# RESPONDING TO AGITATION IN PEOPLE WITH DEMENTIA

Although medication and physical restraint have traditionally been used to treat agitated behaviours, there is growing evidence that holistic approaches can be beneficial, says Jan Dewing

## Summary

Agitation is a symptom rather than a condition and thus an indicator of, for example, unmet care needs or biopsychosocial problems. Non-pharmacological interventions are the first course of action for older people with dementia who are agitated. This article helps nurses to broaden their understanding of agitation, its causes, including trigger factors in the environment and those that nurses may cause. Finally, it summarises evidence on non-pharmacological and pharmacological interventions so that evidence can be incorporated into person-centred care.

## Keywords

Agitation, dementia, person-centred care

FOR MANY older people in hospital and other care settings agitation is a major problem. It is a symptom rather than a condition and therefore an indicator that other factors are at work. In the case of older people with dementia, especially when they have reduced communication skills, agitation can often be a sign that people have an unmet need that is causing them discomfort or distress, that the environment is offering under or overstimulation or of an acute or chronic delirium. This is why it is vital to look beyond the symptom and explore the person, their biography and their known ways of coping.

Opposite page: careful application of preferred music has positive effects on decreasing agitated behaviours Brodaty *et al* (2003) offer a seven-tier model to show how behaviours and psychological signs associated with dementia can emerge throughout the dementia journey (Box 1, page 20). According to this model many people with dementia who have challenging behaviours can and should be managed in a variety of care settings. This will be the case with increasing numbers of older people with dementia entering health and other care settings for other reasons. This article considers agitation in older people with dementia and the nursing response to people living with dementia who are agitated.

## **Understanding agitation**

Cohen-Mansfield (2008) describes behaviour as a form of language and communication. The literature, whether it is biomedical, psychological or person centred, describes a number of behaviours that people with dementia tend to use to communicate their feelings or needs. These may include different patterns of wandering (Dewing 2010), calling out and repetitive questions. As cognitive abilities, including language skills, change and eventually decline, behaviour can become the primary source of communication.

Nurses and other healthcare workers should look beyond the obvious and try to understand what the behaviour shows about the person and their needs. For example, a man sitting in a wheelchair calls out repetitively, 'Why am I being punished... Help me, somebody help me.' The nurses talk about the man as calling out constantly and find him difficult to manage. A short conversation with the man reveals that he is sitting in a non-propelling wheelchair and feels imprisoned because he cannot move himself. Even if his need for freedom of movement is met, he may show the same or a similar behaviour the next day – this is because there is another unmet need.



Agitation is a term used to cover a number of behaviours (Stokes 2000). A primary definition suggested by Cohen-Mansfield and Billig (1986) is an inappropriate verbal, vocal or motor activity that is not judged by an outside observer to be an obvious

## Box 1 Seven-tier model of the behaviours and psychological signs associated with dementias

- **Tier 7:** Dementia with extreme behaviours, for example, physical violence. Prevalence: rare.
- **Tier 6:** Dementia with very severe behaviours, for example, physical aggression, severe depression, suicidal tendencies. Prevalence: <1 per cent.
- Tier 5: Dementia with severe behaviours, for example, severe depression, psychosis, screaming, severe agitation. Prevalence: 10 per cent. Management: in dementia-specific nursing homes, or by case management under a specialist team.
- Tier 4: Dementia with moderately severe behaviours, for example, major depression, verbal aggression, psychosis, sexual disinhibition, wandering. Prevalence: 20 per cent. Management: in most care settings with specialist consultation.
- **Tier 3:** Dementia with mild behaviours, for example, night-time disturbance, wandering, mild depression, apathy, repetitive questioning, shadowing.

Prevalence: 30 per cent. Management: at home or in other care settings by all care workers.

- Tier 2: Dementia with no dementia-associated behaviours. Prevalence: 40 per cent.
- Tier 1: Majority of the population with no dementia. Management: universal prevention, although specific strategies to prevent dementia remain unproven.

