the cause of the increase in behaviours of concern seen among the people who died quickly.

It is distressing for family members to watch their loved ones experience discomfort such as agitation in the final days of life, and may complicate their bereavement if the experience is traumatic for them to watch. Nurses who respond with warmth, calmness, patience and professionalism, and who do everything possible to respect residents and treat them with dignity, can help family members to adjust.

The resident may require sedation for terminal agitation or restlessness: contact the general practitioner for advice. Benzodiazepines are the treatment of choice for terminal agitation. Typically either clonazepam or midazolam are prescribed.
SECTION THREE: TREATMENTS FOR AGITATION

3. Treatments for agitation

Treatments can be classed according to whether they address causes or just the behavioural signs. Neugroschl (2002) outlines a strategy for identifying and controlling the antecedents (presumably causes) and the consequences (outcomes) of agitation. Symptomatic styles of treatment may be an admission that the cause cannot be identified.

Turner (2005) also citing Howard et al (2001) outlines two treatment approaches. The biological-neurological approach concentrates on the organic origins of the problem behaviours, such as disrupted circadian rhythms and neurotransmitter dysfunction. This perspective tends towards pharmacological management whilst allowing for non-pharmacological management. An alternative, the psychological-behavioural approach, looks specifically at behaviours and their context. Challenging behaviour is managed by modifying external triggers or other environmental influences.

Turner (2005) distinguishes between group-level and individually targeted therapies. Group interventions can include staff training, and wider policy initiatives. Therapies targeting the individual resident have produced worthwhile results according to Turner’s review. Turner presents an agitation management flowchart, summarised below:

1. Identify and, where possible, treat any physical conditions causing the agitation. If staff and other residents can tolerate the behaviour and it poses no threat to welfare, including the resident’s, then a more positive interpretation of the behaviour may be sufficient, rather than active treatment. This is the most conservative option.

2. If treatment is required and the behaviour is common throughout the institution, consider a group or system-wide intervention because the same factor could be operating generally. Environmental causes should be suspected if agitation patterns are consistent across residents; there could also be a systematic neglect of care. System-wide interventions can be efficient if they are effective.

3. If the agitation is unique to an individual and intervention is necessary for the welfare of the resident, staff, other residents, visitors and institutional viability, then individualised treatment will be required.
3.1 Non-pharmacological interventions (“positive comfort interventions”)

Emotion-oriented treatment

Finnema et al (2000) 34 describe “emotion-oriented” treatment. Examples are:

- **validation** (attempting to recognize and confirm emotions, restore the person’s self-esteem and understand the person in the context of the reality they perceive themselves to be in at the time);
- **reminiscence** (which attempts to improve social functioning by exchanging memories);
- **simulated presence therapy** (whereby an audio tape or video tape of a former at-home carer relative is played to simulate the continued presence of that carer); and
- **sensory stimulation**.

Finnema et al 34 go on to say that many such approaches lack a “solid theoretical framework” (p. 142). They report favourable results for emotion-oriented treatments for behavioural and psychological problems associated with dementia, but better research designs and outcomes measurement are needed.

Music therapy

In their review, Goodall and Etters 92005) 35 reported favourably on music therapy, as does Potyk (2005) 36. Catering for individual music preferences may be preferable to standard relaxation music, but impossible in a group setting. Reviews have concluded favourably for music therapy, but methodological problems reduce the trustworthiness of findings from many studies – see Sung and Chang (2005) 37, and Lou (2001) 38. Rationales for music therapy, as summarised by Lou 38, are not especially scientific where they are provided at all.

Vink et al (2003) 39 examined five empirical evaluations of music therapy. Each evaluation claimed beneficial results. According to the Vink et al. review, “The methodological quality and the reporting of the included studies were too poor to draw any useful conclusions” (p. 1), so that “there was no substantial evidence to support nor discourage the use of music therapy in the care of older people with dementia.”

Bright light therapy

On the basis of earlier research suggesting that agitation may be caused by circadian rhythm dysfunction or limited sunlight exposure, and some (though by no means unanimous) evidence that increased ambient light may reduce agitation, Lyketos et al (1999) 40 tested bright light therapy for eligible patients without sleep-waking
disturbance (N = only 8). Results indicated an improvement in nocturnal sleep hours but no improvement in behaviour. Schindler et al (2002) concluded that bright light therapy may assist some people, yet be counter-productive for others.

**Multi-sensory rooms**

“Snoezelen” is a trade name for a multi-sensory therapy for reducing agitation and other behavioural disturbances in people with cognitive impairment. A special room is equipped with coloured and moving lights, and other pleasant tactile and olfactory stimuli. Residents are exposed to this environment upon the determination of staff. The goal is to provide a pleasant, stimulating environment without demands. Because cognitive higher function is impaired, the multi-sensory strategy is to reach the individual through more basic channels that are still intact.

Van Weert et al (2005) evaluated Snoezelen using a quasi-experimental, pre-test and post-test design. Various improvements in resident behaviour and disposition were observed, including reduced physical aggression, but no “generalised improvement” (p. 31) in antisocial or restless behaviour, anxiety, restlessness, loss of consciousness, verbal aggression or non-physical aggressive behaviour. In the van Weert et al. study, Snoezelen formed part of a comprehensive, person-centred care plan, so identifying what component of the program brought the changes was difficult.

Minner et al (2004) obtained favourable results with Snoezelen, while mentioning practical problems with this method, including staff training, this difficulty being compounded by staff turnover.

Baker et al (2003) found no advantage of multi-sensory stimulation over more modest control activities, an important finding because if cheaper interventions are just as effective, dedicated Snoezelen rooms become harder to justify.

Consistency of delivery is a challenge for testing any therapy. Many design choices are available for multi-sensory rooms, so a pertinent question is which fittings (e.g., disco mirror ball, fibre optic spray, soft toys) work better than others. Agreed standards need evidence.

