Forgetful but not forgotten: assessment and aspects of treatment of people with dementia by a specialist old age psychiatry service

Council Report CR119
April 2005

Royal College of Psychiatrists
London
Due for review: 2006
Contents

Members of the Working Group 4
About this report 5
Working Group methodology 6
Executive summary 9
1. Diagnostic assessment and investigation 23
2. Principles of treatment of people with dementia 29
3. Working with people with dementia in primary care 33
4. Working with people with dementia and their carers 40
5. Capacity, legal, financial and risk issues in people with dementia 53
6. Treatment of cognitive symptoms in people with dementia 61
7. Treatment of non-cognitive symptoms in people with dementia 67
8. Non-pharmacological approaches to treating people with dementia 71
Appendix: Position statement by the Faculty of the Psychiatry of Old Age on the use of neuroleptic (antipsychotic) agents in treating older people with dementia 78
References 85
Members of the Working Group

Dr R. G. Jones (chair)
Dr S. Benbow
Dr R. Bullock
Professor A. Burns
Dr T. Dening
Professor D. Jolley
Professor I. McKeith
Amy McPherson  Section of Old Age Psychiatry, Nottingham University  (research assistant)

The above group members (from the College’s Faculty of the Psychiatry of Old Age, unless otherwise indicated) initiated the project and led the Consensus on Diagnostic Assessment and Investigation. The remainder of the document was produced by the full Working Group, which included the following members:

Clive Evers  Alzheimer’s Society
Dr S. Iliffe  Reader in Primary Care and general practitioner
About this report

This report describes good practice in old age psychiatry services working with people with dementia and their carers. It began with a focus on diagnostic assessment but has been expanded to look at wider aspects and issues with treatment. Particular attention is focused on working with primary care and on working with carers. Against the background of the National Service Framework for Older People, with expected major improvements in services and its plans for local protocols with primary care on dealing better with problems for people with dementia, the Royal College of Psychiatrists felt it was important to produce guidance.

The report represents a consensus statement from an Expert Working Group of the Faculty of the Psychiatry of Old Age. It has been extensively grounded in the identifiable evidence base and other guidance work where evidence is limited. It has been endorsed by the Faculty of the Psychiatry of Old Age and by the College Council.

The College has produced a report on Services for Younger People with Alzheimer’s Disease and Other Dementias (Royal College of Psychiatrists, 2000) and therefore our report explicitly does not further cover this area – although it thoroughly endorses such a focus and a need for such service development. Similarly, the College strongly advocates joint and interagency working, particularly with social services, but these areas are not more fully addressed here.

The report has been produced in collaboration with the Alzheimer’s Society, and with primary care representation, for whose help we are most grateful.

Rob Jones
Chair, Faculty Working Group
Since the publication of the original Council Report CR49 (Royal College of Psychiatrists, 1995), the Royal College of Psychiatrists has published *EBB Evidence-base briefing: Dementia* (Palmer, 1999), to the production of which considerable time and support were contributed by one of the Working Group members (R.B.) and also by Martin Orrell. The Working Group has extensively used the approach (and much of the content) of this earlier College work. The approach has been to rely on synthesised evidence and systematic summaries of published evidence. Thus, the searching has stopped at the considerable body of secondary sources. It has not included searches for primary research studies in a systematic way.

**Search strategy**

The sources searched for information are detailed in Table 1. In certain chapters specific sources have been extensively used, for example in the discussions of the treatment of cognitive and non-cognitive symptoms.

Searches used the following key words: DEMENTIA, ALZHEIMER’S, GUIDELINES, CONSENSUS, ASSESSMENT, INVESTIGATION, DIAGNOSIS, ELDERLY, MANAGEMENT, PRIMARY CARE, CAPACITY, LEGAL, FINANCIAL, RISK, RISK ASSESSMENT and CARERS.

**Strength of the evidence**

The grading scale used by the Working Group was the same as that used in the earlier Royal College of Psychiatrists publication (Palmer, 1999), which was itself based on that used by the Royal College of General Practitioners. It is summarised as follows:

- *** Based on at least one well-designed randomised controlled trial and recommended with substantial clinical confidence.
- ** Based on well-designed cohort or case-control studies and recommended with moderate clinical confidence.
- * Based on uncontrolled studies, consensus and/or extrapolated from the research. May be recommended in certain clinical situations.
  - No clearly identified strength of evidence for this specific statement.

Different organisations may produce varying definitions and grades for the strength of the evidence on which statements they make are based. The grading
Table 1  Sources searched by the Working Group for this report

<table>
<thead>
<tr>
<th>Evidence Source</th>
<th>From</th>
<th>To</th>
</tr>
</thead>
<tbody>
<tr>
<td>All types</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Evidence Source From To All May 2002</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Web of Science</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Trent Research Information Access Gateway (TRIAGE)</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Organising Medical Networked Information (OMNI)</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Trent Research Information Access Gateway (TRIAGE)</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Organising Medical Networked Information (OMNI)</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Guideline Agency for Health Care Policy Research</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Scottish Intercollegiate Guidelines Network</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>American Psychiatric Association</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Royal College of Psychiatrists library and CD-ROM: ClinPsyc</td>
<td>1988</td>
<td>May 2002</td>
</tr>
<tr>
<td>Medline</td>
<td>1991</td>
<td>May 2002</td>
</tr>
<tr>
<td>In-house collection</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>RCPsych Research Unit’s Guidelines Bibliography</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Guideline database</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Systematic reviews</td>
<td>All</td>
<td>1st qtr 2002</td>
</tr>
<tr>
<td>Cochrane Library, including the Database of Abstracts of Reviews of Effectiveness</td>
<td>All</td>
<td>1st qtr 2002</td>
</tr>
<tr>
<td>National Health Service Centre for Reviews and Dissemination (CRD) publications, e.g. Effective Health Care bulletins and Effectiveness Matters</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Health Technology Assessment Database (at CRD)</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Development and Evaluation Committee reports (Committee stood down March 2000)</td>
<td>All</td>
<td>March 2000</td>
</tr>
<tr>
<td>Economic evaluations</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>National Economic Evaluation Database (at CRD)</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Outcomes</td>
<td>All</td>
<td></td>
</tr>
<tr>
<td>UK Clearing House on Health Outcomes</td>
<td>All</td>
<td></td>
</tr>
<tr>
<td>Critically appraised research summaries</td>
<td>1991</td>
<td>May 2002</td>
</tr>
<tr>
<td>American College of Physicians</td>
<td>1995</td>
<td>May 2002</td>
</tr>
<tr>
<td>Evidence-Based Medicine</td>
<td>Jan 1998</td>
<td>May 2002</td>
</tr>
<tr>
<td>Evidence-Based Mental Health</td>
<td>Jan 1998</td>
<td>May 2002</td>
</tr>
<tr>
<td>Evidence-Based Nursing</td>
<td>Jan 1998</td>
<td>May 2002</td>
</tr>
<tr>
<td>Evidence-Based Practice Patient-Oriented Evidence that Matters</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Bandolier</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Critically appraised research summaries</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Aggressive Research Intelligence Facility</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Critically Appraised Topic Bank</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>National Preferred Medicines</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Centre Inc (PreMec)</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Other</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Standing Medical Advisory Committee</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Joseph Rowntree Foundation</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Department of Health: Circulars on the Internet</td>
<td>All</td>
<td>May 2002</td>
</tr>
<tr>
<td>Relevant voluntary sector organisations</td>
<td>All</td>
<td>May 2002</td>
</tr>
</tbody>
</table>
scale above can be used to provide an equivalence for these differing systems (detailed originally in the EBB).

Overwhelmingly the evidence base found, for good practice issues, was of the category ‘*’, but these category symbols have only been logged for diagnostic assessment and investigation aspects (Chapter 1).

**Primary sources**

The remit and funding of the Working Group did not allow searching for primary sources *de novo*, but the primary sources cited in the secondary sources were assembled. The expert Working Group membership was therefore able to consider these and, in particular, consider whether there were additional or better primary sources known to them that could usefully strengthen the evidence.

**Opinion from a wider expert group**

In its work the Working Group also sought the opinions of the Faculty Executive Committee Members and of the then Professors of Old Age Psychiatry in the College as to how Council Report CR49 (Royal College of Psychiatrists, 1995) might need modification. These views were collated and considered by the Working Group, which then attempted to incorporate them in its general approach and in any consensus for any specific less certain area.

**Areas of practice lacking an evidence base and/or attracting conflicting views**

The Working Group identified areas where an evidence base was lacking (or limited) but where it seemed important that some statement on the range of acceptable practice be made. With some of these areas it was evident that there were conflicting views, and in these situations the Group sought to derive consensus statements that seemed to be both a reasonable representation of expert view and appropriate to recommend for service practice.

