Interventions in the Management of Behavioural and Psychological Aspects of Dementia

A National Clinical Guideline recommended for use in Scotland by the Scottish Intercollegiate Guidelines Network

Pilot Edition Issued in February 1998

SIGN
Getting validated guidelines into local practice
The definitions of the types of evidence and the grading of recommendations used in this guideline originate from the US Agency for Health Care Policy and Research and are set out in the following tables.

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| A | Required: at least one randomised controlled trial as part of the body of literature of overall good quality and consistency addressing specific recommendation.  
(Evidence levels Ia, Ib) |
| B | Required: availability of well conducted clinical studies but no randomised clinical trials on the topic of recommendation.  
(Evidence levels IIa, IIb, III) |
| C | Required: evidence obtained from expert committee reports or opinions and/or clinical experiences of respected authorities.  
(Evidence level IV)  
Indicates absence of directly applicable clinical studies of good quality |

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8 Recommendations for further research

Annexes

1 Details of systematic literature review undertaken for the guideline
2 Notes on good practice in assessment of people with dementia

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Notes for users of the guideline

Development of local guidelines
SIGN consents to the copying of this guideline for the purpose of producing local guidelines for use in Scotland

Statement of intent
This report is not intended to be construed or to serve as a standard of medical care. Standards of medical care are determined on the basis of all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve.

These parameters of practice should be considered guidelines only. Adherence to them will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement regarding a particular clinical procedure or treatment plan must be made by the doctor in light of the clinical data presented by the patient and the diagnostic and treatment options available.

Significant departures from the national guideline as expressed in the local guideline should be fully documented and the reasons for the differences explained. Significant departures from the local guideline should be fully documented in the patient’s case notes at the time the relevant decision is taken.

A background paper on the legal implications of guidelines, prepared by Dr Pamela Abernethy of Simpson & Marwick W.S., is available from the SIGN secretariat.

Review of the guideline
This guideline was issued in February 1998 and will be reviewed in 2000. Comments are invited to assist the review process. All correspondence and requests for background information regarding the guideline should be sent to:

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Summary of recommendations

This guideline makes recommendations for management of the behavioural and psychological aspects of dementia, but excludes interventions in the management of cognitive aspects of dementia.

NON-DRUG INTERVENTIONS

On the basis of the available evidence and the problems associated with drug interventions, non-drug interventions should always be considered along with drug options before treatment is started.

Non-drug management strategies in the management of behavioural and psychological aspects of dementia include reality orientation, behavioural intervention, occupational activities, environmental modification, validation therapy, reminiscence and sensory stimulation.

A care plan should be made for each individual.

NEUROLEPTIC DRUGS

Neuroleptics have been widely prescribed in the management of dementia but evidence for their efficacy is limited.

Patients should only be considered for treatment with neuroleptics if they have serious problems, particularly psychotic symptoms, serious emotional distress or danger from behaviour disturbance.

There is no clear evidence for the superiority of one neuroleptic drug over any other. The side-effect profiles differ.

Low doses should be prescribed initially with a slow and cautious increase if necessary: ‘start low, go slow’.

Treatment should normally be short term and should be reviewed regularly.

The prescriber must be aware of potential side-effects including akathisia and tardive dyskinesia. The routine use of anticholinergic medication is not indicated.

Care should be taken to identify Lewy body dementia because of the increased risk of severe side effects.
USE OF OTHER DRUGS

The evidence for the use of many described drug treatments for behaviour problems is not sufficient to make recommendations.

Marked and persistent depression in the presence of dementia may be treated with antidepressant medication.  

Severe and persistent anxiety in the presence of dementia may require short term anxiolytic treatment.  

Severe and persistent insomnia in the presence of dementia may require short term hypnotic treatment.  

The issue of consent to treatment in the presence of dementia requires careful consideration and use of the Mental Health (Scotland) Act 1984 may need to be considered.  

Further research is required into the measurement of symptoms and the efficacy of interventions of all types.
1 Introduction

1.1 Remit of the guideline
This guideline makes recommendations for management of the behavioural and psychological aspects of dementia. The issue of intervention in behavioural and psychological aspects was chosen because of the frequent occurrence of difficulties and uncertainty about the best interventions to adopt. Problems related to behaviour are frequently the reason for admission to long term care; thus management of behavioural difficulties has particular relevance to these settings. There is evidence of high neuroleptic use in nursing homes and hospitals.\textsuperscript{2,3}

The guideline also describes good practice in the diagnosis and assessment of people presenting with symptoms suggestive of a dementing process, as comprehensive assessment and a definitive diagnosis are vital to the development of an appropriate treatment plan. The guideline development group did not look specifically at the diagnosis of intercurrent infection and delirium, or interventions in the management of cognitive aspects of dementia.