Note: Prevalence is expressed as estimated percentage of people with dementia who are currently included in this category. (Brodaty *et al* 2003) outcome of the individual's needs or confusion. This open definition can include everything other than overt physical and verbal aggression. Agitation in dementia is particular according to Cohen-Mansfield et al (1995), in that its prevalence is linked with the progression of the dementia; even though it is not caused by the dementia alone. For example, Cohen-Mansfield et al (1995) have shown that verbally agitated behaviours are most prevalent in the middle stages of dementia when verbal abilities are still maintained, but the ability to use them effectively is diminishing. In contrast, physically agitated behaviours tend to occur in the later stages of dementia, when verbal communication is usually severely compromised. Additionally, in dementia, agitated behaviours are usually a response to actions by others, which the older person does not comprehend and does not want.

It is helpful to distinguish between aggression and agitation because the terms can be used interchangeably which is inaccurate. Based on the Cohen-Mansfield Agitation Inventory, Rabinowitz *et al* (2005) offer an approximate breakdown of aggressive behaviours and agitated behaviours which can help nurses distinguish between them:

- Aggressive behaviour: hitting, kicking, scratching, biting, pushing, grabbing, throwing objects, cursing or verbal aggression, spitting, tearing items/destroying property, hurting self or others and screaming.
- Physically agitated behaviour: pacing, trying to get to a different place, general restlessness, inappropriate dressing or disrobing, handling items inappropriately.
- Verbally agitated behaviour: complaining, constant requests for attention, repetitive questions, performing repetitious mannerisms and negativism.
- Hiding and hoarding.

However, caution needs to be exercised with this breakdown. It is based on the description of agitated behaviours from one assessment scale only, the Cohen-Mansfield Agitation Inventory. Further, hiding and hoarding have been isolated into a separate category. Older people may hit out in a defensive way to keep others away from them and protect their personal space. This is qualitatively different from a person actively or aggressively hitting out to cause direct harm to another.

Older people at high risk of agitation in hospitals and other care settings include those with cognitive decline, dementia, multiple medical or psychiatric diagnoses and those taking multiple medications. Where agitation does develop it is often associated with acute illness. In particular, agitation can be a major symptom of a delirium (Inouye *et al* 1990, Young and Inouye 2007, Dewing 2009a). Delirium is usually a reversible organic condition that is characterised by altered level of consciousness, attention abnormalities, altered psychomotor activity and a disordered sleep-wake cycle.

Agitation is made worse by pre-existing disorders and syndromes, such as dementia. When an older person with dementia shows signs of agitation it is therefore important to exclude other physical and psychological factors such as pain and tiredness (Doody *et al* 2001), separation from other known people and medical causes.

Agitation can contribute to negative longer-term outcomes for health and wellbeing. From a person-centred perspective, agitation is significant because of how it feels for the person who is agitated. For example, agitation can be experienced as frightening (Burns *et al* 2002). Caregivers have identified agitated behaviours as one of the most challenging in caring for those with dementia (Wagner *et al* 1997). Agitated behaviours may place older people at risk of harm to themselves and others, including their caregivers. Agitation-related behaviours are also a reason for admission into long-term care. When agitation develops, it is most often experienced by others as unwanted or inappropriate behaviour.

Of more concern is that it is often taken at face value. It is also significant because many nurses feel challenged by displays of agitation and powerless to intervene. In part this is connected to the knowledge, values and beliefs that nurses have about dementia and agitation. Nurses may believe agitation is a direct consequence of dementia instead of considering that it may be influenced by various factors including the person's pre-dementia and current personality, lifelong coping strategies, type and severity of cognitive impairment, general health status and environmental factors.

Nurses who consider agitation to be a direct consequence of dementia alone are more likely to have a containment and restraint approach to care, whereas nurses who associate agitation with a range of factors are more likely to adopt a holistic or person-centred approach to care.