**Consensus meetings**

In addition to considerable electronic, postal and telephone discussion of the areas of agreement arising from the evidence, the Working Group met for three day-long meetings in 2001–2002, in order to finalise its consensus work. Particular experts or expert groups led the process of producing the evidence-based consensus for each topic.
Executive summary

Diagnostic assessment and investigation

Recommendations

The clinical diagnosis of dementia should be based on a standardised system such as ICD–10 or DSM–IV. Attempts should be made to specify underlying causes such as Alzheimer’s disease, vascular dementia, dementia with Lewy bodies, frontal lobe dementia and normal-pressure hydrocephalus.

Context of the specialist service

There should be ready access to a local specialist service which is comprehensive, effective, firmly rooted in the locale and its resources, and which works closely with local social services, voluntary agencies and with local primary and secondary health services. Other specialists, particularly geriatric medicine and neurology, may also contribute to the assessment of dementia. The focus is on help and support, with family and carers, to retain as much independence for the person as possible.

The specialist service should deal with all aspects, stages and varieties of psychiatric disorder arising in old age, especially with all stages of dementia, including continuing care for people with severe dementia.

Consideration should be given to the needs of different ethnic communities.

There should be established easy referral and collaboration between the old age psychiatry and geriatric medical services.

Specialist service team

The assessing specialist team should include access to professionals from all the necessary specialties who are experienced in treating older people, especially staff working in community psychiatric nursing, occupational therapy, physiotherapy, clinical psychology, social work and speech therapy.

After initial assessment, the options of further assessment at home, in an out-patient clinic, at a specialist day assessment facility (usually a day hospital) or on an acute assessment ward (usually only necessary when serious behavioural disturbance or risk features are present) must be available.

Assessment should be supervised by the consultant old age psychiatrist. Best practice is for new cases to be seen by the consultant or a senior doctor of the team.

Referral and service practice

For those at home, referral should normally be through (or with the support of) the general practitioner. Easy, early and informative referral should be encouraged. The service should offer urgent (same day) response when necessary. Milder
cases may be seen in out-patient or memory clinics, with a longer time scale accepted, but otherwise (especially with cases requiring home assessment) 2–3 weeks is a reasonable upper limit to be agreed.

Good communication with all involved is essential, including with patients and carers, and including clarification about when the assessment is to be expected. Written communication with the referring doctor is generally provided within a week of initial assessment, although more urgent telephone/fax communication may be necessary.

Clinical assessment
Home assessment should be offered routinely – although the service may decide that a clinic-based assessment is appropriate with early presentations.

A family/carer (collateral) history should be sought in the assessment of all cases, clarifying the problems and the context, including financial and legal aspects.

An expert mental state assessment must be undertaken to elaborate deficits of cognitive function, and possible delirium or depressive illness. Use of a standardised assessment of cognitive function, such as the Mini-Mental State Examination (MMSE), is recommended.

A recent physical examination, looking for aetiological or aggravating factors, with particular attention to neurological examination, is essential for assessment. Other aggravating factors, such as depression compounding dementia, physical illness in the carer, remediable difficulties in the carer–patient relationship or other social, family or psychological stresses, should be considered.

Services should assess systematically for functional impairment, behavioural problems and risk. Other relevant aspects, such as financial capacity and driving safety, should be considered.

Clinical investigation
There is now reasonable evidence and consensus about investigations that would be useful with a person with suspected dementia. The following covers both possible causes of the dementia syndrome and beneficial general health assessment of a person with dementia from whatever cause. It will not be practicable in every case to perform all desirable tests.

The following blood tests are advisable:

- full blood count
- erythrocyte sedimentation rate (ESR) or C-reactive protein
- vitamin B₁₂
- folate
- thyroid function tests
- urea and electrolytes
- calcium
- liver function tests
- glucose.
Blood tests for syphilis, serum lipids and HIV are optional.

Simple urinalysis should be performed. An electrocardiogram (ECG) or chest X-ray should be performed if indicated by significant cardiovascular or respiratory system features; consideration should be given to the need for a baseline ECG when antidementia drugs are to be used.

**Computed tomography and other investigations**

Age should not be a bar to receiving a computed tomographic (CT) brain scan, which should be performed with patients in whom it is clearly indicated by the signs and symptoms of the illness. In milder cases, arguably a scan will discover some potentially reversible pathologic change. Clear indications for priority for CT scanning include atypical presentation or rapid unexplained deterioration; unexplained focal neurological signs or symptoms; history of recent head injury (before onset); urinary incontinence; or gait ataxia early in the illness.

‘Structural imaging by CT is less costly and faster than magnetic resonance imaging (MRI). In most cases, CT is adequate to rule out space-occupying lesions, large strokes, severe atrophy or intracranial haematoma’ (Doraiswamy et al, 1998).

The value of MRI, single photon emission computed tomography (SPECT) or positron emission tomography remains to be established, but it is clear that both MRI and SPECT can provide valuable additional information.

Genetic testing is undertaken in certain specialist centres but is not currently recommended for routine assessment.

Electroencephalography may be useful in differential diagnosis, for Creutzfeldt–Jakob disease and frontal lobe dementia.

Further investigation will be indicated in some cases.

**Service development**

Services should keep under review emerging knowledge on vascular dementia and on more recently highlighted forms of dementia (including Creutzfeldt–Jakob disease), especially Lewy body dementia.

Services should consider how to collaborate with primary care and others to address rising demand to assess early mild cognitive impairment, perhaps through developing a memory clinic.

**Principles of treatment of people with dementia**

**Recommendations**

People with dementia should have fair access to assessment, care and treatment on the basis of need, irrespective of age, gender, social or cultural background.

Care for people with dementia should be truly person-centred, taking into account the personal and social context as well as the biological.
Although there is little substantive evidence for any form of primary prevention, many general health measures will contribute to maintaining the health of people with established dementia.

Training in all aspects of dementia, and in its care and treatment, is hugely important; it should be made as effective as possible and should form part of a wider strategy of dementia care quality improvement.

Services for people with dementia should be integrated, properly planned and adequately resourced.

A patient’s assessment should embrace the identified contextual difficulties, as well as the intrapsychic, historical, interpersonal and societal aspects of the care situation. The assessment should focus on the patient’s perspective, but all perspectives need to be understood for effective care planning.

**Working with people with dementia in primary care**

*Recommendations – referral guidelines*

In the light of the evidence the College recommends that referral to the specialist service is appropriate when there is:

- complexity or uncertainty about the diagnosis after initial assessment and follow-up;
- a request by the patient or the family for another opinion;
- the presence of significant depression and/or psychosis, especially if there is no response to treatment, or acute distress in the patient;
- treatment problems or the need to consider the new specific medications for Alzheimer’s disease;
- difficulty in patient management due to challenging or risky behaviour, multiple problems or concerns about possible abuse; or
- the need for specialist opinion on issues such as financial capacity, driving or similar medico-legal areas.

Finally, all people with suspected dementia should have access to a locality-based specialist service for accurate diagnosis.

*Recommendations on care issues*

Following review of the evidence, and supporting the centrality of the general practitioner and team in the care of the older person with dementia at home, and in the support of any carer, the College recommends the following considerations.

**Identification**

- Case finding is recommended rather than population screening.
- It is important for the practice to re-assess a person who comes to it anew with an established dementia diagnosis.
- The status of mild cognitive impairment is uncertain at this stage: a
history of impairment of function is more useful than a simple complaint of subjective memory impairment.

- A carer/collateral history is essential because of the memory problems.
- It is important to consider the possibility of treatable depressive illness (and this may also coexist with a dementia syndrome).
- Practitioners should be aware that dementia may be complicated by psychotic phenomena or may coexist with pre-existing psychiatric disorder.
- It is useful to use a standardised cognitive function test to identify (and possibly to monitor) cognitive impairment. Use of the MMSE is now suggested by the National Institute for Clinical Excellence (2001) for monitoring therapy with antidementia drugs, and the six-item Cognitive Impairment Test has been recommended.

Examination and investigation in primary care
Physical history aimed at detecting possible reversible causes or comorbid ill health is important. It is also important to look for complicating physical illness, especially with behaviour disturbance.

Full blood count, ESR, biochemistry, thyroid function and simple urinalysis are recommended.

Depression
It is important to look for the possibility of treatable depression mimicking or compounding dementia, and this may be suggested by a past history, family history or recent negative life events. In such circumstances a trial of antidepressant treatment should be considered.

Lewy body dementia
It is important to consider the possibility of dementia with Lewy bodies because of the possible therapeutic implications. It is important to avoid using neuroleptic (antipsychotic) drugs in such patients, and to consider the need for specialist referral.

Managing behavioural disorders in patients with dementia
Physical causes or acute change in physical problems should always be excluded as an underlying cause for behavioural disorder.

Consideration should be given to non-drug interventions before drug therapy is embarked upon.

The ‘psychological environment’ of the care setting and the attitudes of carers may be influential in behaviour problems. As far as possible such causes should be treated before considering neuroleptic medication.

Routine use of neuroleptics (or other tranquillisers) to control behaviour in dementia should be avoided.

For crisis situations short-term use of neuroleptics (antipsychotics) may be justified, but these drugs should only be considered when there are serious
problems, such as psychotic symptoms, serious emotional distress or dangerous behaviour.