1.2 Prevalence and causes of dementia
The syndrome of dementia is a common condition in later life and is a frequent cause of death in old age. The prevalence of dementia rises with age at least into the late 80s, although the incidence may level off in extreme old age. More rarely younger people may suffer from this condition and it may occur in all sections of the community. There are many different causes of dementia syndrome, the commonest of which are:
- dementia of Alzheimer type
- vascular dementia
- dementia of Lewy body type.

1.3 Core symptoms of dementia
The core symptoms of dementia are those of global mental impairment. This impairment affects not only the cognitive aspects of mental functioning but also the complex processes of manipulation of information within the brain, the direction of all the body’s activities and the overall monitoring or executive processes which set standards for all these functions.

The principal research efforts in dementia are presently directed towards enhancing knowledge of the various causes of dementia and seeking therapies which would prevent, arrest or reverse the brain damage or consequent mental impairment. Some modest progress has been made in relation to treatment for the biochemical pathology of Alzheimer’s type dementia.
1.4 **Non-cognitive aspects of dementia**

There are many non-cognitive aspects of dementia. Typical manifestations include those associated with restlessness or over-activity; mood disturbances, including depression, anxiety and irritability; psychotic experiences, including delusions and hallucinations; disordered communications, especially repetitive noisiness; and disturbed behaviour, for example aggression and sexual disinhibition.

There are a number of possible theories for the existence of these features in the dementias but there are two principal theoretical approaches. The first is neurological: that loss of monitoring or inhibitory mechanisms within the brain leads to release of previously inhibited behaviour or emotion and the emergence of symptoms. The second is psychological or behavioural: that the symptoms represent the sufferer’s often disorganised attempts to make sense of the world about them and react to that world. Both explanations are highly probable and, in any particular case, there are likely to be elements of both at play. There is little research evidence to help understand the genesis of disturbed behaviour in dementia, though research in this area is developing.

1.5 **Evaluation of the evidence base**

The literature which the guideline development group has studied (*see Annex 1*) indicates that some researchers have based their therapeutic strategies on one or other theoretical model of disturbed behaviour in dementia, while other authors appear not to be working from a particular theoretical basis but to have considered the issue to be one of symptom management.

The *drug treatments* which have been studied have therefore varied from antipsychotic drugs (neuroleptics) used for specific psychotic symptoms and also as broad spectrum tranquillisers, to specific uses of antidepressants for depressive symptoms.

*Psychological approaches* have ranged from quite specific behavioural interventions in attempts to resolve clearly definable behaviour problems to more general approaches, including psychosocial stimulation, reality orientation, reminiscence therapy and validation therapy. Approaches can be directed both at individuals and their carers.

In developing this guideline, evaluation of the available literature on management of behavioural and psychological aspects of dementia and assessment of the efficacy of therapeutic interventions had to be undertaken in the context of very poor symptom definition, a frequently heterogeneous sample of study patients, a lack of clear theoretical background for the research, and poor definition of outcomes. Since the commonly used behaviour rating scales are not altogether satisfactory, researchers have had to either devise their own rating scale to define
improvements in the particular behaviour being studied or use impressionistic ratings by staff. Neither is satisfactory and there is an urgent need for research to help classify and measure behaviour, mood and psychotic disturbances in dementia.

1.6 Management settings
People with dementia are cared for in many different settings, the majority in their own homes. The pattern of care for people with dementia is evolving and a care programme approach is being introduced nationally. This is to ensure that individuals with severe or enduring mental illness, including dementia, who also have complex health and social care needs receive ongoing care and supervision. The approach should incorporate appropriate packages of services and accommodation to meet patients’ needs and should be fully co-ordinated by the agencies and professionals involved.
2 Assessment in dementia

2.1 General

A definitive diagnosis and a clinical, social and functional assessment of the nature and causes of associated problems is essential for each individual with dementia and their carers. It is necessary to attend to intercurrent illnesses and in particular to detect and treat delirium. Early comprehensive assessment of people presenting with symptoms suggestive of a dementing process will enable:

(a) exclusion of differential diagnoses
(b) identification of co-existing treatable conditions, e.g. depression, physical illness
(c) differentiation of clinical types of dementia
(d) potential for the treatment of the disorder with the advent of new drugs
(e) counselling and support to patient and carer
(f) facilitation of management decisions.