**Relaxation**

Relaxation therapy may consist of therapeutic touch, including massage and expressive physical touching, and is said to be effective. Progressive muscle relaxation may usefully raise the stress threshold associated with dementia. Surh et al (1999) tested progressive muscle relaxation, potentially accessible to those with dementia because the method should bypass cognitive deficits. Results indicated significantly fewer behavioural problems and better results for fluency and short-term memory tests for the muscle relaxation treatment group compared with an imaginal relaxation control group.
Other non-pharmacological interventions

Other non-pharmacological interventions can be as simple as removing objects related to agitation (an environmental intervention), or distracting the agitated resident (behavioural), or assisting care-givers to better manage the resident’s environment or social interactions.

Treatment Routes for Exploring Agitation “TREA” are based on the unmet needs model. The approach is individualised and preventative. Where possible, residents’ idiosyncrasies should be accommodated rather than suppressed. Cohen-Mansfield presents case studies for TREA, suggesting its effectiveness.

Trudeau, Biddle, & Volicer (2003) were interested in whether interventions to decrease agitation by increasing mobility in people with advanced dementia were effective. They used a ‘Merry Walker’ frame to enhance mobility. This frame has an inbuilt seat, surrounded by a frame on four sides, and is on four wheels that allow 360-degree rotation. The study found that people with advanced dementia who used the Merry Walker enjoyed increased freedom of movement. Using the frame was found to improve mood, decrease agitation and passive activity, and received favourable appraisal from clinicians and families.

For more information about the ‘Merry Walker’ frame, see: http://www.merrywalker.com/products.html

Pets can reduce agitation and the late afternoon restlessness known as “sundowning.” Richeson (2003) in a pilot study of animal-assisted therapy with 15 subjects found improvements (reduced agitation and increased social interaction) from pre to post test.

3.2 Institutional regime and environment

Matthews et al. (1996) addressed the entire approach to aged care, arguing for a client-oriented approach in which residents had more freedom, choice and autonomy compared with the regimentation and task-orientation claimed to be typical of aged care institutions. This proposition is controversial, given that structured environments and routines might simplify demands on residents and reduce confusion. Nevertheless Matthews et al. tested for behavioural effects of a change to a more flexible regime. A decrease in verbal agitation behaviours ensued, along with an increase in other agitated behaviours by a small percentage of patients. The sample size was small and there was no control group. There are practical limits to institutional flexibility and autonomous decision making among those with dementia.

McGilton, Rivera, and Dawson (2003) considered the resident’s ability to navigate around the institution. Their prediction, that enabling residents to locate the dining room from their bedroom would have a beneficial effect on agitation, was upheld after behavioural training and navigational support, but not sustained. Continued
assistance may be needed, given the memory impairments associated with dementia.

Reimer et al (2004) tested a purpose-built special care facility against a so-called traditional facility for mid to late stage dementia residents. The special care facility offered more privacy and meaningful activity compared with a conventional facility. Results suggested quality of life at least as good for the special care facility residents compared with traditional facilities. However, increased agitation was noted for the special care facility residents. This finding was interpreted positively, with the suggestion that the special care facility residents had more freedom and possibly fewer medications that may inhibit agitation.

Cox, Burns, and Savage (2004) found a landscaped garden to have offered benefits. Wilkes et al (2005) evaluated a special care unit with unrestricted use of garden areas and wandering paths, more domestic activity for residents, expansive views, personalised, decorated space and with own furniture and bathroom, and access to a Snoezelen room. Physically non-aggressive behaviour and verbally agitated behaviour diminished, but overall aggressive behaviour did not change.

Kovach et al (2004) studied agitated behaviour among 78 residents. Many residents were in a continually aroused state, and agitation was significantly more likely to occur when a resident experienced an imbalance between high arousal and low arousal states. Kovach et al found that individualised interventions that alternated activities and rest periods of approximately 1.5hrs duration reduced episodes of agitation experienced among this group of residents.

### 3.3 Pharmacological treatments

Despite widespread criticism, advocacy of medication for controlling agitation persists. On the critical side, Cohen-Mansfield claimed that medication fails to address the reasons for the behaviour, involves side effects and interactions with other drugs. Medication may be ineffective and can mask an underlying need. Some medication may cause agitation. Pharmacological treatment has been described as chemical restraint, making it an undesirable expedient. The framework proposed in this article minimises the role of medication.

Aromatherapy is a pharmacological treatment. The only worthwhile aromatherapy trial described in Thorgrimsen et al’s (2003) Cochrane review reported a significant finding favourable for aromatherapy, but that study had methodological problems.

If non-pharmacological options fail, and the needs behind the agitation cannot be identified, then pharmacological management may be indicated.

Howard, Ballard and O’Brien (2001) suggest the following points:

- there is no evidence from controlled trials to support the use of benzodiazepines;
• the use of antipsychotics must involve consideration of the risks as well as the benefits;
• older people are sensitive to the common side effects of antipsychotics;
• there may be accelerated cognitive decline and sensitivity in dementia with Lewy bodies;
• there is modest evidence of efficacy for antipsychotic drugs;
• there are no demonstrated differences in efficacy, but atypical agents seem better tolerated;
• begin with the lowest prescribable dose and carefully monitor for side effects;
• only continue medication if there is evidence of efficacy;
• review the continued need for treatment every 3 months;
• for people where antipsychotics are ineffective or not tolerated, carbamazepine and trazodone may be efficacious;
• severe or treatment-resistant agitation merits specialist referral.

Further information about medications for agitation, and treatment algorithms, can be accessed from the following web site:

http://www.psychguides.com/node/56

See the Annotated Bibliography at the back of this document for further information.