There is no clear evidence that one neuroleptic is superior to another, although the side-effects vary.

‘Start low and go slow’, aiming normally for short-term treatment with regular reviews.

All involved with the care of the patient should be aware of potential side-effects. The routine use of anti-Parkinsonian medication is not indicated.

Neuroleptics should be avoided in patients with dementia with Lewy bodies.

**Antidementia drug therapies**

Drug therapy should be given in accordance with present National Institute for Clinical Excellence (NICE) guidance, which means on the recommendation of an appropriate specialist.

Attention to good control of blood pressure and risk factors for cerebrovascular disease is beneficial. At present no other treatment has a clearly established place in vascular dementia.

The benefits of specialist referral to consider the usefulness of emerging treatments should be kept in mind.

**Falls**

People with dementia are prone to falls, and to falling again once having fallen, and the risks may be compounded by the unwanted effects of medication. Falls are more common in those people with dementia who are more physically capable.

Consider referral to an appropriate specialist team if such problems are serious.

**Working with carers**

There should be special sensitivity to the effects that caring for a person with dementia may have on a caregiver. This is likely to be more related to behaviour, relationship or psychological factors.

Depressive illness is common in such carers, and its treatment should be considered.

Carers value acknowledgement of their role, attention to their distress and receiving information on dementia.

Referral to a carers group and/or a voluntary/self-help group should be offered (in particular to the Alzheimer’s Society).

Referral for a full carer’s assessment of need from social services, which may lead to respite services and supportive day care or other services, should be offered.

**Treatment of sleep problems**

Physical health or environmental factors should be considered. Short-term hypnotic treatment may be necessary with severe persistent insomnia. With such medication, the danger of promoting falls or promoting incontinence should be considered.
General follow-up, monitoring and assessment
General practice should remain involved with the management of the person with dementia and any carer.

Regular review of progress and the appropriateness of management is essential. Review of physical health, and of remediable or potentially remediable problems, is essential.

The general practitioner can have an important role in the monitoring of antidementia treatments within a shared care protocol, but this may require supportive training.

Shared care
All patients referred for specialist assessment potentially may be referred back for general practice management.

An agreement to share care or monitoring may be justified by the complexity of the problems or management. Appropriate transfer of information is crucial to getting this right.

Regular updates of shared care protocols are essential for the maintenance of appropriate care of people with dementia.

Psychotic features, behavioural problems, evident difficulty in managing risks or concerns about abuse may particularly justify such shared care.

The NICE guidelines suggest partnership with general practice in managing antidementia drugs.

Working with people with dementia and their carers
Recommendations
Comprehensive assessment of the needs of people with dementia should include assessment of the needs of their carers.

It is important for service providers not to assume a level of need; rather they should work together with the carer and the person with dementia to assess what needs are perceived to exist.

It should not be assumed that it is impossible to involve people with dementia in assessments of need; on the contrary, attempts should be made to involve them.

Carers of people with dementia should be provided with full information about dementia, its prognosis, treatments, support and services by all agencies they are in contact with. This information should be relevant to their needs, be communicated sensitively and be timely.

Carers can benefit from education programmes, which should be more widely available through statutory and voluntary agencies.

Advocacy services should be available for people with dementia and their carers, and such services should be aware of possible differences between the interests of patients and carers.
Befriending schemes for people with dementia may have benefits for both the person with dementia and the carers. A randomised trial would be valuable and should be undertaken.

Clinicians should be aware that imparting information to people with dementia and their carers undoubtedly includes elements of counselling.

Clinicians should consider that although psychotherapeutic approaches to people with dementia may have benefits for both patients and their carers, the most effective use of such resources has not been shown empirically.

Caregiver counselling and support programmes should be researched to see if they are effective in the UK.

Support groups are a useful adjunct to other services and are a valuable source of social support to carers, which clinicians should consider.

Despite the lack of evidence from randomised controlled trials for its effectiveness, respite care should be viewed as an important source of support to carers of people with dementia.

A range of respite options need to be available, including home care (sitting services), day care and short-stay respite care.

People with dementia should only be admitted to acute medical wards if they have a physical illness requiring such treatment.

There should be a range of alternatives to hospital admission, with services able to respond to out-of-hours social needs and emergency situations.

Standards of care in general hospitals must be appropriate for the needs of people with dementia, and staff looking after patients with dementia must be competent to assess their needs and provide proper person-centred care.

All those working with people with dementia, and their carers, may need to provide supportive and palliative care as death approaches, and they must therefore have the competence to do so.

Carers of people with dementia require information about long-term care at an early stage, including details of homes available locally, the process for seeking a placement and information about the likely financial and other consequences.

Carers of people with dementia often require ongoing support from services after a person with dementia has moved into long-term care, as there are often practical problems and emotional issues (including feelings of bereavement and guilt) to address.

Carers of people with dementia should be routinely involved in service planning and evaluation. This requires the provision of adequate resources, including transport, for the purpose.

People with dementia should be informed of their diagnosis whenever possible. This requires careful explanation using appropriate terms, and time, both when the information is being imparted and subsequently, for reflection and to answer questions that arise. Information about prognosis needs to imparted with similar care and sensitivity.
The views of people with dementia regarding the care and services offered to them should be routinely sought. People with dementia have a valuable part to play in the design and evaluation of services.

With regard to treatment, the views of people with dementia should be sought wherever possible. In all cases, the possibility that their perspective might differ from that of their carers should be borne in mind, although it is also vital to consider the carers’ views when making treatment decisions.

Training in dementia and its care is needed at many levels, but to be successful it must be integrated with a general approach to improving quality.

Coverage accorded to dementia in health care curricula should be in proportion to its health, social and economic importance.

**Capacity, legal, financial and risk issues in dementia**

*Recommendations for good practice with capacity, legal and financial issues*

Points to consider:

- Whether the patient has the capacity to consent to treatment:
  - if there is capacity, the patient’s wishes must be respected, unless there is a serious mental health problem for which the use of an order under the Mental Health Act would be appropriate;
  - if there is incapacity, it is good practice to seek the support of the next of kin/carer for giving treatment for serious physical illness in the patient’s best interest, as appropriate;
  - if a patient is incapable and in need of treatment for mental disorder, consideration should be given to the use of compulsion under mental health legislation.

- Whether financial incapacity issues arise and there is a need to advise the patient/carer about them.
- Whether there is a need for an enduring power of attorney or the Court of Protection.
- Whether the Public Trust Office should be approached to authorise a suitable person to manage finances on behalf of an incapable patient with less than £5000.
- Whether an arrangement with a social security office for a person to deal with these payments on behalf of an incapable patient (Appointeeship) is needed.
- Whether Agency (collecting pension on behalf of the individual) is needed.
- Whether there is the possibility that testamentary capacity might be impaired, with a consequent need for advice.
- Whether Guardianship (under the Mental Health Act 1983 in England and Wales) could usefully legitimise necessary access to the patient’s home to provide supportive care.
In the UK, patients who drive and are diagnosed with dementia must be informed of the diagnosis by the specialist and of the necessity for them to report this diagnosis to the Driver and Vehicle Licensing Authority (DVLA). Clinicians should keep themselves updated with respect to the DVLA standards. Other measures may be necessary.

When a firearms licence (e.g. for a shotgun) is held, consideration should be given to whether capacity issues or mental ill health (and consequent safety/dangerousness) issues arise which may necessitate a report by the doctor to licensing authorities as a result of serious public safety concerns.

Resuscitation – the specialist needs to consider the appropriateness of cardiopulmonary resuscitation for in-patients with dementia and whether the patient is capable of taking part appropriately in discussion of this; involvement of the carer also is essential, all the more so if incapacity is present.

Advance directives should be given appropriate consideration and may well have full legal validity in all the circumstances.

A contentious area is the covert administration of medication to incapable patients who resist it when it is given openly (incapacitated patients who do not comply). Treloar et al (2000) found that staff in most long-term care settings resort to this at times, mixing medication in food or drink. They argued that such actions, although a last resort, are ethically legitimate in exceptional circumstances. Common law has to be invoked when the Mental Health Act does not apply. They argue that it is important to balance ease of access to good clinical care against restrictions that aim to prevent abuse.

‘If medication is given covertly, then it should be discussed between the doctor, nurse, pharmacist and relative or advocate, and recorded, so that legal redress is possible. The opportunity for legal redress is, of course, a key element of the UK Human Rights Act 1998’ (Treloar et al./Jones, 2001).

Although there is no consensus in this area yet, it is important that the consultant addresses the issues and does not simply collude with unexamined, unregulated and poor practice. For nurses the UKCC has issued guidance (UKCC, 2001). Similar considerations arise with what may amount to de facto detention.

**Recommendations**

- People with dementia should be involved in all decisions affecting their care and assisted to make whatever decisions they can for themselves.
- Staff who become aware of potential risks should share that information with others involved in the person’s care.
- Concerns about risk and actions taken or recommended to minimise risk should be documented.
Recommendations

Risk should always be considered during assessment of the patient and documented in a standard way (perhaps using a simple instrument). The responsibility to record this rests with the initial assessor and subsequently the care manager. It is useful for such records to show whether risks were identified:

- as part of the assessment
- as the care situation subsequently changed
- at a later agreed review.