The guideline development group did not review assessment of the individual with dementia in detail. However it seemed important to emphasise the need to make a thorough assessment and to make some recommendations as to what is considered to be good practice in this area. A suggested approach is described in Annex 2.

2.2 Definition of the problem

In order to identify the most likely cause of problem behaviours, assessment should include a specific description of the behaviour in question, including its severity and frequency. Broad descriptions such as ‘aggressive’ or ‘attention seeking’ are not informative and are likely to be unreliable: they are open to different interpretations by different observers. A more specific example might be ‘this person hits out at nursing staff with a walking stick, usually in the mornings and evenings’. In this way a description of the problem is obtained. This helps to identify possible causes and influences on the occurrence and on the frequency of the behaviour.

It is also important to consider who has the problem. Is it the person with dementia, the carer or other people in the setting? Such a question may indicate where to target any intervention, or indeed whether any intervention is required. If the behaviour is not a danger to the person or to others, and not distressing to the person themselves, then minimal or no intervention may be necessary. For instance, a person wandering around a nursing home may be quite safe and not upset, so this behaviour is not a problem for that person.
2.3 **Assessment techniques**

There are a variety of assessment methods, including the following:

2.3.1 **Direct observation of behaviour**

This provides information about the actual behaviour as it occurs, and can be more detailed and less informant-biased than rating scales (*see below*). However, it tends to be more time-consuming and labour intensive.

2.3.2 **Informant reports**

Information from informants can be obtained via rating scales and/or interview. There are considerations about ensuring the reliability of information obtained in this way.

2.3.3 **Rating scales**

Rating scales have been used particularly in research. There is an ever-increasing array of scales available, and the choice of any particular one depends on the purpose of the assessment, e.g. on which areas of behaviour are being assessed.⁵

Two important points to be considered when using such scales are that:

- *The scale should be one developed for use with people with dementia.* Many studies use scales which are not designed for such a group, with no information to support their suitability.
- *The scale should be standardised,* with readily available data regarding its reliability, validity and norms relevant to this population.

No one scale will fit all the criteria for a good assessment instrument. Indeed a rating scale is best not regarded as an assessment on its own, but rather as providing part of the assessment process.

2.4 **Defining outcomes**

*In any assessment for intervention, it is important to consider the outcome.* When targeting behaviour problems, the desired outcome should be specified in terms of the person’s behaviour. This avoids some of the pitfalls of reducing behavioural excess, such as aggression or agitation, at the expense of increasing behavioural deficits such as apathy or withdrawal—replacing one behaviour problem with another.

2.5 **Managing difficult behaviour**

Based on the results of the assessment, a specific care and treatment plan should be made for each individual and their carers if appropriate.⁶ The plans should normally be co-ordinated by a named person, monitored and regularly reviewed.


3 Non-drug interventions

3.1 Continued concern regarding the inappropriate use and dosage of neuroleptic drug medication for behavioural disturbance in dementia (see section 4) has turned attention to non-drug and psychological interventions.\(^7\,8\) Non-drug interventions for behavioural disturbance and other symptoms such as insomnia and anxiety are advocated and practised extensively (particularly in the USA, where guidelines have been introduced)\(^7\) but await full assessment. There is no conclusive evidence for benefit from any particular intervention (see section 8 Recommendations for further research). Much of the enthusiasm for these therapies is based on anecdotal reports and there are a number of methodological issues in research on non-drug interventions which make it difficult to make strong recommendations on the basis of the available evidence.\(^10\,11\) For example, it is very difficult to undertake double-blind assessments of some non-drug treatments. Studies are usually small and methodologically flawed, and the nature of the interventions makes controlled investigation difficult.

3.2 Although there may be scant evidence to support behavioural improvement due to psychological interventions, quality of life may be enhanced in patients exposed to these therapeutic efforts. Their use may do much to enthuse staff and stimulate the patient, effects which might not exist in the absence of these endeavours. These interventions are generally perceived as safe although, again, there is a lack of evidence on this.

*There is insufficient evidence to make detailed recommendations on the use of non-drug interventions, although individual patients may benefit.*

**Non-drug interventions should always be considered, with an individual person centred approach required in each instance**

*Grade C*

3.3 In deciding on an intervention, an approach relevant to the cause of the symptom or problem (see section 2) should be adopted.\(^12\,13\)

3.4 The following specific interventions have been described:\(^14\)

3.4.1 **Reality orientation**\(^15\,16\)

Reality orientation (RO) involves providing accurate information aimed at orientating the person to his or her surroundings. This includes a variety of methods, such as communication, reinforcement of appropriate behaviour, and changes to the environment. While research evidence does suggest that RO is associated with improved verbal orientation, there is little evidence regarding changes in behaviour.
The methodological problems of undertaking studies of reality orientation, particularly in measuring behaviour changes, make it difficult to draw any firm conclusions regarding the effects of RO on behaviour problems in people with dementia.