3.4 Physical restraint

Mott et al (2005) define physical restraint as any device nearby or attached to the body, and restricting movement or access. As with pharmacological treatment, physical restraint is an expedient to protect the resident and others. No one advocates physical restraint as the ideal response to agitation. Its use is associated with adverse outcomes and seems antithetical to good care.

The physical restraint literature includes advice for reducing the need for this measure. Using a randomised controlled trial, Testad, Aasland, and Aarsland (2005) evaluated staff training as a way of reducing use of restraint to control agitation. The result was a 54% reduction in restraint use among the treatment group (for whom the staff received training) despite a measured increase in behavioural symptoms. An increase in staff tolerance for agitated behaviours may account for this observation. An 18% increase in restraint use occurred for the control group.

Conclusions regarding treatments for agitation in residential aged care

Two factors complicate the management of agitation in residential aged care. First are the disparate theoretical approaches to agitation. Consensus is lacking on what agitation is, how it is caused, how it should be measured, and factors associated with its incidence and consequences. Agitation as commonly defined all but precludes a simple one-to-one correspondence between clinical presentation and treatment. The literature points to diverse presentations for agitation and a multiplicity of causes.
Any framework for treatment must therefore work at a general level. Identifying one, universally applicable treatment for agitation will remain naively simplistic. The literature reveals no such treatment. Instead, a higher-order, problem-solving approach is needed, and is proposed in the framework below.

The second complication is the allegedly poor quality of research into treatments, as documented in systematic reviews. The evidence for evidence-based treatments is either lacking or inconclusive. Of the treatments reviewed above, multi-sensory rooms appear to have the strongest evidence for effectiveness. However, as with music therapy, the issue of how multi-sensory treatment should be implemented remains a challenge because the many options could differ in their effectiveness.

Whilst the proposed framework encourages institution-wide interventions where these would benefit, at times the clinician must work on a case-by-case basis, judging “what works with whom” at a given time and context; yet individualised treatment should be anything but ad hoc. In one example of a systematic implementation of individualised treatment, Kovach et al (2006) 25, 26, 63 successfully used a system of tailored interventions to address the problems of physical and affective discomfort in people with advanced dementia. Residents were randomized to either treatment or control groups. Nurses were trained to use a series of assessments and treatments to improve discomfort in residents. Results showed a significant improvement in the discomfort felt by residents, with behaviours indicating discomfort reduced or eliminated. This type of intervention moves beyond unguided trial and error: the clinician can assess, identify causes, and tailor treatments to causes. Applying these principles will demand close observation of the resident and their environment, and insight into the resident that is best achieved through long acquaintance and engagement. To solve the problems of the individual, the clinician must know the individual, and apply general principles to the individual’s situation. An issue for individualised therapies is their likely expense. Verbal therapies such as reminiscence therapy or multi-sensory rooms can be labour intensive or impractical to offer for numerous residents at a time.

The financial cost of therapy may seem a cynical line of discussion. However, practical limits must be acknowledged, especially when aged care services are run as businesses. However, agitation may have its own costs in terms of its burden on individuals and the institution. Aside from their intrinsic benefits, successful interventions could represent a sound investment as much as an overhead. Unsurprisingly, the cost effectiveness of agitation treatments is rarely mentioned in the clinical literature, although we might presume that institution-wide actions will be more efficient than individual therapies, and therefore should be tried first where they seem applicable.

Multi-sensory rooms, relaxation therapy and other inventions designed to mitigate symptoms rather than treat the causes should not substitute for high quality basic care. If a resident’s physical condition or a modifiable stressor is causing the agitation, that problem should be fixed in preference to symptomatic treatments irrelevant to the cause. Behavioural techniques have been suggested, but the expectation that people with severe dementia can learn new patterns of behaviour may be unrealistic. Physical restraint and pharmacological treatments have been deprecated on grounds that they are unenlightened, ineffective and even counter-
productive. They should be reserved for extenuating circumstances, and not used continuously or routinely.

The unmet needs model offers the most useful direction. The resident’s agitation can be interpreted as a clinical sign. Vulnerability models tie in with the unmet needs model because they claim that aged care residents need a less stressful environment. Addressing unmet needs is more enlightened than any form of restraint, the latter measure mainly serving the needs of others rather than the resident. Unmet needs models point to the importance of thorough investigation to uncover reasons for the agitation. If agitation resists the initial intervention, the resident should be reassessed to see whether the unmet need still exists or whether a different need drives the agitation. The sequence of assessing the resident, inferring the unmet need causing agitation, treating that cause and evaluating the outcome is a general and recommended approach to agitation.

Environmental and vulnerability models can be similarly incorporated into assessment and treatment. The carer searches for an external factor provoking frustration, irritation, distraction or distress in someone rendered vulnerable through dementia. Once identified the trigger can be neutralised directly, or the agitated person relocated, even if temporarily, to more agreeable surroundings such as a multi-sensory room.

The question of appropriate levels of stimulation and demand presents a challenge for environmental models. As noted earlier, agitation can result from under-stimulation, boredom and monotony from the routine of institutionalised life; and it can result from over-stimulation, including from staff undertaking their duties, and the presence or behaviour of other residents and visitors, any of which could be confusing, arousing or over-taxing for the resident with dementia. Within two extremes there lies an ideal level of stimulation for each resident.

Stimulation must be defined, and will be hard to measure in field settings. Residents’ needs for stimulation may vary with the hour, with the progress of their dementia, with other conditions they may have, and according to the individual. Kovach et al (2004) found that arousal states and thus agitation could be affected by changing activity schedules.

Interventions such as music that calms one resident may agitate another. Optimising stimulation for every resident simultaneously could be impossible. Failure of institution-wide measures will imply the need for individualised therapy.
SECTION FOUR: THE FRAMEWORK 
ELEMENTS

Introduction

The proposed framework for managing agitation amongst aged care residents with dementia involves a staged sequence of actions, starting with the highest priority, namely preventative measures targeting the individual. Next in priority are interventions operating at the institutional (system) level. Lastly are the remedial interventions targeting the individual, these being required when agitation continues despite preventative and system-wide measures. Within each stage of the sequence, a range of prevention and treatment options may be available and chosen following assessment.