Treatment of cognitive symptoms in people with dementia

Practice guidance recommendations

The prescription of a cholinesterase inhibitor should be considered as one component of the management of Alzheimer’s disease.

No particular set of diagnostic criteria was proposed by NICE. One of the standard operationalised schemes, such as ICD–10 (World Health Organization, 1992), DSM–IV (American Psychiatric Association, 1994) or the National Institute of Neurological and Communicative Disorders and Stroke and Alzheimer’s Disease and Related Disorders Association (NINCDS–ADRDA) criteria, should be adopted for consistent use within a given service.

The importance of accurate baseline assessment is emphasised since it is against this that subsequent judgements about response will be made. Details of the precise tests to be used were not given in NICE guidance and thus may vary according to local practice. The MMSE, which will be performed at baseline, should suffice as a cognitive outcome measure. Other more detailed tests may be added if desired.

The NICE absolute requirement for an MMSE score greater than 12 at baseline is likely to mean difficult clinical decisions in patients with scores at or below this threshold. Due allowance should be made in patients with specific difficulties leading to inability to cope with the MMSE, such as serious dysphasia.

The views of the patient, carer and clinician should be recorded separately in case notes and a consensus view about global change documented as the basis for management decisions.

Since it may take 3–4 months to achieve a maintenance dose with some cholinesterase inhibitors, the NICE guidance would suggest that the first follow-up assessment visit might be 6–8 months after baseline. It is suggested that, in practice, more regular contact will be required for dose titration and side-effect monitoring. A visit from the community psychiatric nurse and/or telephone contact may be useful.

If patients show clinically significant deterioration following cholinesterase inhibitor withdrawal which was instigated solely on the grounds of their MMSE score having fallen below 12, reinstatement of medication should be considered.
It may be appropriate for clinicians to treat patients with Lewy body dementia or mixed vascular/Alzheimer’s disease with cholinesterase inhibitors, particularly in patients with behavioural symptoms or global disturbance which have proved refractory to other interventions. Such treatment is outside of the licensed indication. There is no evidence to support the use of cholinesterase inhibitor in frontal lobe or pure vascular dementia.

There is insufficient evidence to support the use of any medications other than cholinesterase inhibitors for treating the cognitive symptoms of dementia. Some patients with dementia may benefit from *Gingko biloba* extract but sufficient evidence-based efficacy data are lacking. Vitamin E (1000 IU twice daily) may be considered in an attempt to slow progression of Alzheimer’s disease but its use for this purpose has not been licensed. Non-steroidal anti-inflammatory drugs and oestrogens have not been shown to have symptomatic effects on cognition in Alzheimer’s disease and should not be prescribed for the treatment of dementia.

Psychosocial interventions and particularly cognitively oriented treatment may be helpful to some patients and carers, but do have potential to precipitate or worsen depression, anxiety or frustration. In the absence of clear evidence of efficacy, such treatment programmes should be considered in the light of the patient’s cognitive capacity and level of tolerance, and possible adverse effects of the treatment must be monitored.

**Treatment of non-cognitive symptoms in people with dementia**

*Recommendations with behavioural and psychological symptoms*

Thorough assessment to establish the cause of the symptoms is the first essential. Neuroleptic (antipsychotic) agents are appropriate to treat agitation or psychosis in people with dementia where other approaches have failed (Doody et al, 2001). The following recommendations from Howard et al (2001) are supported:

- Non-pharmacological management should always be the treatment of first choice, examining the antecedents of the behaviour, the behaviours themselves and the consequences.
- Staff education in homes, carer education and behaviour management techniques have all had some success in alleviating agitation and aggression, and should be considered.
- Consider that there is a lack of evidence from controlled trials to support using benzodiazepines.
- The use of neuroleptics (antipsychotics) should only follow full consideration of the risks as well as benefits.
- Consider that older people are especially sensitive to the common side-effects of antipsychotics.
- Consider that there may be accelerated cognitive decline in Alzheimer’s disease associated with neuroleptic (antipsychotic) use.
Consider that neuroleptic sensitivity can occur particularly in patients with Lewy body dementia.

Consider that the evidence shows a modest level of efficacy for neuroleptic (antipsychotic) drugs.

Consider that there is no demonstrated difference in efficacy, but atypical agents seem better tolerated.

Start at the lowest prescribable dosage and carefully monitor for side-effects.

Only continue medication if there is evidence of efficacy.

Review the need for continuing treatment every 3 months.

Consider that for patients in whom neuroleptics (antipsychotics) are ineffective or not tolerated, carbamazepine or trazodone may be efficacious.

Consider that if agitation is severe or treatment-resistant, specialist referral is merited.

**Recommendations for the treatment of depression**

We support the recommendation of Doody et al (2001) that depression in patients with dementia may be treated with a selected tricyclic antidepressant, monoamine-oxidase type B inhibitor or selective serotonin reuptake inhibitor, with the side-effect profile guiding the choice of drug.

**Non-pharmacological approaches in people with dementia**

**Recommendations**

The recommendations of the American Academy of Neurology (Doody et al, 2001) are supported, namely:

- Educational programmes should be offered to families caring for people with dementia, to reduce the burden of care and to postpone institutional admission.
- Staff in nursing and residential homes should receive education about dementia, aiming to minimise the use of antipsychotic pharmacotherapy.
- Consider the use of behaviour modification, scheduled toileting and prompted voiding to improve urinary continence.
- Functional independence should be improved through the use of graded assistance, practice and positive reinforcement in activities of daily living.

Further, in relation to non-pharmacological approaches, we recommend the following:

- The various specific and non-specific therapies should continue to be developed and refined, and their place in the spectrum of care be clarified. Components of these approaches should be available within all services.
• There is a particular need to increase the availability of training for staff and carers in techniques for coping with memory impairment, and this need might best be met by incorporation in the routine activity of memory clinics.

• Services should also consider the need for training for staff and carers in coping better with the non-cognitive aspects of dementia.
1. Diagnostic assessment and investigation

Specialist old age psychiatry services began in the UK during the 1960s. With speciality recognition in 1988, they are now in place in almost every health authority. Although different styles and models of service have developed, guidance from government and the Royal Colleges has encouraged broadly similar levels and patterns of provision, with roots in mental health and a consistent record of working well with other health and social care agencies for older people.

Services for older people with dementia (and other mental health problems) were addressed by the Audit Commission’s report *Forget Me Not* (Audit Commission, 2000). Guidelines from the National Institute for Clinical Excellence encourage responsible prescribing of cholinesterase inhibitors for Alzheimer’s disease, driving improvement in and equity of access to specialist services. Future development and quality improvement will be influenced by the National Health Service (NHS) Plan, particularly through involving users and carers more. The National Service Framework for Older People (Department of Health, 2001), alongside that for mental illness (Department of Health, 1999a), was intended to identify specific standards and milestones for their achievement.

This summary by the Working Group covers both areas shown to be backed by significant evidence/consensus documents (**) and others that the Working Group has simply agreed in consensus as good practice (*).

**Recommendations**

- The clinical diagnosis of dementia should be based on a standardised system such as ICD–10 (or DSM–IV).
- Attempts should be made to specify underlying causes such as Alzheimer’s disease, vascular dementia, dementia with Lewy bodies, frontal lobe dementia and normal pressure hydrocephalus.

**Context of the specialist service***

There should be ready access to a local specialist service which is comprehensive, effective, firmly rooted in the locale and its resources, and which works closely with local social services, voluntary agencies and with local primary and...
secondary health services. Other specialists, particularly in geriatric medicine and neurology, may also contribute to the assessment of dementia. The focus is on help and support, with family and carers, to retain as much independence as possible for the person with dementia (Royal College of Psychiatrists, 1995; Palmer, 1999).

The specialist service should deal with all aspects, stages and varieties of psychiatric disorder arising in old age, especially all stages of dementia, including continuing care for people with severe dementia (Royal College of Psychiatrists, 1995; Royal College of Psychiatrists & Royal College of Physicians, 1998; New Zealand Guidelines Group, 1997; Palmer, 1999).

Consideration should be given to the needs of different ethnic communities. (Royal College of Psychiatrists, 1995; Royal College of Psychiatrists & Royal College of Physicians, 1998; New Zealand Guidelines Group, 1997; Palmer, 1999; Department of Health, 2000, 2001).

There should be established, easy referral and collaboration between the old age psychiatry and geriatric medical services (Royal College of Psychiatrists, 1995; Royal College of Psychiatrists & Royal College of Physicians, 1998; New Zealand Guidelines Group, 1997; Palmer, 1999).

**Specialist service team**

The assessing specialist team should include access to professionals from all the necessary specialties who are experienced in treating older people, especially staff working in community psychiatric nursing, occupational therapy, physiotherapy, clinical psychology, social work and speech therapy* (no evidence – consensus good practice; Royal College of Psychiatrists, 1995; Palmer, 1999).