3.4.2 **Behavioural intervention**\(^{17, 18}\)

Using a detailed analysis of the specific problem behaviour and the context in which it occurs, behavioural interventions aim to change a person’s behaviour by altering the triggers and/or the consequences of the behaviour. There are few studies reported with this population. These tend to be small-scale, with small groups or single case descriptions.

A recent development has been the use of cognitive-behavioural interventions, for treating depression in people in the early stages of dementia. In addition to changing behaviour, these aim to help the person alter the negative or maladaptive thought patterns considered to underly their behaviour.\(^{19}\) This research is very much in the early stages and no firm conclusions can yet be drawn.

3.4.3 **Occupational activities**

These are intended to provide positive stimulation and hence to reduce some of the possible causes of difficult behaviour, e.g. boredom, reduced participation in domestic/daily activities, loss of previous interests.

There have been reports of *music therapy* as an intervention for agitation\(^{20, 21}\) and this is seen as one of the most ‘successful’ activities being widely used in dementia care. The method is worthy of note but it is uncertain whether music therapy has therapeutic effect, due to methodological weakness of the research.

*Activities programmes* designed for the needs of people with dementia are used as a strategy in helping with difficult behaviour. The evidence of one paper\(^{6}\) supports this view, pointing to a reduction of behavioural disturbance and a decrease in associated drug use, although criticisms can be made of the methodology.\(^{8}\) Activities programmes as interventions in response to challenging behaviour are used on an everyday basis by practitioners and carers, often apparently successfully, although they are not always an easy option.

3.4.4 **Environmental modifications**

These include physical changes to the environment, prosthetic environments and changes in care routines. Again there are methodological flaws in the studies which makes it difficult to draw any firm conclusions.
3.4.5 **Validation therapy**

The aim of this approach is empathically to reflect and validate the person’s view of reality, with behaviour seen as likely to be resulting from a person’s life experience and unresolved conflicts. Most accounts are anecdotal and more systematic attempts at evaluation have provided mixed results, again being subject to methodological difficulties.

3.4.6 **Reminiscence**

There are a number of types of reminiscence work, ranging from straightforward recall of past events to more formal life review work. Studies are few and reminiscence techniques and theoretical approaches tend to vary, making comparisons difficult.

3.4.7 **Sensory stimulation**

This is based on the hypothesis that sensory deprivation and unchanging sensory input can increase confusion in elderly people. A variety of methods have been used, including touch and bright light. However studies are small and firm conclusions cannot be drawn.

3.5 Interventions involving working with carers, such as carer education, are particularly important. Family carers may need additional support in order to implement the interventions. Further assessment and evaluation is needed before any firm conclusions can be drawn.
4 Neuroleptic drugs

4.1 Background
Although there is a widespread practice of using neuroleptic drugs for difficult behaviour associated with dementia,\textsuperscript{2, 3, 8, 25, 26} there is very limited evidence of efficacy from double-blind, placebo controlled trials to support this practice.\textsuperscript{27-35}

4.1.1 Only one broadly based meta-analysis was identified.\textsuperscript{35} This looked at the seven studies of neuroleptic drugs which the author found to be satisfactory, i.e. the trials which had a placebo control and which were double blind. No individual study showed a statistically significant difference between the active treatment and placebo groups. However, by combining the studies the difference did reach significant levels. The meta-analysis showed that there was a modest improvement in behaviour difficulties. Neuroleptic use showed an 18\% benefit over placebo and there was also a high placebo response.

4.1.2 There is strong evidence for the benefits of neuroleptic drugs in schizophrenia but there is no clear evidence that the ‘psychotic’ symptoms which occur in dementia are of a similar nature to the experiences of schizophrenia.

4.1.3 Trials do not show any consistency in the selection of patients, in defining those behaviours which are found to be difficult, or in the nature of the dementia of their study populations. This makes interpretation difficult.

4.1.4 Studies are usually in inpatient populations. Results may not necessarily be applicable to other settings.

4.1.5 There is no standard measure for assessing alteration of behaviour in these patients. Most studies use measures which have not been standardised to the populations studied and which are too general to assess specific behaviours adequately.

