# Managing behavioural problems in dementia

Behavioural and psychological symptoms are integral to the dementia syndrome and manifest at all levels of severity, even during the pre-dementia stage. Successful management of these symptoms reduces the burden of distress experienced by both patients and caregivers.



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Most people with dementia exhibit behavioural or psychological symptoms at some point in their illness and around half of this group requires some form of intervention. There are several different ways in which these patients and their carers can be assisted. A clear and logical approach to clinical management will reduce the likelihood of therapeutic disappointment and it is important that any intercurrent medical problem causing pain, discomfort and/or delirium be excluded before treatment is initiated on a symptomatic basis.

#### Prevalence and clinical features

Dementia affects about 6% of people aged over 65 years and approximately 20% of people aged 80 years and older. After the age of 60 years, the disease doubles in prevalence every five years. In the developed world, most cases of dementia are due to Alzheimer's disease, cerebrovascular disease or a mixture of the two. Other less common causes include frontotemporal lobar degeneration, dementia with Lewy bodies, Parkinson's disease with dementia, and alcohol-related dementia. In all, there are about 70 different known causes of dementia.

Behavioural and psychological symptoms are found in all types of dementia and in all stages of the disease. Even in people with mild dementia, most of whom are still living at home, these symptoms are relatively prevalent and include:

- apathy (present in 30% of cases)
- depression (in 20% of cases)
- delusions (in 20% of cases)
- anxiety (in 15% of cases)

- Behavioural and psychological symptoms are common in people with dementia. These symptoms can occur in mild, moderate and severe dementia.
- General medical problems can exacerbate existing confusion and induce behavioural and/or psychological symptoms in dementia. For this reason, patients should be assessed for intercurrent illness, adverse effects of prescription medications, drug and alcohol abuse and dehydration before being treated for behavioural and psychological symptoms.
- A variety of nonpharmacological treatments are worth trying in patients who present with behavioural and psychological symptoms.
- Antidepressant medication can be effective in patients with dementia and depression.
- Low-dose antipsychotic medication is sometimes useful in patients with dementia complicated by marked agitation, aggression or psychosis.

- agitation (in 10% of cases)
- hallucinations (in 10% of cases).

Approximately half of all patients with dementia develop clinically significant behavioural or psychological symptoms warranting some form of intervention. In a study undertaken by the author's group in nursing home patients, most of whom had dementia, overt behavioural disturbance occurred frequently and included restlessness, verbal abuse, pacing, hitting other people and screaming (Figure 1).

#### Causes of behavioural and psychological symptoms

Beyond their obvious relationship to dementia, the underlying causes of behavioural and psychological symptoms remain relatively obscure. There is, however, evidence that the premorbid personality of the person with dementia and the type of dementia they have contribute to the likelihood of behavioural disturbance.

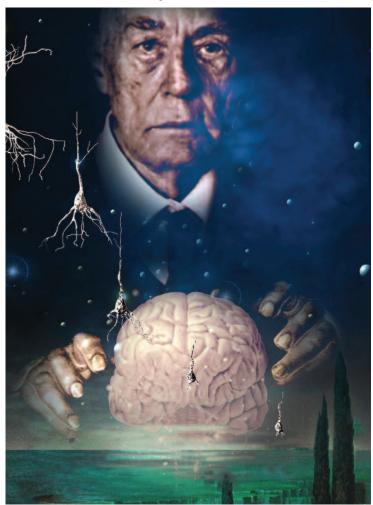
Aggression and psychosis have been linked to polymorphisms in dopamine receptor genes, and psychotic symptoms have also been linked to polymorphisms in serotonin transporter genes and in the catechol-O-methyl transferase gene. Other factors linked to behavioural symptoms include caregiver behaviour and environmental characteristics. For example, verbal or physical aggression on the part of caregivers commonly provokes aggressive responses from the person with dementia, and institutional settings with rigid care schedules sometimes provoke negativistic responses from the person with dementia, making nursing care tasks more difficult to administer.