After initial assessment, the options of further assessment at home, in an outpatient clinic, at a specialist day assessment facility (usually a day hospital) or on an acute assessment ward (usually only necessary when serious behavioural disturbance or risk features are present) must be available* ** (Clarfield, 1991; American Academy of Neurology, 1994; Small et al, 1997; Frank, 1998; Patterson et al, 1999; Working Party consensus).

Assessment should be supervised by the consultant old age psychiatrist. Best practice is for new cases to be seen by the consultant or a senior doctor of the team** (American Academy of Neurology, 1994; Agency for Health Care Policy and Research, 1996; American Psychiatric Association, 1997; Centre for Health Services Research, 1998; Working Party consensus).

**Referral and service practice**

For those at home, referral should normally be through (or with the support of) the general practitioner. Easy, early and informative referral should be encouraged.
The service should offer urgent (same day) response when necessary. People with milder disorders may be seen in out-patient or memory clinics, with a longer time scale accepted, but otherwise (especially in cases requiring home assessment) 2–3 weeks is a reasonable upper limit to be agreed.

Good communication with all involved is essential, including with patients and carers, and including clarification about when the assessment is to be expected. Written communication with the referring doctor is generally provided within a week of initial assessment, although more urgent telephone/fax communication may be necessary.

Clinical assessment**

Home assessment should be offered routinely – although the service may decide that a clinic-based assessment is appropriate with early presentations*. ** (Melzer et al, 1994; Agency for Health Care Policy and Research, 1996; American Psychiatric Association, 1997; Centre for Health Services Research, 1998; Audit Commission, 2000; Working Party consensus).

A family/carer (collateral) history should be sought in the assessment of all cases, clarifying the problems and the context, including financial and legal aspects*, ** (O’Connor et al, 1989; Agency for Health Care Policy and Research, 1996; Jorm et al, 1996; Centre for Health Services Research, 1998; Patterson et al, 1999; Working Party consensus).

An expert mental state assessment must be undertaken to elaborate deficits of cognitive function, and possible delirium or depressive illness. Use of a standardised assessment of cognitive function such as the Mini-Mental State Examination (MMSE; Folstein et al, 1975) is recommended*, ** (Uhlmann & Larson, 1991; Rouleau et al, 1992; Crum et al, 1993; American Academy of Neurology, 1994; Melzer et al, 1994; Agency for Health Care Policy and Research, 1996; American Psychiatric Association, 1997; Small et al, 1997; Esteban-Santillan et al, 1998; Fillit & Cummings, 1999; Patterson et al, 1999; Working Party consensus).

A recent physical examination, looking for aetiological or aggravating factors, with particular attention to neurological examination, is essential for assessment*. ** (Melzer et al, 1994; Agency for Health Care Policy and Research, 1996; American Psychiatric Association, 1997; Centre for Health Services Research, 1998; Patterson et al, 1999; Working Party consensus).

Other aggravating factors, such as depression compounding dementia, physical illness in the carer, remediable difficulties in the carer–patient relationship or other social, family or psychological stresses, should be considered*. ** (Melzer et al, 1994; Agency for Health Care Policy and Research, 1996; American Psychiatric Association, 1997; Small et al, 1997; Patterson et al, 1999; Audit Commission, 2000; Working Party consensus).

Services should assess systematically for functional impairment, behavioural problems and risk*. ** (Agency for Health Care Policy and Research, 1996;
American Psychiatric Association, 1997; Small et al, 1997; Patterson et al, 1999; Audit Commission, 2000; Working Party consensus). Other relevant aspects, such as financial capacity and driving safety, should be considered.

Clinical investigation**

There is now reasonable evidence and consensus about investigations that would be useful in the case of a person with suspected dementia. The following covers both possible causes of the dementia syndrome and beneficial general health assessment of a person with dementia from whatever cause. It will not be practicable in every case to perform all desirable tests.

Blood tests

The following blood tests are advisable:

- Thyroid function tests*, ** (Clarfield, 1991; American Academy of Neurology, 1994; American Psychiatric Association, 1997; Small et al, 1997; Centre for Health Services Research, 1998; Doraiswamy et al, 1998; Frank, 1998; Fillit & Cummings, 1999; Foster et al, 1999; Patterson et al, 1999)


Urinalysis

Simple urinalysis*, ** (American Academy of Neurology, 1994; Small et al, 1997; Patterson et al, 1999; Working Party consensus) should be performed.

Electrocardiogram, chest X-ray

Electrocardiography and chest X-ray*, ** (Melzer et al, 1994; Agency for Health Care Policy and Research, 1996; American Psychiatric Association, 1997; Small et al, 1997; Centre for Health Services Research, 1998; Patterson et al, 1999; Working Party consensus) should be performed if indicated by significant cardiovascular or respiratory system features; consideration should be given to the need for a baseline electrocardiogram when antidementia drugs are to be used (Cummings, 2000; Royal College of Psychiatrists, 2004).

Brain imaging

Computed tomography (CT) scans*, ** (Clarfield, 1991; Chui & Zhang, 1997; Doraiswamy et al, 1998; Freter et al, 1998; Fillit & Cummings, 1999; Foster et al, 1999; Patterson et al, 1999; Working Party consensus) should be performed with patients in whom it is clearly indicated by the signs and symptoms of the illness. Age should not be a bar. In an ideal world, every patient with suspected dementia should receive a CT scan. In milder cases, arguably this will discover some potentially reversible pathologic changes. Clear indications for priority for CT scanning include atypical presentation or rapid unexplained deterioration; unexplained focal neurological signs or symptoms; history of recent head injury (before onset); or urinary incontinence or gait ataxia early in the illness (Waldemar et al, 2000; Knopman et al, 2001).
‘Structural imaging by CT is less costly and faster than MRI. In most cases, CT is adequate to rule out space occupying lesions, large strokes, severe atrophy or intracranial haematoma’ (Doraiswamy et al, 1998)* **

The value of magnetic resonance imaging (MRI), single photon emission computed tomography (SPECT) or positron emission tomography remains to be established, but it is clear that MRI and SPECT can both provide valuable additional information (Waldemar et al, 2000; Knopman et al, 2001).

Genetic testing
Genetic testing is undertaken in certain specialist centres but is not currently recommended for routine assessment.*

EEG

Further investigation will be indicated in some cases* ** (Waldemar et al, 2000; Knopman et al, 2001).

Service development*
Services should keep under review emerging knowledge on vascular dementia and on more recently highlighted forms of dementia (including Creutzfeldt–Jakob disease), especially Lewy body dementia* (McKeith et al, 1999; Ballard et al, 2000).

Services should consider how to collaborate with primary care and others to address rising demand to assess early mild cognitive impairment (Petersen et al, 1999; Ritchie & Touchon, 2000), perhaps through developing a memory clinic.*

These approaches and the evidence quoted to support them are further strengthened by the reviews of the Scottish Intercollegiate Guidelines Network (1998) and of the American Academy of Neurology (Doody et al, 2001; Knopman et al, 2001).

Other important literature considered
2. **Principles of treatment of people with dementia**

This section sets out certain general themes that can be regarded as principles underlying the assessment, care and treatment of people with dementia, and the provision of support to their carers.

**Equity and avoiding ageism**

The term ‘ageism’ covers a range of unfavourable attitudes towards older people. There is also age discrimination, through which people are excluded, for example from treatments or services, solely by virtue of their age. This form of discrimination is not illegal in the UK, in contrast to discrimination on the grounds of gender, race or disability. However, in England and Wales the National Service Framework for Older People (Department of Health, 2001) aims to root out age discrimination, with services to be provided on the grounds of clinical or social need, irrespective of age.

It is also of paramount importance that people with dementia have fair access to services, irrespective of other factors. Particular attention needs to be paid to ensuring access by people from ethnic minority groups.

**Person-centred care**

Someone with dementia is an individual person with a personal history and a social and cultural context, all of which should be recognised and valued (Kitwood, 1997). The National Service Framework sets out the following advice for person-centred care for older people, all of which is very apt for dementia (Department of Health, 2001):

- listen to older people;
- respect dignity and privacy;
- recognise individual differences and specific needs, including cultural and religious differences;
- enable older people to make informed choices, involving them in all decisions about their needs and care;
- provide coordinated and integrated service responses;
- involve and support carers whenever necessary.

**Health promotion**

A detailed account of health promotion and the possible impact of preventive measures on the incidence of dementia is beyond the scope of this report. However, it is likely that measures to improve general health in populations,
and among older people in particular, have an effect on the occurrence and course of illnesses that cause dementia. The most obvious example is cardiovascular disease and the rates of vascular dementia. It is likely that general health measures, such as better diet, smoking cessation and moderation in alcohol consumption, can be significant measures in the prevention of dementia, although at present evidence for any primary preventive effects is scanty.

Health promotion among people who have developed dementia is also important (see Chapter 3). People with dementia should receive careful attention to their general health. Those who retain capacity should be encouraged to participate in health screening programmes such as mammography. Rational prescribing and regular review of medication can do much to prevent new problems arising from drug side-effects and interactions.