\textit{Neuroleptics should only be considered for patients with serious problems, in particular psychotic symptoms such as delusions and hallucinations, or in the presence of serious distress or danger from behaviour disturbance}

\textit{Non-drug treatment should always be considered along with drug options before treatment is started}

\textit{Grade C}
4.2 **Dosage and duration of treatment**

Clinical trials in patients with dementia use varying doses of neuroleptics. The optimum dose thus cannot be established from the literature. There is some evidence that very small doses may be at least as effective as larger doses, presumably with a lower incidence of side effects.\(^{36}\)

In almost all the trials reported to date the period of treatment studied does not exceed six weeks and indeed is often shorter. Longer studies are necessary to account for many of the more prominent side effects of neuroleptic drugs, which may not develop for some weeks or even months after treatment commences. This applies particularly to akathisia and tardive dyskinesia.

The trials which show some improvement fail to demonstrate whether the treatment has continuing efficacy.\(^{35}\) There is some evidence that, in an inpatient population, long term neuroleptics can be stopped without detrimental effects.\(^{37-39}\)

\begin{center}
\textbf{Where it is felt that neuroleptic treatment is indicated, low dosage should be prescribed initially, with slow and cautious increase as necessary}

\textbf{The prescriber must be continually aware of the risk of side effects and balance this risk against any perceived benefit}

\textit{Grade C}
\end{center}

\begin{center}
\textbf{Treatment should normally be short term and should be regularly reviewed}

\textbf{The dose should be reduced as soon as possible and treatment stopped if it is no longer essential}

\textit{Grade B, level IIb}
\end{center}

4.3 **Side effects and choice of drug**

There is no clear evidence of any difference in efficacy between different neuroleptics\(^{35, 40-47}\) and the role of the new neuroleptic drugs in the management of behavioural and psychological aspects of dementia has still to be defined. The research information about side effects in individuals with dementia is limited. While some drugs such as thioridazine have a lower incidence of extrapyramidal effects this is at the expense of a higher incidence of anticholinergic effects such as confusion, constipation and increased cognitive impairment, to which this population is particularly vulnerable.\(^{7}\) With other drugs such as haloperidol the converse is true. Many patients do not require anticholinergic medication, as not all develop extrapyramidal side effects.\(^{48}\)
Akathisia is a common side effect of these drugs and is characterised by a subjective sensation of restlessness and a decreased ability to sit still.\textsuperscript{49} It should not be confused with the worsening of agitation. If there is doubt then the drug dose should be lowered or the drug stopped. Abnormal involuntary movements including tardive dyskinesia may be a side effect of treatment and, once established, may be irreversible.\textsuperscript{50}

### 4.4 Lewy body type dementia

The prescriber must be aware of the possibility of the patient having Lewy body dementia.\textsuperscript{51} These patients are particularly at risk of neuroleptic sensitivity. Indeed neuroleptic use may be associated with significant mortality in this group.

Dementia of Lewy body type is characterised by fluctuating cognitive impairment affecting both memory and higher cognitive functions (such as language, visuospatial ability, praxis, or reasoning skills). The fluctuation is pronounced, with both episodic confusion and lucid intervals, as in delirium, and is evident either in repeated tests of cognitive function or by variable performance on daily living skills (see figure 1).
Figure 1

Summary of operational criteria for diagnosis of dementia of Lewy body type\textsuperscript{51}

At least one of the following:

- **Visual or auditory hallucinations or both, usually accompanied by secondary paranoid delusions.**
- **Mild spontaneous extrapyramidal features or neuroleptic sensitivity syndrome**—that is, exaggerated responses to standard doses of neuroleptics.
- **Repeated unexplained falls, or transient clouding of or loss of consciousness, or both.**

Notes:

- Despite the fluctuating pattern the clinical features persist over a long period (weeks or months), unlike delirium which rarely persists as long. The illness progresses, often rapidly, to an end stage of severe dementia.
- Exclusion by appropriate examination and investigation of any underlying physical illness adequate to account for the fluctuating cognitive state.
- Exclusion of past history of confirmed stroke or evidence of cerebral ischaemic damage, or both, on physical examination or brain imaging.
5 Use of other drugs

5.1 Background
Non-neuroleptic medication has been advocated for management of behavioural and psychological aspects of dementia. This may be due to unsatisfactory response to neuroleptics, or concern about their adverse effects and long term safety.

5.1.1 The use of lithium, β-blockers, anxiolytics and selegeline has been reported. However, the efficacy and safety of non-neuroleptics in modifying behavioural symptoms have been insufficiently studied. The evidence consists mainly of case reports and series, and of open design or small placebo-controlled studies.