The framework borrows from the biological, behavioural, environmental, vulnerability and unmet needs models, and particularly from Turner (2005) 32. The framework avoids specific treatment recommendations because agitation’s diverse manifestation and aetiology prevents a narrowly prescriptive approach. Instead a general problem-solving rationale is proposed.

Therapeutic activities

Therapeutic activities within the framework fall into three categories described below in order of precedence, from most to least preferred.

Category 1: removing negative causes of agitation

Removing negative causes of agitation, thereby fixing the causes of agitation such as care deficiencies, unmet needs (e.g., social contact); and reducing task demands and environmental stressors. This category is both preventative and curative. The intervention can be system-wide or individually targeted. Removing the negative could include relocating the resident away from an aggravating influence, as the environment is incompletely controllable.

Category 2: applying positive interventions

Applying positive interventions, such as music or relaxation therapy, multi-sensory rooms, and verbal and diversionary therapies additional to everyday maintenance care. These strategies should be implemented as treatments for agitation only when no negative causes can be identified or modified. They function mainly at the individual level, but might also be offered routinely to many residents for reasons other than agitation. This approach could be preventative or curative.

Category 3: applying negative interventions

Applying negative interventions, such as physical restraint and pharmacological treatments. Such measures are controversial and should be limited to when other options are exhausted and the agitation threatens the welfare of the agitated
resident, or other residents, staff or visitors, and the institution’s functioning, despite reasonable allowances for the behaviour.

Risks to the resident should be considered against the intervention’s aims and expected benefits. If negative interventions must be used, it should be sparingly, reluctantly, individually, only as a temporary expedient, with ongoing observation, not as matter of course, only curatively and never preventatively, never punitively or as a substitute for positive measures and quality care.

Implementing the framework

The framework’s sequence is as follows. For further information, refer to the ‘Guidelines for nurses’ and flowcharts provided with this information.

Facility-wide management of agitation

Consider whether a number of residents are behaving similarly, showing “epidemic agitation,” and if so try to identify institution-wide triggers amenable to control. Review:

1. the physical environment;
2. the behaviour of staff, visitors or other residents;
3. whether there are common care deficiencies;
4. whether the residents are receiving too few or too many social interactions and diversional activities.

Example countermeasures include removing environmental triggers, training staff so they can avoid inadvertently stimulating agitation, and generally improving care and providing social engagement and meaningful activity to those who might benefit. This stage is both preventative and curative, and amounts to removing the negative and applying the positive at the group or system level. Removing the negative should take precedence, because positive interventions may not otherwise succeed.

Individualised management of agitation

Where agitation appears idiosyncratic to the resident, staff should identify and manage:

1. treatable physiological causes of agitation specific to that individual. The stage is both preventive and curative, and derives from the biological and unmet needs models, and again represents removing the negative at the individual level;

2. modifiable features of the institutional environment that might frustrate or annoy an individual resident with dementia sufficiently to trigger agitation. The rationale is that residents with dementia could be provoked by what
would irritate anyone else; yet the resident is even more vulnerable. Furthermore, residents have limited control of their environment, and impaired ability to communicate with those who might act on their behalf. Agitation becomes the available response, and might be considered reasonable under some circumstances. The environmental vulnerability model underpins this preventative stage, which exemplifies removing the negative at the individual level;

3. meaningful social interaction and stimulating activity, as well as solitude and rest as desired by the individual resident. This positive intervention could be preventative or curative, derives from the unmet needs model and operates at the individual level;

4. agitation with no identifiable cause. Responsible staff should decide whether the continued agitation threatens the welfare of any resident; or humiliates the agitated resident in front of staff, other residents or visitors; disturbs other residents; compromises operations; or causes concerns sufficient to damage the institution’s reputation. If not, then treatment may be unnecessary other than remaining vigilant to the resident’s needs. As a matter of course, staff working with residents should be trained to have realistic expectations of residents with dementia. Staff should know that dementia predisposes a person to agitation. Subject to safety and other practical provisos, staff should tolerate aberrant behaviour among this class of resident. Staff should also know how to identify unmet needs and other triggers for agitation, and watch for those. This stage effectively represents a passive, individualised intervention, neither positive nor negative in character;

5. agitation that threatens the comfort, safety or welfare of other residents, staff or visitors, or is otherwise unacceptable and defeats countermeasures listed so far. In this case, more intensive positive interventions such as individualised therapies, relaxation, diversion and multi-sensory rooms may be attempted, over and above normal provisions. These interventions are relegated to late in the sequence because they will be resource-hungry, and in any event should occur only when there are no apparent negative influences to remove;

Failing all of the above measures (i.e., removing the negative and instituting the positive) and only as a last option, consider:

6. negative interventions such as restraint or medication, subject to the precautions listed earlier.

As a general principle, monitoring of the resident’s behaviour and condition, the effects on others in the vicinity, and the outcomes of interventions should be continual. It will be evident that many aspects of the above framework simply reiterate principles of client-centred care, which should be applied as a matter of course, implying that high standards of nursing care are the best preventative, and the treatment of choice.
SECTION FIVE: ASSESSMENT TOOLS

The Brief Agitation Rating Scale (BARS)

The BARS \(^6\) is based on the Cohen-Mansfield Agitation Inventory \(^6\) and is suitable for use in residential aged care facilities. It measures the frequency of key behaviours associated with agitation, but not the severity of the behaviours. Three types of agitation are included: physically aggressive behaviour (hitting, grabbing, pushing); physically non-aggressive behaviour (pacing or aimless wandering, repetitious mannerisms, restlessness); and verbally agitated behaviour (screaming, repetitive sentences or questions, making strange noises, complaining). The version of the BARS attached to this document was adapted by the Institute for Algorithmic Medicine \(^6\).