Training

The training implications of working with people with dementia and their carers are discussed in more detail in the relevant section, but all the sections of this guidance indicate a need for more training in various areas, from primary care through general hospital services to specialist dementia services, not to mention staff working in social care, and also for carers and users of services. There is a need for training to be of the right quality; and, to be effective, it needs to be coupled with an overall strategy aimed at improving the quality of dementia care.

Services

Various aspects of the services required for the assessment, diagnosis, treatment and care of people with dementia, and the provision of support to their carers, are discussed throughout this report. Although there is current optimism about new treatments, the vast bulk of the monetary cost of dementia is spent on forms of supportive care, including informal care (Lowin et al, 2001). Thus, the way in which services are organised and delivered will have a major impact upon the nature and quality of care received by people with dementia and their carers. Local services for people with dementia need to be adequately resourced and well organised, with a clearly agreed multi-agency local strategy for service development and clear protocols for referrals and management. This includes specialist multidisciplinary teams as set out in the National Service Framework for Older People (Department of Health, 2001).

Comprehensive assessment

Assessment should encompass the overall care situation and particularly should include the following aspects.
**Context**

Paramount in the picture should be the context and perspective of the patient, rather than the views of the assessor, of other care workers or of the family. Important considerations include whether the person lives alone or with a spouse, how close is the nearest support and the safety of the dwelling situation. Other key factors are the coping and attributional styles of any carers, and their mental health.

**Difficulties**

It is important to assess the deficits the patient exhibits and the consequent difficulties created. These will be evident from physical examination, from psychiatric examination and from cognitive, functional and behavioural assessment.

**Intrapsychic factors**

The service should evaluate the responses of patients to their situation – both adaptive and maladaptive. Inappropriate refusal of help may have reasons that can be understood and worked with.

**Effects of the past**

Part of the assessment should be a detailed history, as this can reveal past events that affect the current care situation and how it has developed. Past ways of responding may be repeated, and family dynamics need to be understood.

**Interpersonal factors**

Assessments should clarify how patients get on with those around them. Marital and other premorbid relationships may determine the limits to possible care at home, as may, for instance, gaps in age between patients and paid carers, both at home and in residential care.

**Societal considerations**

Assessment should be sensitive to the local reaction to the situation, as the values, possible ageism and capacity to help in the neighbouring community may determine responses, and how risk is interpreted. Again, however, actions must be in the patients’ best interests, rather than primarily in the interests of those around them.

**Recommendations**

- People with dementia should have fair access to assessment, care and treatment on the basis of need, irrespective of age, gender and social or cultural background.
• Care for people with dementia should be truly person-centred, taking into account the personal and social context as well as biological factors.
• Although there is little substantive evidence for any form of primary prevention, many general health measures will contribute to maintaining the health of people with established dementia.
• Training in all aspects of dementia, and in its care and treatment, is hugely important; it should be made as effective as possible and should form part of a wider strategy of dementia care quality improvement.
• Services for people with dementia should be integrated, properly planned and adequately resourced.
• A patient’s assessment should embrace the identified contextual difficulties, as well as the intrapsychic, historical, interpersonal and societal aspects of the care situation.
• The assessment should focus on the patient’s perspective, but all perspectives need to be understood for effective care planning.
3. Working with people with dementia in primary care

Referral

The evidence base for referral guidelines is limited and there is no evidence from randomised controlled trials. The following is the best-supported formulation; it is adapted from the Canadian Consensus Conference on Dementia recommendations (Patterson et al, 1999) but also incorporates suggestions from other references (listed below).

Guideline

People with suspected dementia will usually be assessed by their general practitioner and much of the management of their dementia will also be through primary care services. However, in some cases, referral to specialist medical services will be appropriate. Some of these circumstances are:

- complexity or uncertainty about the diagnosis after initial assessment and follow-up;
- request by the patient or the family for another opinion;
- the presence of significant depression, especially if there is no response to treatment, or acute distress in the patient;
- treatment problems, or failure with new specific medications for Alzheimer’s disease, or difficulties in patient management due to (for example) challenging or risky behaviour;
- where caregiver support and/or respite care is needed;
- where there is a need to involve other health care professionals, voluntary agencies or other specialist services;
- when genetic counselling is indicated;
- when research studies into diagnosis or treatment are being carried out (Grade B Level 3 in Patterson et al, 1999).

This also incorporates suggestions from the Agency for Health Care Policy and Research (1996), Alzheimer’s Disease Society (1995), Clarfield (1991), Haines & Katona (1992), Palmer (1999) and US Department of Veterans Affairs & University Health System Consortium (1997). (Other supportive references for this guideline are listed below, but no strength of evidence ratings are given in this document.) However, this guideline uses language and describes some circumstances that are applicable in North American (and perhaps New Zealand) practice and are less appropriate for the UK setting. Thus, the first two sentences of the guideline would be better phrased for the UK, especially from a primary care perspective (Iliffe & Drennan, 2001), as:
The clinical suspicion that an individual has some form of dementia is likely to arise first in consultations with the general practitioner, although family members or friends may have begun to think about this possibility beforehand. Subsequent care is provided in different ways in different places, depending on the interest and skills of general practitioners, the existence of supportive voluntary organisations, the availability of community psychiatric nurses and the resources and organisation of social care.

Similarly, the appropriate circumstances for referral would differ slightly in the UK, thus:

- National Institute for Clinical Excellence (NICE) guidance is that all patients with an early diagnosis of Alzheimer’s disease should be seen by specialists to initiate cholinesterase inhibitor treatment;
- caregiver support and/or respite care would be seen as a social care responsibility as much as a medical one;
- involvement of other health care professionals, social services or voluntary agencies should occur in all cases where this is appropriate and should not depend on or require referral to specialist services.

In 2001 the National Service Framework for Older People (Department of Health, 2001) for England and Wales stated that referral to the specialist mental health service should be considered for those with suspected dementia:

- if diagnosis is uncertain;
- if certain behavioural and psychological symptoms are present, for example aggressive behaviour;
- if there are safety concerns, for example if an older person is wandering;
- for risk assessment, for example if an older person is thought to be at risk of abuse or self-harm;
- if there is a need for specialist assessment of dementia, for example testamentary capacity or driving;
- for consideration of treatment of antidementia drugs in accordance with local protocols;
- if the older person has complex or multiple problems, for example, where an older person needs specialist methods of communication owing to sensory impairments;
- where there is dual diagnosis, for example, possible dementia and learning disability or dementia and other severe mental disorders (Department of Health, 2001).

An evidence base for this statement is not given, but mostly these points seem consistent with the formulation adapted from Patterson et al (1999).

Recommendations

In the light of the evidence, the College recommends that referral to the specialist service is appropriate when any of the following six circumstances obtain:
• complexity or uncertainty about the diagnosis after initial assessment and follow-up;
• a request by the patient or the family for another opinion;
• the presence of significant depression and/or psychosis, especially if there is no response to treatment, or acute distress in the patient;
• treatment problems or the need to consider the new specific medications for Alzheimer's disease;
• difficulty in patient management due to challenging or risky behaviour, multiple problems or concerns about possible abuse;
• there is a need for specialist opinion on issues such as financial capacity, driving or similar medico-legal areas.

Finally, all people with suspected dementia should have access to a locality-based specialist service for accurate diagnosis.

**Care issues**

With current secondary sources some guidance exists on:

• general clinical management
• management of psychosis and agitation
• management of sleep problems
• physical screening of a person with dementia
• general follow-up, monitoring and assessment
• medication
• service provision: primary care
• management of behavioural disturbances
• treatments
• management of depression in patients with dementia
• behavioural disorders
• falls
• antidementia drug therapies.

None of this provides randomised controlled trial or evidence-based guidance specifically tested in or arising from the primary care setting, as opposed to expert opinion, and it is not specific either to joint working between primary care and specialist services.

An important aspect is that there is currently no system for documenting carers in general practice information systems, which are completely patient-focused. Information technology systems need to be adapted to enable such carer issues to be addressed.

**Recommendations**

These guidelines lean heavily on others, especially the North of England evidence-based guideline development project (Centre for Health Services Research, 1998),
the New Zealand Guidelines (New Zealand Guidelines Group, 1997) and the
Scottish Intercollegiate Guidelines Network (1998), to which grateful
acknowledgement is given.

Following review of the evidence, and supporting the centrality of the general
practitioner and team in the care of the older person with dementia at home and
in the support of any carer, the College recommends the following considerations
(based as noted on the evidence or consensus cited).

Identification
Case finding is recommended rather than population screening (Iliffe et al, 1994,
2002; Brayne et al, 1995; Tobiansky et al, 1995; Centre for Health Services Research,
1998).

It is important for the practice to re-assess a person who comes to it anew with
an established dementia diagnosis (Working Group consensus).