5.1.2 Carbamazepine has been used for specific behaviours such as aggression, over-activity or impulsivity. However, results of studies to date are conflicting.

5.1.3 There are very few studies comparing the effects of neuroleptics (e.g. haloperidol) with anxiolytics and hypnotics (e.g. diazepam, nitrazepam, oxazepam, chlormethiazole and buspirone). Any improvements seen even in these limited studies were modest and no one drug could be said to be more efficacious than another.

5.1.4 Trazodone and other antidepressants have been used to reduce agitated behaviour associated with dementia but there is insufficient evidence to propose this as a treatment.

5.1.5 There is no evidence of benefit from new anticholinesterase drugs for behavioural symptoms.

There is insufficient evidence to make a recommendation on the use of any of the above drugs in the management of behavioural and psychological aspects of dementia (see section 8).

5.2 Antidepressant medication
Depression and associated symptoms may be associated with dementia. Apparent behaviour disturbance may sometimes be secondary to depression. Antidepressant medication may be indicated and should be considered if the symptoms are marked and persistent. Although treatment should be kept under review, longer term treatment may be required for serious depression. There is no clear evidence for the superiority of any particular antidepressant but side effect profiles must be kept in mind.
Marked and persistent depression in the presence of dementia may be treated with antidepressant medication

Grade B, level IIb

5.3 Anxiolytic treatment
Anxiety may occur in the presence of dementia. If severe and persistent, anxiolytic treatment may be indicated in the short term but only if the drug is prescribed as described in the British National Formulary.

Severe and persistent anxiety in the presence of dementia may require short term anxiolytic medication

Grade C

5.4 Hypnotic treatment
Insomnia may occur in the presence of dementia. If severe and persistent, hypnotic treatment may be indicated in the short term but only as described in the British National Formulary.63, 73

Severe and persistent insomnia in the presence of dementia may require short term hypnotic treatment

Grade C
6 Consent

6.1 It is disappointing to note that the issue of consent for treatment of psychological or behavioural disorder in dementia was rarely discussed in the literature the guideline development group studied.

6.2 The mental impairment of dementia brings a gradual loss of understanding, including a loss of understanding of the person’s own feelings and behaviour. It is likely that beyond the mild stages of dementia the person will have decreasing insight into his or her condition. Patients who are disturbed in their dementia may not recognise this or may believe that their actions are entirely normal. It would therefore not be surprising if, when treatment for the disorder is offered, a patient were to decline it. The Mental Health (Scotland) Act 1984 provides a statutory framework for any necessary treatment for people with mental disorder who are unwilling or unable to give consent (Part X of the Act). Where a patient repeatedly refuses necessary treatment for disturbed behaviour the provisions of the Act should be carefully considered.

6.3 It has to be recognised, however, that the vast majority of people with dementia are not detained in terms of the Act and may be being treated in settings where the Act cannot be applied (their own houses or in residential or nursing homes). Neither formal nor informal carers have any right to administer a medicine without the consent of a patient and this could only be justified on the basis of the common law principle of necessity. Necessity is usually taken to mean that without the treatment the patient would die, suffer severe pain or distress, or his or her condition would deteriorate severely.

Relatives and staff have no right to give consent for treatment on a patient’s behalf, although it is important that, if treatment is considered necessary, relatives and all staff involved are asked whether they are in agreement. The therapeutic relationship is between the patient, the doctor prescribing and the nurse administering the drug; or between the patient and whoever is carrying out any therapeutic intervention.

Those involved should be aware that if the principle of necessity cannot be invoked, then therapeutic interventions could be seen in legal terms as a form of assault. The degree of intrusiveness of the therapeutic intervention and the likelihood of significant side effects have an important bearing on the degree of necessity which must be shown. A second opinion may be valuable in difficult or contentious cases. Again, the Mental Health (Scotland) Act should be considered in difficult cases.
6.4 In practical terms a doctor being asked to prescribe medicine or a therapeutic regime for a person with dementia and behaviour or other disturbance should consider the following issues:

- Who is being treated—i.e. is it the individual concerned, or the effect their behaviour has on others?
- Does the patient have insight into the disorder being treated?
- Does the patient have a reasonable understanding of the treatment being proposed, the likely benefits and risks?
- Is the patient able to consent to the treatment?
- Does the patient consent to the treatment?
- Who will be administering the treatment?
- Is administration likely to involve any degree of restraint, coercion or subterfuge?