The BARS takes about 2 minutes to complete. Residents with dementia who are agitated should have the BARS completed once per shift for 4 days (suggest Monday to Thursday) as part of the assessment for agitation.

The Confusion Assessment Method (CAM)

The CAM \(^18\) is used to detect delirium. The CAM Shortened Version is attached to this document. The diagnosis of delirium requires the presence of both feature 1 (acute onset and fluctuating course) AND feature 2 (inattention) as well as either feature 3 (disorganized thinking) OR feature 4 (altered level of consciousness).

The CAM Shortened Version takes only 1 or 2 minutes to complete.

Behavioural Analysis Form

The Behavioural Analysis Form is used to collate information relating to the triggers of agitated behaviour, and the outcome of interventions. A Behavioural Analysis Form can be used any time that a review of triggers, treatments and outcomes will be required. It is recommended that this form be used during assessment relating to each step of the framework. This will provide evidence for the general practitioner or other specialist clinicians if the agitation does not settle.
SECTION SIX: QUALITY IMPROVEMENT

Facility-wide strategies to improve the monitoring and management of agitation for residents with advanced dementia

In order to provide better monitoring and management of agitation in residents, a number of strategies may be implemented by the facility. These include:66-68

1. Form a working party to review how the facility manages challenging behaviours, including agitation.

2. Develop policies and procedures relating to screening for delirium, and assessing and managing agitation.

3. Build regular monitoring of agitation assessment and management into the regular quality improvement cycle in the facility.

4. Ensure staff have updates on agitation assessment and management programmed in to their regular education.

5. New staff need a comprehensive introduction to how the facility assesses and manages challenging behaviours, including agitation, during their orientation. Give out policies and paperwork at this time, and ensure all staff are aware of their role in the management of agitation.

Standards of care 69:

1. Observe for changes of behaviour every shift that could indicate the presence of delirium (hypoactive or hyperactive);

2. Assess residents for physical causes of agitation before trying any other interventions;

3. Use an assessment tool before and after any intervention for agitation to allow more objective assessment of the outcome for the resident;

4. Review the care plan for agitation regularly;

5. All staff have a role in preventing agitation, including ensuring they employ strategies to maintain a balance between understimulation and overstimulation. Remove agitated residents for a short period to a quieter environment to reduce ‘epidemic agitation’;

6. Encourage regular exercise within the capabilities of each resident as a preventive measure for agitation.
Education and Training:

- All nurses should be able to complete a BARS agitation rating scale;
- All nurses should be able to complete a CAM to screen for delirium, and know what to do if the result is positive;
- All registered nurses should be able to accurately assess a resident for pain and other physical conditions that might be causing agitation;
- All staff responsible for developing or implementing interventions used for agitation should understand the interventions, and be competent in using them.

Quality improvement monitoring of agitation intervention outcomes:

- All (100%) residents should have a behavioural needs assessment completed on admission as part of the ACFI process, prior to the care plan being developed.

Review and record at regular intervals:

- The % of residents who require interventions for agitation;
- The % of residents who have unmet needs assessed and documented before other interventions for agitation are trialled. For example, the % of residents who have a physical assessment completed;
- The % of residents with advanced dementia who have their goals of care documented.

Quality Improvement (QI) audits

- Consider commencing auditing with a select number (eg 5-10) resident files per month;
- Summarise the results, determine whether additional education or training is required;
- If progress is satisfactory, change monitoring to quarterly and monitor a select number eg 15-20 resident files per quarter;
- If progress is not satisfactory, continue monthly audits until the results are acceptable;
- Continuously monitor and summarise the results, provide feedback and further education to the care staff as necessary.
SECTION SEVEN: CONSENT AND CAPACITY ISSUES
Refer to your facilities’ policies and procedures relating to consent and capacity.

Capacity to give informed consent.

Before medical or dental treatment is provided to a resident, there is professional and legal responsibility to obtain consent for the treatment. Verbal consent is required: in most instances involving advanced dementia, another person will be required to make substitute consent (see below). Ensure that clear documentation of the consent process is made in the resident’s records.

Key points relating to capacity to give informed consent:
- it is presumed that a person has the capacity to make their own healthcare decisions unless proven otherwise, (similar to the presumption of innocence until proven guilty);
- an abnormal Mini-Mental State Examination (MMSE) score alone does not equal incapacity;
- evidence of incapacity should not be based on ignorance. The individual whose capacity is being assessed must be given relevant information;
- careful documentation is required, especially for borderline cases;
- competency to consent to medical treatment by an individual is a legal concept and legal decision, made finally by a court of law. To assess the capacity of individuals to consent to their own medical treatment is a time-consuming but necessary process.

A person who has the capacity to give consent to medical treatment should be able to:
- express in his or her own words what the problem is;
- express in his or her own words what the treatment choices are, including “do nothing”;
- express in his or her own words what the foreseeable consequences of each treatment might be;
- all of the above must not be based on delusional ideas.

Incapacity is present if a person:
- does not know what the issue is; OR
- does not know the possible choices; OR
- does not appreciate the reasonably foreseeable consequences; OR
- the decision is based on a delusional construct; AND
- cognitive or mental impairment is present.

Substitute consent

In NSW, the Guardianship Act 1987 establishes who can give valid substitute consent if an individual is incapable of doing so. A substitute decision-maker can be the ‘person responsible’ or a guardian: either an Enduring Guardian appointed by
the person when they had the capacity to do so, or a guardian appointed by the Guardianship Tribunal.

The Guardianship Act 1987 identifies four levels of treatment: urgent; major; minor; and special treatment. Urgent treatment (aimed at saving a person’s life) may proceed without valid substitute consent; all other treatment requires valid substitute consent. (See the Guardianship Tribunal website www.gt.nsw.gov.au for full details).