#### Specific challenges

Some types of dementia have the potential to present particular challenges to the treating doctor. These include:

- frontotemporal dementia which often presents before the age of 65 years and the onset of which is often characterised by marked behavioural changes in the absence of obvious memory problems
- early onset Alzheimer's disease which commonly progresses rapidly and may be associated with challenging behaviours in an otherwise fit and healthy person
- dementia with Lewy bodies which is

#### Behavioural problems in dementia



Behavioural and psychological symptoms are found in all types of dementia and at all stages of the disease, including the pre-dementia stage. Successful management of these symptoms is likely to be rewarded by reduced distress for the person with dementia and reduced burden and distress for his or her caregivers.

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often associated with prominent visual hallucinations.

However, even the common type of dementia, late onset dementia, which can be due to mixed Alzheimer's disease and cerebrovascular disease or to one of these diseases acting alone, is frequently associated with significant behavioural and psychological symptoms. In this form of dementia,

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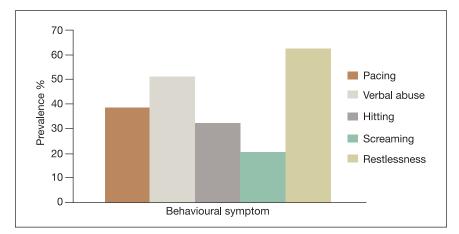


Figure 1. Prevalence of behavioural symptoms in 805 nursing home residents, 62.3% of whom had dementia. Behavioural symptoms were rated by nurses using the Cohen-Mansfield Agitation Inventory.

Source: Byrne (unpublished data: 2007).

psychological symptoms such as apathy, depression and anxiety often precede the development of delusions and hallucinations and overtly disturbed behaviour.

#### Pre-dementia states

Recent research has demonstrated that behavioural and psychological symptoms are highly prevalent even in pre-dementia states such as mild cognitive impairment (MCI), in which the cognitive symptoms or functional impairment are too mild to warrant the diagnosis of dementia. For this reason it is clear that these symptoms are not an occasional complication of the dementia syndrome but integral to it.

#### Impact on carers

Behavioural and psychological symptoms in people with dementia are associated with a variety of consequences for carers. Many carers report considerable burden, some report psychological distress and some develop a depressive illness. The doctor's role in managing patients with dementia includes assisting carers to cope with the burden they experience, mitigating psychological distress through information giving, support and counselling, and treating depression in the usual manner.

## Medical assessment Intercurrent medical problems

Many patients with dementia have a reduced capacity to report their own symptoms, so the doctor must maintain a high index of suspicion for common problems. Psychological symptoms and behavioural problems, particularly if of recent onset, may be due to intercurrent illness leading to pain, discomfort or delirium. Arthritis, reflux and constipation occur commonly and may cause pain or discomfort. Infections of the urinary tract, chest and skin are also highly prevalent among older people, particularly those over 80 years of age who are also the group most at risk of dementia. Such intercurrent general medical problems may simply cause an exacerbation of existing confusion, behavioural or psychological symptoms. General medical problems may, however, also precipitate frank delirium, which often complicates dementia and is highly prevalent among older people in nursing homes.

#### Prescription medications

Adverse effects from prescribed medications also commonly precipitate behavioural and psychological symptoms in people with dementia. Many modern

medications have central nervous system effects that can cause increased confusion, psychotic symptoms and agitation or depression in vulnerable older people. Sedatives, antiparkinsonian agents and drugs with strong anticholinergic properties are particularly likely to do this.

A review of prescribed medication is an essential component of the general medical assessment of people with dementia. Consulting pharmacists are now available in some areas to review the prescribed medications of older people living in residential aged care facilities and may recommend modifications to treatment regimens.

#### Alcohol and substance abuse

Although abuse of alcohol and other substances is much less prevalent among older people than young or middle-aged people, it is not unknown in people with dementia. Marked memory difficulties may make it difficult for older people to monitor their alcohol intake, leading to the development of alcohol abuse in the context of dementia, although more often the abuse is a continuation of a habit that developed earlier in life.