The status of mild cognitive impairment (Ritchie & Touchon, 2000) is uncertain
at this stage: a history of impairment of function is more useful than a simple
complaint of subjective memory impairment (American Psychiatric Association,
1987; Agency for Health Care and Policy Research, 1996; Graham et al, 1996;
Centre for Health Services Research, 1998; Larson et al, 1998; Medical Research

A carer/collateral history is essential because of the memory problems

It is important to consider the possibility of treatable depressive illness (and
this may also coexist with a dementia syndrome) (Burns et al, 1990b; American
Psychiatric Association, 1997; Small et al, 1997; Centre for Health Services Research,
1998; Scottish Intercollegiate Guidelines Network, 1998; Patterson et al, 1999;
Waldemar et al, 2000).

Practitioners should be aware that dementia may be complicated by psychotic
phenomena or may coexist with pre-existing psychiatric disorder (Ciompi, 1985;
Cummings et al, 1987; Rubin et al, 1988; Burns et al, 1990a,b; Campbell, 1997).

It is useful to apply a standardised cognitive function test to identify (and
possibly to monitor) cognitive impairment (Koss et al, 1993; Bowers et al, 1990;
O’Connor et al, 1993; Centre for Health Services Research, 1998). The Mini-Mental
State Examination (MMSE; Folstein et al, 1975) is now suggested by the National
Institute for Clinical Excellence (2001) as a suitable test for the monitoring of
antidementia drugs, and the six-item Cognitive Impairment Test (Brooke &
Bullock, 1999) has been recommended.

Examination and investigation in primary care
Physical history aimed at detecting possible reversible causes or comorbid ill
health is important. It is also important to look for complicating physical illness,
especially with behaviour disturbance (Bayer et al, 1987; Siu, 1991; Centre for
Health Services Research, 1998; Doraiswamy et al, 1998; Fillit & Cummings, 1999;
Full blood count, ESR, biochemistry, thyroid function and simple urinalysis have been recommended (Bayer et al, 1987; Siu, 1991; Centre for Health Services Research, 1998; Doraiswamy et al, 1998; Fillit & Cummings, 1999; Patterson et al, 1999; Waldemar et al, 2000).

**Depression**

It is important to look for the possibility of treatable depression mimicking or compounding dementia, and this may be further suggested by a history of this condition, a family history or recent negative life events (Bums et al, 1990c; American Psychiatric Association, 1997; Small et al, 1997; Centre for Health Services Research, 1998; Scottish Intercollegiate Guidelines Network, 1998; Patterson et al, 1999; Waldemar et al, 2000).

In such circumstances a trial of antidepressant treatment should be considered (Small et al, 1997; Centre for Health Services Research, 1998; Doody et al, 2001).

**Lewy body dementia**

It is important to consider the possibility of dementia with Lewy bodies because of the possible therapeutic implications (Knopman et al, 2001).

It is important to avoid using neuroleptic drugs in such patients (and consider the need for specialist referral: McKeith et al, 1992).

**Managing behavioural disorders in patients with dementia**

Physical causes or acute change in physical problems should always be excluded as an underlying cause for behavioural disorder (Beck & Shue, 1994; Nilsson et al, 1998; Patterson et al, 1999).

Consideration should be given to non-drug interventions before drug options are embarked upon (Allen-Burge et al, 1999; Proctor et al, 1999; Terri et al, 2000; Howard et al, 2001).

The ‘psychological environment’ of the care setting and the attitudes of carers may be influential in behaviour problems (Kitwood & Bredin, 1992; Allen-Burge et al, 1999). As far as possible, such causes should be treated before considering neuroleptic prescription (Kitwood & Bredin, 1992; Allen-Burge et al, 1999; Proctor et al, 1999; Terri et al, 2000; Howard et al, 2001).

Routine use of neuroleptics (or other tranquillisers) to control behaviour in dementia should be avoided (McKeith et al, 1992; McGrath & Jackson, 1996; McShane et al, 1997; Howard et al, 2001).

For crisis situations short-term use of neuroleptics (antipsychotics) may be justified but these drugs should only be considered when there are serious problems, such as psychotic symptoms, serious emotional distress or dangerous behaviour (Centre for Health Services Research, 1998; Ballard & O’Brien, 1999; Doody et al, 2001; Howard et al, 2001).

There is no clear evidence that one neuroleptic is superior to another, although the side-effects vary (De Deyn et al, 1999; Katz et al, 1999; Street et al, 2000).
‘Start low and go slow’, aiming normally for short-term treatment with regular reviews (Howard et al, 2001).

All those involved with the care of the patient should be aware of potential side-effects (Centre for Health Services Research, 1998). The routine use of antiparkinsonian medication is not indicated (Centre for Health Services Research, 1998). Neuroleptics should be avoided in patients with dementia with Lewy bodies (McKeith et al, 1992).

**Antidementia drug therapies**

Antidementia drugs should be given in accordance with present NICE guidance (National Institute for Clinical Excellence, 2001), which means on the recommendation of an appropriate specialist.

Attention to good control of blood pressure and risk factors for cerebrovascular disease is beneficial (Antiplatelet Trialists’ Collaboration, 1994; Centre for Health Services Research, 1998). At present no other treatment has a clearly established place in vascular dementia (Doody et al, 2001).

The benefits of specialist referral to consider the usefulness of emerging treatments should be kept in mind (Department of Health, 2001).

**Falls**

People with dementia are prone to falls, and to falling again once having fallen, and the risks may be compounded by the unwanted effects of medication (Melton et al, 1994; Asada et al, 1996; Nuffield Institute for Health & NHS Centre for Reviews and Dissemination, 1996). Falls are more common in people with dementia who are more physically capable.

Consider referral to an appropriate specialist team if such problems are serious (Department of Health, 2001).

**Working with carers**

There should be special sensitivity to the effects that caring for a person with dementia may have on a caregiver (Parks & Pilisuk, 1991; Stephens et al, 1991; Vitaliano et al, 1991; Russo & Vitaliano, 1995; Centre for Health Services Research, 1998). This is likely to be more related to behaviour, relationship or psychological factors (Parks & Pilisuk, 1991; Stephens et al, 1991; Vitaliano et al, 1991; Russo & Vitaliano, 1995; Centre for Health Services Research, 1998; Murray et al, 1999, 2001).

Depressive illness is common in such carers and treatment should be considered (Livingston et al, 1996).

Carers value acknowledgement of their role, attention to their distress and receiving information on dementia (New Zealand Guidelines Group, 1997; Murray et al, 1999, 2001; Waldemar et al, 2000; Nolan & Keady, 2001).

Referral to a carers group and/or a voluntary/self-help group should be offered, especially to the Alzheimer’s Society (Coyne, 1991; New Zealand Guidelines Group, 1997; Melzer et al, 1999).
Referral for a full carer’s assessment of need from social services, which may lead to respite services and supportive day care or other services, should be offered (Department of Health, 1989, 1999b).

*Treatment of sleep problems*

Physical health or environmental factors should be considered (Victor & Howse, 1999; British Medical Association & Royal Pharmaceutical Society of Great Britain, 2001).

Short-term hypnotic treatment may be necessary in cases of severe persistent insomnia (British Medical Association & Royal Pharmaceutical Society of Great Britain 2001). With such medication the dangers of promoting falls or promoting incontinence should be considered (Melton et al, 1994; Asada et al, 1996; Nuffield Institute of Health & NHS Centre for Reviews and Dissemination, 1996).

*General follow-up, monitoring and assessment*

General practice should remain involved with the management of the person with dementia and any carer (Department of Health, 2001).

Regular review of progress and the appropriateness of management is essential (Centre for Health Services Research, 1998).

Review of physical health, and of remediable or potentially remediable problems, is essential (Siu, 1991; Doraïswamy et al, 1998; Fillit & Cummings, 1999; Patterson et al, 1999; Waldemar et al, 2000; Doody et al, 2001).

The general practitioner can have an important role in the monitoring of antidementia treatments within a shared care protocol, but this may require supportive training (Department of Health, 2001).

*Shared care*

All patients referred for specialist assessment potentially may be referred back for general practice management (Working Group consensus).

An agreement to share care or monitoring may be justified by the complexity of the problems or management (Working Group consensus). Appropriate transfer of information is crucial to the success of shared care (Working Group consensus).

Regular updates of shared care protocols are essential for the maintenance of appropriate care of people with dementia (Working Group consensus).

Psychotic features, behavioural problems, evident difficulty managing risks or concerns about abuse may particularly justify such shared care (Working Group consensus).

4. Working with people with dementia and their carers

There are 6 million carers in the UK. Nine out of ten look after a close relative; 58% are women; and they are most likely to be aged 45–64 years. Half of all carers look after someone over 75 years old (Department of Health, 1999b). There are an estimated 400,000 carers for people with dementia in the UK.

Having a co-resident carer reduces the risk of entering residential or nursing home care by 20 times (Murray et al., 2001).

Carers are not a homogeneous group. There are differences associated with the relationship to the person with dementia, whether the carer is co-resident, differences between male and female carers, and in the caring roles and expectations within different ethnic groups (Briggs & Askham, 1999).