## Traditional management of agitation

Traditional management has generally relied on methods of restraint. Agitation influences older people's care experiences and their health outcomes. For example, successful rehabilitation/re-enablement relies on the improvement of functional health outcomes and, for this to happen, physical and *Caregivers have identified agitated behaviours as one of the most challenging in caring for those with dementia* 

emotional wellbeing are important. Restrained patients have increased length of hospitalisation, higher rates of complications, are less likely to be discharged home, are more likely to be discharged to a long-term care facility and are at a higher risk of death in the acute care setting than unrestrained patients (Paterson *et al* 2003, Evans 2010).

There are various forms of restraint in use: mechanical, physical, technological, chemical and psychological (RCN 2008). Use of restraints, however indirect, lessens older people's ability to participate fully in rehabilitation/re-enablement, thereby extending lengths of stay and adversely influencing discharge destination.

**Chemical restraint** The National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence (2006) state that non-pharmacological interventions should be used first, before medication, in cases of challenging behaviours. The difficulty for health professionals is that the evidence base for many of the non-pharmacological interventions is limited, often relying on findings from single case studies.

Banerjee (2009) highlighted increasing concerns about the use of antipsychotic drugs in dementia care. The report confirmed that there are significant issues in terms of quality of care and patient safety. Banerjee further stressed that antipsychotic drugs appear to be used too readily and, at their likely level of use, the potential benefits are probably outweighed by their overall risks. The difference between a chemical restraint and a treatment centres on the extent to which the patient has been assessed and medication prescribed as part of a treatment plan or whether it has been given specifically to control the patient's behaviour for the convenience of staff and other patients.

Poole and Mott (2003) conclude that nursing actions often do not meet best practice standards in the care of older, agitated patients. In a small-scale, qualitative study they found that an antipsychotic drug indicated for use in psychoses was the chemical intervention favoured by nurses. Evidence suggests that this drug can cause severe extrapyramidal symptoms, hypotension, parkinsonism and side effects that mimic symptoms of agitation (Mintzer and Burns 2000). Poole and Mott (2003) highlight that nurses may not place a high priority on therapeutic intervention when older people experience agitation. They note the frustration of nurses who needed to 'get out and get some other work done' or who were disappointed when medical prescriptions were inadequate because they wanted instant results to enable them to complete their essential work.

**Physical restraint** Poole and Mott (2003) suggest that the use of physical restraints is common in the management of agitation, particularly in residential care facilities. Weiner *et al* (2003) concur with Poole and Mott's (2003) findings, although they found that agreement to use restraint was higher in medical wards. However, physical restraints are reported to be associated with reduced continence, pressure ulcers, immobility, more agitated behaviours, sometimes referred to as 'paradoxical agitation' and infections that ultimately contribute to increased morbidity and mortality (RCN 2008). In addition, abnormal changes in body chemistry, basal metabolic rate and blood volume have been reported (Poole and Mott 2003).

Physical restraint has also been associated with muscle and motor weakness, immobility, skin breakdown, cardiac stress, lower extremity oedema, nutritional impairment, agitated behaviours, cognitive impairment, unsocial behaviour and injury that results in increased morbidity and mortality (Capezuti *et al* 1996, Dawkins 1998, Bartels *et al* 2003). Psychological damage related to physical restraint is also considerable (Evans 2010). The use of restraints might contribute to regressive, disorganised and unsocial behaviour as well as loss of self-image, disorientation, withdrawal, feelings of discomfort, dependency, resistance, fear and anger.

In summary, agitated behaviours have traditionally been managed in a compartmentalised way, with the use of psychotropic medications or physical restraints and often the broader needs of the person as a human being overlooked. These treatments may cause negative effects (Bradley *et al* 1995, Bartels *et al* 2003, Cohen-Mansfield 2004). Concerns have led to research seeking alternative approaches to reduce the need for chemical or physical restraints in the care of older people with dementia. To date the evidence available for nurses is, in some aspects, reasonably convincing and in others variable.

Using aspects of familiar environments such as objects from home can stimulate remote memories associated with positive feelings

## **Evidence-based interventions**

Assessment Accepting people's interpretations of where they are and their lived experiences, or their version of reality, is an important starting point and can co-exist alongside a more clinical assessment method. Assessing agitation should form part of a broader person-centred assessment method, however medical and behavioural-based knowledge can be usefully incorporated into nursing assessment. Stokes (2000) suggests creative brainstorming as a time-effective starting point as this avoids the detailed periods of observation and recording that most assessment tools and methods specify. When creativity fails to produce quick answers or when agitation is complex, a more systematic assessment may be called for.