Key points relating to valid substitute consent:

- a ‘person responsible’ (in order of hierarchy) may be a guardian or enduring guardian who has the function of consenting to medical, dental or health care treatments; or the most recent spouse or defacto spouse with a close continuing relationship with the person; or an unpaid carer who is providing or was providing care to the person prior to admission to the residential aged care facility; or a relative or close friend who has close personal contact with the person;
- the ‘person responsible’, including an enduring guardian, cannot override a person’s objections to treatment if they are objecting;
- the ‘person responsible’ is required to act in the best interests of the person, and needs to take the person’s previously expressed wishes into account but MAY act contrary to those previously expressed views if the action is in the best interest of the person;
- for minor treatment, if the person is NOT objecting, but the person responsible cannot be located, the doctor or dentist may treat without consent 73, and clearly document in the resident’s notes that the treatment was necessary to promote the resident’s health and well-being, and that the resident did not object. Treatment may not proceed if the person is objecting;

A doctor may make an application to the Guardianship Tribunal to consider consent to a treatment if the guardian or ‘person responsible’ is objecting to the proposed treatment.

**When is a person objecting to treatment?**

Treatment may not be instituted if the person objects. Key points:

- objection is considered to be continuous and strenuous refusal;
- the behaviour of the individual will need to be interpreted;
- if verbally refusing, while physically doing what is required eg accepting and swallowing oral medication, but saying “no”, then that is not considered to be continuous and strenuous refusal;
- if both verbally refusing to have the treatment (eg, saying “no, no, no”) AND physically resisting to the treatment (eg clenching mouth so medication cannot be given), then that is evidence of continuous and strenuous refusal.

**TREATMENT MAY NOT PROCEED, EVEN IF THE PERSON RESPONSIBLE HAS GIVEN CONSENT.** The Guardianship Tribunal will need to be contacted to consent to the treatment despite the objections.
SECTION EIGHT: FAMILY CONFERENCES AND DEVELOPING PLANS OF CARE

Planning care for a resident by holding a family conference has two-fold benefits. Firstly, by discussing the goals of care for the resident the outcomes for the resident may be improved. Secondly, relationships between all the caregivers may improve by having everyone meeting together. The general practitioner (GP) can be paid under Medicare Item Numbers 734, 736 or 738 if he or she organises and coordinates the conference, or items 775, 778 or 779 if he or she participates in a conference (not more than 5 in twelve months).

When to hold a family conference

- Newly admitted resident to determine the goals and plan of care;
- As part of the annual ACFI review;
- Whenever an unforeseen significant change in the resident’s medical condition has occurred.

Tips for increasing the participation of the general practitioner in family conferences

Organising a family conference is time consuming, and it may be difficult for the general practitioner to organise, or attend. To increase the chance that the GP will participate, the following tips may be useful:

- Reduce the administrative burden on the GP. Contact the GP’s surgery and try to use the Practice Manager or Practice Nurse to assist with the planning;
- Try to fit the family conference in at a time when the GP is already visiting the facility;
- Always give the GP the option of participating when you are organising a family conference. If he or she wants to participate, try to work out any barriers to involvement so he or she can contribute;
- Offer the GP different levels of involvement eg the GP may be willing to be involved in a 10-15 minute teleconference instead of attending in person;
- When contacting the GP’s office, remind the receptionist that you want to talk about one of their patients eg “I want to talk to Dr X about Mrs X”. Be specific, this may assist in getting past the ‘gatekeeper’;
- Think about the care of the resident being the GP’s responsibility, so the Practice Nurse may be useful. If you tell the Practice Nurse about concerns you have about a particular resident, and the need for a family conference, the Practice Nurse may be willing to raise the issues with the GP on your behalf;
- Define the GP’s role in the family conference, be very specific about what you want to achieve from the family conference. GP’s prefer family conferences when they occur at specific difficult points in the disease trajectory of a resident;
- Make sure all the lines of communication are clear to both GP and facility staff.
Steps in holding a family conference

To ensure the GP is remunerated for his or her coordination of and participation in the family conference, the following steps are required to be performed:

1. Identify the resident’s need for a family conference;
2. Contact the GP’s Practice Nurse or Practice Manager to assist with coordinating the family conference, and be the single point of contact for all attendees;
3. The Practice Nurse or Manager will consult with facility staff and determine which health professionals will be involved. NB, there must be 2 other healthcare providers present at the family conference, as well as the GP. These providers can be a nurse and a diversional therapist from the aged care facility, but could be another health service provider such as a physiotherapist, palliative care specialist or geriatrician. The other health service providers may charge a fee for their attendance;
4. Arrange a time, preferably at least 4 weeks in advance of an annual review, or as soon as possible after an unforeseen significant change in the resident’s medical condition;
5. Develop an agenda and an introduction letter, the coordinator will then send these to participants;
6. The resident’s consent is required, or if unable to give his or her own consent, the person responsible’s consent. Verbal consent is all that is necessary. Ensure that the resident/person responsible understands there will be a Medicare charge generated for the GP’s involvement, and other health service providers may also charge for their time;
7. Conduct the family conference. All members of the family conference team must participate for the whole of the conference. The conference may be face to face, or via telephone, video link, or a combination. Issues to discuss include:
   - The resident’s medical history;
   - Review of the previous goals and plan of care;
   - Identify current multidisciplinary care needs;
   - Identify the outcomes to be achieved by members of the multidisciplinary care team;
   - Identify tasks that need to be undertaken in order to achieve outcomes and allocate tasks to team members;
   - Identify whether previously identified outcomes have been achieved.
8. A record of the family conference must be kept in the resident’s records, and a copy offered to the resident/ person responsible, and other health service providers (with the consent of the resident/person responsible).