#### Dehydration

People with dementia, particularly those who live alone, are at risk of inadequate nutrition and dehydration. Both of these factors can contribute to the development of behavioural and psychological symptoms.

#### **Clinical investigations**

A general medical review of the patient with dementia who is behaviourally disturbed should include taking a history from a reliable informant, a physical examination of the patient and some screening investigations. Recommended minimum investigations include:

- a full blood examination
- erythrocyte sedimentation rate or C-reactive protein level
- serum biochemistry

- thyroid-stimulating hormone level
- vitamin B<sub>12</sub> level
- red cell folate level
- urinalysis.

An ECG is also recommended as acute myocardial infarction may present in older people who have acute confusion or behavioural change without chest pain. A chest x-ray and brain CT scan may be warranted in selected cases, particularly where changes in behaviour are recent and severe and cannot be readily understood, where the patient appears generally unwell or where there is a history of recent head injury or a suspicion of such.

#### Assessment of mental status and behaviour

Mental state examination should assess the extent of cognitive impairment, preferably with the assistance of a brief scale such as the Mini-Mental State Examination (MMSE)1 or the General Practitioner Assessment of Cognition (GPCOG) scale.2 The presence of depression or anxiety should also be noted and the doctor assessing the patient should be alert for indications that the patient may have psychotic symptoms such as hallucinations and/or delusions (see the box on this page).

The patient's level of insight into his or her dementia and its behavioural accompaniments should be explored and, where a patient lacks insight (as is often the case), history taking from a reliable informant is likely to be critical. Where feasible, the doctor should also assess the quality of the relationship between the patient and his or her spouse, partner and/or other carer. The development of a therapeutic alliance with a carer who enjoys a good quality relationship with the person with dementia is likely to make the doctor's job much easier.

#### Informal assessment

Informal behavioural assessment by the doctor should focus on the precise nature of the behaviour and its significance for the patient and his or her carers. In

particular, it is important to establish whether the patient's behaviour is dangerous to him or herself or others and whether the patient's behaviour is causing great distress.

#### Challenging behaviours

Challenging behaviours such as motor overactivity, which can include pacing, following or wandering, noisy behaviour (such as shouting, swearing, repetitive questioning), agitation and aggression, should always be assessed in detail.

It is important to assess the behaviour in the context of what is known about the patient's personal history and also in light of the physical and social environment in which he or she lives. Sometimes information about the patient's lifelong personality, interpersonal relationships, habits and former occupation can help clarify the nature of certain unusual behaviours.

#### Formal assessment

In situations where a behavioural problem is particularly recalcitrant and has not responded to simple measures to ameliorate it, formal behavioural assessment is probably needed. Referral to an experienced clinical psychologist who is able to visit the patient in his or her own home or residential care environment is likely to be of great assistance. Such an assessment entails an analysis of the precise nature and significance of the problematic behaviour together with its antecedents and consequences. This type of formal assessment is a necessary prelude to the development of an individually tailored behavioural intervention program. Clinical psychologists from each State and Territory who might be able to undertake such assessment and intervention programs can be identified via the beyondblue website.3

#### Intervention

#### General nonpharmacological interventions

In situations where the behavioural and

#### Common signs of delusions and hallucinations in people with dementia

#### Responding to stimuli not seen or heard by others

- · Talking to unseen people
- · Throwing things at the wall or striking the ceiling or floor with a stick
- Reporting music or singing when none can be heard

#### Suspicious mood and/or false accusations

- · Accusing relatives, neighbours or tradespersons of stealing things from the house
- · Accusing spouse of infidelity or of being an imposter
- Insisting that someone else is in the house

psychological problems complicating dementia are mild and/or not particularly distressing to the patient, and are not interfering greatly with the ability of carers to look after the patient, it is often preferable to avoid the use of psychotropic medication.