6.5 If there are problems in any of these areas there should be a full multidisciplinary discussion of the issues involved, involving specialist help if necessary, looking at alternatives to the therapeutic intervention suggested and considering very carefully whether the proposed treatment is necessary. Use of the Mental Health (Scotland) Act 1984 should be considered.
7 Implementation of the guideline

7.1 Development of local guidelines

It is expected that the guideline will be adopted after local discussion involving primary and secondary care clinical staff and management. Local arrangements will then be made for the derivation of specific local guidelines to implement the national guideline in individual hospitals, units and practices. This would enable a local interpretation to be made of the national guidelines.

Careful clinical procedures need to be put in place. These include:

- A proper diagnostic process. It is particularly important to diagnose Lewy body dementia in view of potential difficulties with neuroleptics (see figure 1 on page 12).
- A global assessment of the individual and the behaviour or the symptom in question.
- A risk-benefit analysis for each patient (although the guideline development group is unable to offer a formula at present).
- A system to monitor progress and treatment of individual patients and also the emergence of side effects.

7.2 Audit

Audit projects also need to be devised and the Area or Trust Clinical Audit Committee should be fully involved. Work on outcomes in psychiatry is at a very early stage and this certainly applies in this field of dementia. The following are suggested measures which could be the subject of audit:

7.2.1 Some system of monitoring the use of neuroleptics and other interventions. The stated reasons should be recorded and compared with the criteria and the guideline.

7.2.2 Regular reviews of efficacy should be made of interventions. The reasons for continuation should be recorded and again compared with the guidelines.

7.2.3 There is a need to define what is a desired outcome, e.g. reducing behaviour excesses such as aggression may be at the expense of increasing behaviour deficit such as withdrawal or apathy.

7.2.4 The duration of intervention should be recorded. In many cases of drug treatment this should be short term, although it is be difficult to give a target figure. Non-drug interventions, however, may require time to have effect.
7.2.5 **Drug-induced complications** e.g. falls, fractures should be monitored.

7.2.6 **The effects of not intervening** may also need to be monitored, e.g. aggressive outbursts, assaults on others etc. Again it is difficult to give targets.

7.2.7 **Place of care**—the effect of interventions on placement should be monitored.

7.2.8 **Dependency**—the degree of care required can be monitored, although targets may be difficult to set.

7.2.9 **The effect of interventions on family or carers** should also be mentioned, where appropriate.
8 Recommendations for further research

There is a considerable need for rigorous and well-conducted research in virtually all areas of the subject of this guideline:

- It is necessary to continue to develop good, well standardised scales for measuring severity and change in behavioural and psychological symptoms of dementia. Brief scales are required for routine work and more elaborate ones for experimental work. It is also necessary to devise effective rating scales for side effects.

- The efficacy of all interventions in behavioural and psychological aspects of dementia requires further research. This applies particularly to non-drug interventions and there is a need for funding bodies to encourage well-designed studies of these which address the methodological issues in this area. Large group investigations may not always be appropriate for non-drug approaches. The relationship of interventions to particular symptoms requires further assessment.

- Work on dose-ranging and duration of drug therapy and on the duration and intensity of non-drug interventions is necessary.

- Research is required into the grounds for intervention and the cost and benefits of interventions for individual patients and their carers.

- The aetiology and time course of the symptoms and behaviours complicating dementia requires further definition.
Annex 1

Details of the systematic review undertaken for this guideline

The agreed remit of the group was ‘an assessment of interventions in the management of behavioural and psychological aspects of dementia’. The enhancement of cognitive performance was excluded.

A MEDLINE and EMBASE search was carried out covering the 15 years up to September 1996. Psychological abstracts and the Cochrane database were also searched. Help was obtained from the Scottish Health Purchasing Information Centre (SHPIC). The search involved dementia categories, a list of psychiatric and behavioural symptoms, a range of psychotropic drugs and psychological treatment and behaviour modification.

An initial shortlisting of the approximately 3,000 papers identified was undertaken to exclude non-clinical papers, diagnosis and assessment, the natural history of dementia, non-dementia diagnosis, non-English abstracts and treatments which enhanced cognitive performance. The shortlist was then divided into five groups for review by teams of three members of the guideline development group. Randomised controlled trials were selected; in fields where they were not available, open trials were considered.

The shortlisted papers were reviewed in detail and graded according to SIGN/AHCPR levels of evidence (see inside front cover). Grades were reduced if randomised control trials had serious imperfections. No further analysis of data was undertaken. Sections of the report were then drafted by members of the guideline development group and critically reviewed by the whole committee.
Notes on good practice in the assessment of people with dementia

GENERAL ASSESSMENT

1 A global approach is required in assessment which should embrace the patient’s:
   • psychological state
   • physiological condition
   • social status
   • lifestyle, life history, needs and preferences

   Much of the assessment process can be undertaken by trained non-medical staff.