What to discuss during a family conference for a resident with advanced dementia

A number of decisions relating to the future care needs of a resident can be made in advance of their occurring, and can be included in a family conference discussion.
One study\(^7\) of death from dementia has revealed that:

- 85% of people with dementia die before the very end stage of dementia is reached;
- death, regardless of when it occurs, is most commonly associated with cachexia/ dehydration (35.2%), cardio-vascular disorders (20.9%), and acute pulmonary diseases such as pneumonia (20.1%);
- over half of residents who reach the very end stage of dementia will die of cachexia/dehydration;
- approximately 9% of people with dementia die of an unknown, acute cause.

Therefore, in discussing the goals and plan of care for a resident with advanced dementia, the following issues could be included on the agenda:

- the typical trajectory of dementia;
- the symptoms the resident is currently experiencing that are causing distress, and how they will be managed;
- the likelihood of symptoms that may occur in the future, and how each will be addressed;
- the benefits and burdens of any treatments should be clearly articulated so decisions made about current or future care are based on objective information:
  - urinary incontinence; repeated urinary tract infections;
  - gait disturbances that leave the individual at high risk of falls; injuries resulting from falls;
  - pneumonia;
  - swallowing problems: pouching of food, dysphagia;
  - feeding issues and aversive feeding behaviours;
  - weight loss due to cachexia;
  - dehydration;
  - risk of decubitus ulcers;
  - aspiration pneumonia;
  - anxiety, agitation, aggression, depression, psychotic symptoms;
  - loss of ability to communicate verbally, and how symptoms such as pain are recognised and treated;
- the family member’s role in care;
- the site of care: a palliative approach to care given in the facility; times when transfer to hospital may be necessary; curative treatments offered in hospitals;
- cardiopulmonary resuscitation (CPR);
- medically provided nutrition and hydration (PEG feeds, subcutaneous hydration);
- blood transfusions;
- antibiotic therapy: in the facility/ in hospital (via intravenous infusion), and whether or not to give antibiotics or/and palliate symptoms with analgesics, antipyretics, sedatives.
In the absence of an advance care directive recording wishes for future healthcare, (made by the individual when they had the capacity to do so), the person responsible needs to make decisions based on either the known or probable wishes of the resident; or what is in the ‘best interest’ of the resident: the relative benefits and burdens of a particular treatment choice in terms of the ability to relieve any suffering and maintain comfort and dignity and the best possible quality of life 77. Nurses can assist persons responsible by reassuring and encouraging them to think of times when there were conversations about what the resident might have wanted, so that the known or probable wishes of the resident become clearer.

Conflicts are most likely to occur around two main issues—aspiration pneumonia and neurogenic dysphagia 77. Many clinicians and families find it harder to discontinue a therapy than to withhold it in the first place, so it is particularly important that the person responsible is aware of the burdens and benefits of medical interventions such as PEG feeds. In some instances, it may be easier to institute a trial intervention for a specific time frame eg a trial of oral antibiotics for one week for repeated urinary tract infections, which can be discontinued if unsuccessful 78. Research in NSW 79 has shown some evidence that residents have an increased survival rate if their plan of care opts for them remaining in an aged care facility rather than transfer to hospital for care, compared to those without a plan of care.

Facility staff not involved in the development of the plan of care during the family conference need to be informed of the outcomes, and be given the opportunity to discuss any decisions they find ethically challenging, so that consensus about the goals of care are reached, and potential for conflict avoided.

**General practitioner contribution to a care plan**

A GP may contribute to the care plan of a resident, and be paid under Medicare item no. 731. The recommended interval between reviews is 6 months, but may be 3 monthly. To ensure the GP is remunerated, the following steps need to be undertaken75, 80:

1. Invite the GP to contribute to the ‘nursing and personal care plan’ of the resident;
2. The resident or person responsible need to be informed that the GP will be consulted, and consent recorded;
3. Provide the GP with the resident’s notes, to review alongside the GP’s own patient notes;
4. The GP will contribute to the care plan by discussing it with facility staff and giving any additions, changes or other recommended management;
5. The fact that the GP contributed to the care plan is documented on the care plan in the facility;
6. The GP is also required to document in the resident’s medical records that he or she has contributed to the care plan. The documentation may just be a date, signature, and comment that a contribution to the care plan has been made, but it is also recommended that the GP includes a brief summary of recommendations;
7. Facility staff may write detailed notes into the care plan after verbal discussion with the GP;
8. Once an Item 731 has been claimed by the GP, and it is documented that the resident requires Allied Health or dental services the resident may be eligible for access to up to 5 Allied Health and 3 Dental care services per year.
SECTION NINE: REFERENCES


71. Merl H, Bauer L. *Time to think about Aged Care & Dementia*. Sydney: Central Coast Dementia Advisory Service, North Sydney Central Coast Health, Central Coast Division of General Practice; 2005.


SECTION TEN: ATTACHMENTS
The Brief Agitation Rating Scale (BARS) for Residents of Aged Care Facilities

The BARS measures the frequency (not severity) of agitated behaviour.

**When to complete this tool:** a caregiver who has spent time with a resident can complete the tool any time a resident is exhibiting agitated behaviour. For a resident with uncontrolled agitation it is recommended that the BARS be completed once per shift (ie morning, afternoon and night) for 4 days to gather evidence of the frequency of agitated behaviours.