The use of nonpharmacological interventions has been extensively reviewed in recent years and the quality of research evidence has been found to be generally rather poor.4 There is, however, some evidence supporting general nonpharmacological measures such as:

- education of staff and family carers
- individualised music
- aromatherapy
- massage
- light exercise
- activity programs
- distraction
- pet and doll therapy.

People with dementia often benefit from being cared for in an environment that is familiar to them or that has reminders of past familiar environments. In

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residential care settings it is useful to display personal objects in the immediate environment of the person with dementia.

Training in dementia care is now widely available for the staff of residential aged care facilities and also for family carers. Such training can be invaluable in correcting mistaken beliefs about dementia and related behavioural problems. The available evidence strongly suggests such training is beneficial for both the person with dementia and his or her carers. Organisations such as Alzheimer's Australia offer excellent education and training programs for family carers. Its website has lots of practical advice for carers, including help sheets.<sup>5</sup>

A further source of information for carers is the Australian Government Department of Health and Ageing, whose website provides copies of its dementia carers' guide on request. This website also has useful information for carers and doctors, including an excellent guide to the recognition and management of delirium. The National Dementia Behaviour Advisory Service (telephone: 1800 699 799) is another source of information about the management of behavioural problems in people with dementia.

#### Specific behavioural therapy

After a behavioural analysis has taken place, two commonly applied techniques to manage behaviour problems are stimulus control and contingent reinforcement. Stimulus control involves the modification of the physical environment and/or modification of the caregivers' behaviour. Contingent reinforcement techniques include rewarding desirable behaviour and/or ignoring undesirable behaviour. These techniques require the assistance of a clinical psychologist and willing nursing staff or family carers.

To illustrate, if an older man with dementia is physically aggressive towards female personal care staff when he is being showered in the morning, stimulus control principles would suggest trialling one or more of the following:

- changing the personal care staff to males
- giving him a bath rather than a shower
- conducting the ablutions in the afternoon rather than the morning.

Alternatively, consider the situation in which an older female nursing home resident spends much of the day screaming, which causes distress to herself, other residents and staff. Conventionally, staff would attend to such a patient when she was noisy and ignore her when she was quiet. Such an approach would tend to increase the period of time during which noisy behaviour occurred. If there was no underlying cause of pain or discomfort and no evidence of clinically significant depression, it might be appropriate to introduce a behavioural intervention in which the patient was rewarded with increased staff time and attention during spontaneous quiet periods and ignored during periods of noisy behaviour. This contingent reinforcement technique would have the effect of increasing the amount of quiet time.

Contingent reinforcement interventions are often felt by staff to be counterintuitive and sometimes unethical, and for this reason they need to be preceded by staff education.

#### Psychotropic medication

#### Apathy

Psychotropic medications are widely used in attempts to mitigate the effects of behavioural and psychological symptoms in people with dementia. Apathy, the most common neuropsychiatric symptom in dementia, sometimes responds to treatment with one of the cholinesterase inhibitors, such as donepezil (Aricept), galantamine (Reminyl) or rivastigmine (Exelon), or with the N-methyl D-aspartate-receptor antagonist (NMDA-receptor antagonist) memantine (Ebixa).

#### Depression and anxiety

Patients with dementia who present with depression and anxiety often respond to standard antidepressant medications. These include selective serotonin receptor antagonists, such as sertraline (Concorz, Eleva, Setrona, Xydep, Zoloft), citalopram (Celapram, Ciazil, Cipramil, Talam, Talohexal) and fluvoxamine (Faverin, Luvox, Movox, Voxam), and the non-selective monoamine oxidase type A inhibitor, moclobemide (Amira, Arima, Aurorix, Clobemix, Maosig, Mohexal).

#### Agitated behaviour

Although cholinesterase inhibitors have sometimes been recommended as treatment for agitated behaviour, a recent report indicates that donepezil is no better than placebo at treating agitation in patients with Alzheimer's disease.<sup>7</sup>

Treatment with memantine is sometimes associated with improvement in agitated behaviour in patients with dementia. However, this drug is not currently subsidised under the Pharmaceutical Benefits Scheme (PBS) for this indication.