2 Details are required of current medical status, including:
   • medical history
   • current state of health
   • current medication.

3 The needs of informal carers are particularly important. Under recent legislation both people with dementia and informal carers are entitled to social work assessment in their own right.75, 76

4 Current functional status is also important and a review of lifestyle and ability to carry out activities of daily living to establish needs and required support services is essential.

5 Standardised assessment procedures are recommended, with the routine use of simple tests of:
   • disorientation
   • memory tests
   • attention and concentration
   • other features of cognitive function such as aphasia, apraxia and agnosia
   • mood
   • activities of daily living.

   These can and should be assessed and consideration should be given to the patient’s previous life history.
BEHAVIOUR

Behaviour is a complex phenomenon, and may have multiple causes. Therefore behaviour problems such as aggression and agitation are best considered as broad categories of behaviour with a variety of causes rather than as unitary or uniform concepts.

Accurate assessment of behaviour which is perceived as a problem is crucial in identifying the most likely causes, hence contributing to the focus of any intervention and increasing the chances of its success.

Multi-causal model of behaviour
An assessment should consider the following factors:

1  Person with dementia
   • premorbid personality, including coping mechanisms
   • premorbid relationship with carers
   • nature and extent of impairment
   • physical/medical problems, including medication, nutrition, alcohol consumption
   • emotional reactions to losses, frustrations, life events, etc.
   • depression/anxiety etc.
   • non-cognitive aspects of dementia (as described in section 1.4).

2  Environment
   • change, e.g. from home to residential care
   • over/under stimulation
   • lack of privacy
   • lighting
   • noise
   • deprivation of dignity and individual rights
   • smoking.

3  Caregivers
   • relationship to person with dementia
   • attitudes and coping mechanism
   • approach to caring
   • knowledge of dementia
   • emotional reactions
   • physical and mental health.
References


27 Auer SR, Monteiro I, Toressian E, Sinaiko E, Boksay I, Reisberg B. The treatment of behavioural symptoms in dementia, haloperidol, thioridazine and fluoxetine. 5th International Conference on Alzheimer’s Disease and Related Disorders, Osaka, Japan 1996.


Interventions in the Management of Behavioural and Psychological Aspects of Dementia

A Quick Reference Guide

Assessment
A definitive diagnosis and a clinical, social and functional assessment is essential

Consider:
- psychological state
- physiological condition
- social status
- lifestyle, life history, needs and preferences

<table>
<thead>
<tr>
<th>Non-drug interventions</th>
<th>Neuroleptic Drugs</th>
<th>Other drug treatments</th>
</tr>
</thead>
<tbody>
<tr>
<td>❖ Non-drug interventions should always be considered along with drug options before treatment is started</td>
<td>❖ Neuroleptics have been widely used but evidence for their efficacy is limited</td>
<td>Consider:</td>
</tr>
<tr>
<td>❖ Neuroleptics should only be considered for patients with serious problems, in particular psychotic symptoms, or in the presence of serious distress or danger from behaviour disturbance</td>
<td>❖ There is no clear evidence for the superiority of one neuroleptic drug over any other</td>
<td>❖ Antidepressant medication for marked and persistent depression</td>
</tr>
<tr>
<td>❖ Side effect profiles differ</td>
<td>❖ Neuroleptics should normally be short term and should be reviewed regularly</td>
<td>❖ Short term anxiolytic or hypnotic treatment for severe and persistent symptoms</td>
</tr>
<tr>
<td>❖ Low doses should be prescribed initially, with slow and cautious increase as necessary: ‘start low, go slow’</td>
<td>❖ Dose should be reduced as soon as possible and treatment stopped if no longer essential</td>
<td>❖ Evidence for the use of many other described drug treatments for behaviour problems is not sufficient to make recommendations</td>
</tr>
</tbody>
</table>

Consent
The issue of consent to treatment in the presence of dementia requires careful consideration. Use of the Mental Health (Scotland) Act 1984 may need to be considered

Key

A refers to grade of recommendation

B

C

Derived from the National Clinical Guideline recommended for use in Scotland by the Scottish Intercollegiate Guidelines Network (SIGN), 9 Queen Street, Edinburgh, EH2 1JQ

This Quick Reference Guide was issued in February 1998 and will be reviewed in 2000