**How to score:** Total the scores for each of the 10 behaviours to obtain a total agitation score.

**Date:** …………………… **Time:** ……………………… **Resident name:** ………………………………

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<tr>
<th>Behaviour</th>
<th>Frequency of each behaviour and score</th>
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<tbody>
<tr>
<td></td>
<td>None (score = 0)</td>
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<td></td>
<td>Once or twice (score = 1)</td>
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<td></td>
<td>Occasionally (score = 2)</td>
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<td></td>
<td>Often or continuous (score = 3)</td>
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<td>Hitting</td>
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<td>Pushing</td>
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<td>Pacing or aimless wandering</td>
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<td>Repetitious mannerisms</td>
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<td>Restlessness</td>
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<td>Screaming</td>
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<td>Repetitive sentences or questions</td>
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<td>Making strange noises</td>
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<td>Complaining</td>
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<td><strong>Total Score</strong></td>
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<td><strong>Comments</strong></td>
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CONFUSION ASSESSMENT METHOD (CAM) SHORTENED VERSION WORKSHEET

EVALUATOR: .................................................. DATE: ...........................................

1. ACUTE ONSET AND FLUCTUATING COURSE

a) Is there evidence of an acute change in mental status from the patient’s baseline? No _____ Yes _____

b) Did the (abnormal) behavior fluctuate during the day, that is tend to come and go or increase and decrease in severity? No _____ Yes _____

2. INATTENTION

Did the patient have difficulty focusing attention, for example, being easily distractible or having difficulty keeping track of what was being said? No _____ Yes _____

3. DISORGANIZED THINKING

Was the patient’s thinking disorganised or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject? No _____ Yes _____

4. ALTERED LEVEL OF CONSCIOUSNESS

Overall, how would you rate the patient’s level of consciousness?

-- Alert (normal)

-- Vigilant (hyperalert)
-- Lethargic (drowsy, easily aroused)
-- Stupor (difficult to arouse)
-- Coma (unarousable)

Do any ticks appear in this box? No _____ Yes _____

If all items in Box 1 are ticked and at least one item in Box 2 is ticked a diagnosis of delirium is suggested.

Explanation of features used in the Confusion Assessment Method (CAM) Shortened Version

**Feature 1: Acute Onset and Fluctuating Course**
This feature is usually obtained from a family member or nurse and is shown by positive responses to the following questions: Is there evidence of an acute change in mental status from the patient's baseline? Did the (abnormal) behaviour fluctuate during the day, that is, tend to come and go, or increase and decrease in severity?

**Feature 2: Inattention**
This feature is shown by a positive response to the following question: Did the patient have difficulty focusing attention, for example, being easily distractible, or having difficulty keeping track of what was being said?

**Feature 3: Disorganised thinking**
This feature is shown by a positive response to the following question: Was the patient's thinking disorganised or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject?

**Feature 4: Altered Level of consciousness**
This feature is shown by any answer other than "alert" to the following question: Overall, how would you rate this patient's level of consciousness? (alert [normal], vigilant [hyperalert], lethargic [drowsy, easily aroused], stupor [difficult to arouse], or coma [unarousable])

The diagnosis of delirium by CAM requires the presence of features 1 and 2 and either 3 or 4.
# BEHAVIOURAL ANALYSIS FORM

<table>
<thead>
<tr>
<th>BEFORE INCIDENT</th>
<th>INCIDENT</th>
<th>AFTER INCIDENT</th>
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<tbody>
<tr>
<td>Date:</td>
<td>Observed behaviour:</td>
<td>Strategy used:</td>
</tr>
<tr>
<td>Time:</td>
<td>Duration of behaviour:</td>
<td>Outcome (include repeat BARS score):</td>
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<tr>
<td>Location:</td>
<td></td>
<td>Resolution time:</td>
</tr>
<tr>
<td>BARS Score:</td>
<td>PRN medication:</td>
<td>Signature:</td>
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<td>Persons in the vicinity:</td>
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<tr>
<td>What was the resident doing at the time of the incident?:</td>
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<tr>
<td>Trigger (if known)</td>
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**RECOMMENDATIONS:**

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SECTION ELEVEN: ANNOTATED BIBLIOGRAPHY

1. Checklists for auditing delirium screening / assessment within residential age care facilities. Access from:


   These checklists would be useful for nurses and managers required to establish systems of quality improvement monitoring relating to delirium.


   These guidelines provide recommendations for the identification and management of delirium in Australian healthcare settings, including residential aged care. They would be useful as a teaching aid for nurse educators, and to have available for visiting medical practitioners.


   These Guidelines inform the safe practice of using chemical and physical restraint in residential aged care facilities in NSW. They replace a previous NSW Health document: ‘The best practice model for the use of psychotropic medication and guidelines on the management of challenging behaviour in residential aged care facilities in NSW’.


   Guidelines relating to agitation in dementia were developed via survey of 100 leading experts in dementia care. These guidelines are neatly summarised in a flowchart, which would be useful for visiting medical practitioners considering pharmacological management of severe agitation. The flowchart can be accessed from the EKS® Expert Consensus Guidelines® series. To access, go to:

   [http://www.psychguides.com/node/56](http://www.psychguides.com/node/56) There are downloads suitable for families and caregivers as well as the expert guidelines for managing agitation.

These guidelines provide comprehensive information to assist doctors and nurses discuss prognosis and end of life issues with people with eventually terminal conditions, and their caregivers. These guidelines would be very useful to use as part of education sessions relating to communicating difficult issues. Topics included in the guidelines are timing of discussions, preparation, setting, how to discuss prognosis and end-of-life issues, facilitating hope, commencing or changing treatments, discussing future symptom management, discussing the process of death and dying, managing conflict, and discussing medically futile treatments.

The guidelines can be retrieved for use from:


6. North West Melbourne Division of General Practice. GP and Residential Aged Care Kit. Clinical Information Sheet: Pneumonia; and


These information sheets were written to assist general practitioners and nurses in residential aged care facilities involved in the care of residents with two common causes of infection in aged care facilities: pneumonia and urinary tract infection. The information contained in each sheet includes background information about the issue, assessment, investigations and management of the infection. Information enabling the clinician provide palliation of symptoms is also included.

The information sheets can be retrieved for use from:

http://www.nwmdgp.org.au/pages/after_hours/GPRAC-CIS-12.html (pneumonia) and