The anticonvulsants carbamazepine (Tegretol, Teril) and sodium valproate (Epilim, Valpro) have also been used for the treatment of nonspecific agitation, although the evidence for the efficacy of carbamazepine is modest and for sodium valproate is weak.

## Psychotic symptoms, agitation and aggression

Patients with dementia who have psychotic symptoms and/or marked agitation or aggression sometimes respond to treatment with low-dose atypical antipsychotic medication such as risperidone (Risperdal) or low-dose typical antipsychotic medication such as haloperidol (Serenace).

The use of atypical antipsychotics olanzapine (Zyprexa) and quetiapine (Seroquel) for the treatment of patients with dementia is not currently subsidised under the PBS and the available evidence

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for the efficacy of both of these drugs for the treatment of psychotic symptoms and marked agitation or aggression in people with dementia is weaker than that for risperidone.

It is important to note that the overall effectiveness of antipsychotic medications for the treatment of patients with dementia is modest.<sup>8</sup> Both typical and atypical antipsychotic medication classes may be associated with the development of Parkinsonism and other extrapyramidal adverse effects. An appropriate starting dose of either risperidone or haloperidol would be 0.25 to 0.5 mg once or twice daily. The final dose in older patients with dementia should not normally exceed 2 mg per day and many patients can be treated with 1 mg or less per day.

#### Risks associated with antipsychotic medications

The use of antipsychotic medications in older nursing home residents with dementia has been associated with cerebrovascular adverse effects, including transient ischaemic attacks and stroke. An increase in 'all causes' mortality has also been reported in older people with dementia who have been treated with antipsychotic medication. These effects apply to the old and new antipsychotic medications.

Treatment complications occur most frequently in patients with pre-existing risk factors for cerebrovascular disease and the absolute level of increased risk is modest. However, it is important to share this information with family carers and substitute decision-makers before prescribing such medication.

Appropriate adjustments should be made to the dose of all medications prescribed for older people with dementia. The general principle of 'start low, go slow, and check frequently' applies.

#### Referral

When local resources have been exhausted and significant behavioural and psychological symptoms persist in the context of dementia, it is an appropriate time to consider calling in the local older persons' community mental health team. Such multidisciplinary teams now exist in most major cities and some provincial towns. These teams are often supervised by a psychiatrist with a particular interest in older people.

In the absence of such a team, referral to a local psychiatrist, geriatrician or clinical psychologist is worth considering. Occasionally, a patient with dementia and behavioural or psychological symptoms may require hospital admission for more detailed assessment and more assertive management. Specialised psychogeriatric inpatient units are available in some locations. Electroconvulsive therapy (ECT) is sometimes used to treat older people with dementia whose illness has been complicated by severe depression. Many such patients have a past history of successful treatment of depression with ECT.

#### Consent

Assessment and treatment of people with dementia requires a valid consent. As this is often not available from the person with dementia, due to his or her incapacity, it is important for the doctor to discuss major new assessment and management strategies with the patient's substitute decision-maker. In many cases, this will be the patient's next-of-kin or statutory health attorney. In some cases, it might be an attorney appointed by the patient under an enduring power or a guardian appointed by a tribunal for this purpose. Laws dealing with substitute decisionmaking vary according to jurisdiction and doctors working with people with dementia need to be familiar with local requirements.

#### Conclusion

Behavioural and psychological symptoms are integral components of the dementia syndrome and occur at all levels of severity, including during the pre-dementia phase. A variety of pharmacological and nonpharmacological interventions are now available, although the quality and strength of the evidence for many treatments is not high.

Despite this, straightforward behavioural and drug treatments are certainly worth trialling in patients with distressing or challenging behaviour. Successful management of behavioural and psychological symptoms is likely to be rewarded by reduced distress for the person with dementia and reduced burden and distress for his or her caregivers.

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