The Cohen-Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield 2000) is a 29-item caregiver rating questionnaire for the assessment of agitation in older persons. It includes descriptions of 29 agitated behaviours, each rated on a seven-point frequency scale. There is also a short form (SF) version of this scale. The CMAI-SF contains 14 items to be rated by caregivers on a five-point frequency scale. The items are based on the factor structure (relationship between the variables) of the original inventory. Once the actual behaviour(s) have been identified, they can be mapped until a picture is built up over a 24-hour period. This helps to identify the frequency, situations and even more precise trigger factors to the behaviour. Carrying out a baseline assessment is also helpful, if not essential, before making referral for specialist assessment to mental health services.

A broader-based model for use in a needs-led approach to care, specifically in residential and nursing care settings, is the Newcastle model (James *et al* 2006). The Newcastle model provides a framework for drawing together a number of possible causes of the behaviour and a process by which a range of therapeutic interventions can be delivered. The model works on the basis that the challenging behaviour is a consequence of an unmet need. The Newcastle model has been influenced by Kitwood's work on person-centred dementia care and Cohen-Mansfield's work on challenging behaviour.

Environmental factors: under or overstimulation

People with dementia are acutely sensitive to the environment they live in. Generally, they are less able to handle uncertainty and even situations that they could manage before living with dementia (Cohen-Mansfield and Werner 1995, Cohen-Mansfield 2004). The ideal environment for a person with dementia is not easy to arrange in most healthcare

## Feature

#### Box 2 Haloperidol: recommendations from a systematic review

- 1. Haloperidol appeared to provide no improvement in agitation among patients with dementia compared with placebo, but side effects were frequent.
- There was a high level of the drug being discontinued in several studies in the review suggesting that side effects led to discontinuation of treatment in some patients.
- Because of the wide focus of this meta-analysis, not enough information was provided to permit recommendations linking haloperidol treatment of agitated dementia to degree of dementia, manifestations of agitation, or dosage and duration of treatment with haloperidol.
- 4. Individual analysis of reports indicated that higher dose haloperidol (more than 2mg per day) may have been more effective than lower dose haloperidol (less than 2mg per day) in controlling

settings. Noisy, poorly lit or improperly heated areas can cause increased agitation (Doody *et al* 2001, Dewing 2009b).

Older people with dementia are especially susceptible to the incongruence created by an environment that is unfamiliar. This may result in negative psychosocial outcomes, such as anxiety and agitation (Hall and Buckwalter 1987, Sung and Chang 2005).

Extremes in the social environment can also cause problems, for example, if someone is left alone for long periods or is overwhelmed by being around too many people. Medical procedures are particularly disruptive and can lead to sudden agitation or increased disorientation in a person who was calm at home. Creating a sense of familiarity in the environment through using aspects of previous familiar environments such as objects and pictures from home can be a way to stimulate remote memories associated with positive feelings in older people with dementia. This can also enable people to interact and connect with objects. An added benefit is that people are also more likely to engage to some level with an activity or occupation.

Debates about caring for people with dementia separately from those without dementia continue. However, a recent systematic review found that there are no identified randomised controlled trials (RCTs) investigating the effects of special care units on behavioural symptoms in dementia, and also there is no strong evidence of benefit from the available non-RCTs (Lai *et al* 2009).

The researchers conclude that it is probably more important to implement best practice than to focus on providing a specialised care environment. aggression, but not other manifestations of agitation among patients with mild to moderate dementia.

- 5. Similar analysis suggested that prolonged therapy with haloperidol (more than three to six weeks) or higher dose (more than 2mg a day) was more likely to result in side effects than short-term therapy (three weeks) or lower dose (less than 2mg a day).
- 6. The reports provided too little information to permit interpretation of the effect of degree or type of dementia on response to haloperidol. Except for a favourable response of aggression to haloperidol, no other manifestations of agitated dementia were found to have improved after therapy with haloperidol, compared with controls.

(Lonergan et al 2002)

**Other therapies** There are promising signs of other therapies being useful, although in limited cases. For example, Bayles *et al* (2006) suggest simulated presence therapy can reduce agitation and social isolation for people living in care homes who have moderate to severe dementia of the Alzheimer type. As yet there is no evidence that it is effective in other settings. Music therapy and aromatherapy (Ballard *et al* 2002) have also shown some signs of reducing agitation.

Music can be used to modify environmental stimuli (Hall and Buckwalter 1987, Gerdner and Buckwalter 1999) and some types of music may create a neutral environment to mask noises and prevent overstimulation. However, for older people who are already overstimulated the use of even preferred music requires careful application. A literature review by Sung and Chang (2005) found that preferred music decreases agitated behaviours in older people with dementia. It should be noted that preferred music needs to be used rather than any music to hand.

**Pharmacological treatment** Concluding a systematic review, Kindermann *et al* (2002) state that conventional antipsychotics modestly improve psychosis and agitation in older people with dementia. Newer treatments, such as atypical antipsychotics, are at least effective and have fewer adverse effects. The authors add that there is no ideal drug treatment available and that psychosocial management is an essential part of treatment. However, in a larger systematic review Lonergan *et al* (2002) made six conclusions about the drug haloperidol. The review is noteworthy

## Training for staff in psychosocial care interventions seems to reduce the need for pharmacological treatments

because many nurses and junior doctors often consider using this drug in cases of agitation (Box 2).

Updating a previous Cochrane review, Lonergan and Luxenberg (2009) examined the evidence for the use of valproate preparations to manage agitation in people with dementia. The updated review supported the earlier findings that valproate preparations are ineffective in treating agitation among people with dementia. The review confirms that valproate therapy is associated with an unacceptable rate of adverse effects. The researchers conclude that on the basis of current evidence, valproate therapy cannot be recommended for management of agitation in dementia.

It should be remembered that most pharmacological studies have focused on mixed populations of people with dementia, so it is not possible to assess a medication's relative efficacy in specific forms of dementia. For example, people with dementia of the Lewy body type may be more sensitive to neuroleptics (Doody *et al* 2001).

**Education and training** Deudon *et al* (2009) reported that an education programme for care staff run over eight weeks reduced the presence of agitation and other behavioural symptoms in people with advanced dementia living in care homes. The effect continued for at least three months after the end of the programme. This suggests that education and training should be ongoing rather than a one-off event. Fossey *et al* (2006) evaluated the effectiveness of a training and support intervention for nursing home staff in reducing the proportion of residents with dementia who were prescribed a specific type of medication known as neuroleptics.

The researchers found the proportion of residents given these medications in the intervention homes (23 per cent) was almost half the rate seen in the control homes (42.1 per cent). They report an average reduction in neuroleptic use of 19.1 per cent. While it might be assumed that levels

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## Feature

of agitation decreased, it should be noted that no significant differences were found in the levels of agitated behaviour between intervention and control homes. Similarly, Testad *et al* (2005) report on an educational programme that led to a significant reduction in the use of restraint and again levels of agitation did not significantly change. Training and support for nursing and care staff in psychosocial care interventions seem to reduce the need for pharmacological treatments.

## Conclusion

Agitated behaviours have traditionally been managed with the use of psychotropic medications or physical restraints: treatments that may cause negative effects. Non-pharmacological interventions should be the first choice and should always form part of treatment for agitated behavioural disturbances. Interventions need to sit in a broader holistic or person-centred assessment and care plan. Where holistic interventions fail to reduce agitation, short-term use of atypical antipsychotics is preferred because of lower adverse event rates. Non-psychotics should be reserved as second-line treatment. However, drug treatments should never be a first resort and, where they are introduced, they should be started with the lowest possible dose with regular monitoring for adverse events. Pharmacological treatment should not be used as the only means of response.

## Find out more

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