Morbidity and stress among carers

There is an extensive literature on carer stress, burden and morbidity, and on the factors associated with it (Donaldson et al., 1997; Schneider et al., 1999). Carers’ psychological well-being is a key factor in admission into nursing or residential care (Levin et al., 1994).

Behaviour problems are consistently identified as having a major impact on caregiver well-being and on the risk of admission to residential or nursing home care (for example, Levin, 1997). This is shown in longitudinal as well as cross-sectional studies (Donaldson et al., 1997; Schneider et al., 1999; Murray et al., 2001).

Caring for people with dementia is associated with higher levels of stress and depression than caring for other conditions (Livingston et al., 1996), and there are both a significant financial impact and high levels of unmet need (Philp et al., 1995). However, it is also important to look at the capabilities of carers, the satisfactions that they experience and how they cope in practice (Nolan & Keady, 2001). Reported areas of satisfaction include a feeling of job satisfaction, continued reciprocity and mutual affection, companionship, and the fulfilment of a sense of duty (Murray et al., 1999).

Existing guidance

The literature on carers is uneven. There are numerous studies of carer stress, but fewer publications on interventions, of which even fewer are reports of randomised trials. Systematic reviews of interventions for carers do not report positive findings (Thompson & Spilsbury, 2001), but this may be due to the small sample numbers and heterogeneity of trials.
Existing guidelines recommend that carers should have their own assessments, and that information, education, training and support be provided to them. For example:

‘Assessment of caregivers’ distress and needs, and administration of intervention programmes for caregivers, should be an integral part of the management of patients with dementia’ (Waldemar et al, 2000).

‘Carers should have specific information and counselling for emotional problems throughout the illness’ (Department of Health, 1999b).

‘Carers need services that are timely, appropriate and individually planned’ (Audit Commission, 2000).

‘Training programmes for family carers should be available throughout the country, resourced by [health authorities]. Appropriate funding for the Alzheimer’s Society’s administration of its national awareness and information programmes should also be made available’ (New Zealand Guidelines Group, 1997).

This section also considers the increasingly important area of working with people with dementia, in particular the question of diagnosis, and also user perspectives on services. Existing guidelines generally support the idea of disclosing the diagnosis to the person with dementia, for example:

‘Although each case should be considered individually, in general the diagnosis of a dementing condition should be disclosed to the patient and family. This process should include a discussion of prognosis, diagnostic uncertainty, advance planning, treatment options, support groups and future plans. Exceptions to disclosing prognosis to the patient could be severe dementia where understanding of the diagnosis is unlikely, phobia about the diagnosis or severe depression’ (Patterson et al, 1999).

Assessment of carers

What is a carer? Several definitions are available, and there is overlap with other terms, such as ‘caregiver’. A useful definition is ‘a family member (or friend), helping someone on a regular (usually daily) basis with tasks necessary for independent living’ (Zarit & Edwards, 1996). Traditionally, the emphasis has been on the performance of tasks, but this is changing with earlier diagnosis, as the person newly diagnosed may still be functionally independent. In such circumstances, a family member or friend who provides a supporting role should also be regarded as a carer, with a right to consideration of their needs as affected by the diagnosis of dementia.

Assessment of carers is essentially about assessing their needs. There are difficulties in defining ‘need’, which involve problems of judgement. Perceived needs are not objective and may be subjectively influenced by the value system of the person or system defining the needs (Cheah et al, 1998). A distinction can be made between ‘need’ and ‘demand’ (Stevens & Gabbay, 1991): ‘need’ relates to intervention, through which people benefit, but ‘demand’ is what people ask for. It can be wrong to assume that need equates with a professional’s assessment, which could be related to the service’s perspective. Full assessment of need should cover factors such as the nature and course of the disease, the ability to
carry out activities of daily life, and the carer’s situation – and, thereby, give information as to what type of service provision is required, e.g. preventive, rehabilitative or supportive.

The needs of carers interact with the particular setting. A carer’s needs may be in conflict with those of the person with dementia; the needs of a person with dementia living alone may challenge the services that can be provided by the care sector; the needs of people with dementia in residential care, and their carers, will differ from those of similar people residing in the community.

**Involving carers and people with dementia in assessing needs**

Ten key components of services for people with dementia and their carers have been identified by Enid Levin (Levin, 1997). These elements can be seen as the desirable end-points of individualised needs assessments. They are:

- early identification of dementia
- integrated medico-social assessment
- active medical treatment
- timely referral
- information, advice and counselling
- continuing back-up and review
- regular help with household and personal care tasks
- regular breaks from caring
- regular financial support
- permanent residential care (when necessary).

Involving carers and people with dementia in an assessment of their needs is embodied in community care legislation (National Health Service and Community Care Act 1990): ‘Those needing services and those caring for people who need services should have a greater individual say in how they live and the services they need to help them do so’ (Department of Health, 1989). Giving equal weight to the perceptions of both user and service provider has the practical benefit of allowing differences to be discussed (Slade, 1994).

**Measurements, scales and assessments of need**

Needs assessment is a process that can occur in stages, starting with an initial screening, progressing to more detailed enquiry, including more confident diagnosis, and resulting in a care plan, and continuing ‘monitoring’ in care plan delivery. Various forms of assessment have been developed, ranging from comprehensive assessment schedules (see, for example, guidance on the single assessment process; Department of Health, 2002) to more specific measurements of particular areas of functioning.

A comprehensive collection of assessment scales for old age psychiatrists has been compiled by Burns et al (1999). It includes scales for depression and other
psychiatric symptoms, neuropsychological tests, activities of daily living, global assessments/quality of life, physical health and ‘caregiver assessments’. Twelve scales for caregiver assessment are included. Psychological distress is most often measured using the General Health Questionnaire (GHQ; Goldberg & Williams, 1988). Lists of the number of problems exist, and other scales cover activity and difficulties in more detail. The gold standard remains the Problem Checklist and Strain Scale (Gilleard, 1984). However, even this substantial work is not complete and omits some quite specific scales such as the Behavioural and Instrumental Stressors in Dementia (Keady & Nolan, 1996). There are also scales that emphasise ‘carers as experts’, including such aspects as carer satisfaction and how carers cope successfully (Nolan & Keady, 2001).

Key points

- Assessment of need is a complex area with particular problems arising from different definitions of and perspectives on needs.
- Carers can face many difficulties when their ‘needs’ are assessed by service providers (e.g. not having enough information about services available in order to make an informed decision).

Recommendations

- Comprehensive assessment of the needs of people with dementia should include assessment of the needs of their carers.
- It is important for service providers not to assume a level of need; rather, they should work together with the carer and person with dementia to assess what needs are perceived to exist.
- It should not be assumed that it is impossible to involve people with dementia in assessments of need; on the contrary, attempts should be made to involve them.

Interventions

Information

Research in this area has emerged only since the 1990s, even though information-giving has long been a function of statutory and non-statutory agencies. Those caring for people with dementia often perceive that their needs for communication and information are not met adequately (Twigg & Atkin, 1990; Coyne, 1991; Kohner, 1992; Keady & Nolan, 1995; Mudge, 1995). The need for information is ongoing (Keady & Nolan, 1995). Keady & Nolan suggest that carers fall into two groups as far as information needs are concerned: those who want ‘everything and anything on dementia as soon as possible’ and those who want ‘just a little at first, I’m not sure how much I want to know’ (Keady & Nolan, 1995).
For this report no specific study concerning the impact of providing carers with information was identified, but some studies have described the outcome of establishing information services for carers and families affected by dementia. An American study (Coyne, 1991) examined information and referral usage, showing that most requests from carers of people with dementia were for in-home service information, followed by requests for information and education about dementia. Satisfaction with the information given was rated highly by carers.

An evidence-based review from the Royal College of Psychiatrists (Palmer, 1999) makes the following recommendations on providing information for patients and carers:

- Health professionals should be aware that depressive illness is common in carers of people with dementia and is influenced by behavioural problems, and higher care (needs), in the service user.
- Physicians should inform the patient and their family about the probable diagnosis of Alzheimer’s disease. This disclosure should ordinarily occur in a joint meeting and should allow time for questions and discussion. With disclosure comes responsibility to direct the patient and family to resources, and to agree on a care plan. The utility of information from genetic testing has yet to be tested.

Recommendations

Carers of people with dementia should be provided with full information about dementia, its prognosis, treatments, support and services by all the agencies they are in contact with. This information should be relevant to their needs, be communicated sensitively and be timely.

Carer education

Several published studies, including randomised controlled trials, indicate the benefits of education and training programmes for carers of people with dementia. Carer training programmes can improve adjusted rates of survival at home, with fewer deaths, and delay in institutionalisation of people with dementia (Brodaty & Peters, 1991; Brodaty et al, 1997). Haupt et al (2000) demonstrated that psychoeducative group intervention with carers of people with dementia can be helpful to the patients themselves.

Additionally, there are reports of extensive carer education programmes being delivered with significant levels of satisfaction by voluntary groups. At the Alzheimer’s Society Symposium in 2000 at Nottingham University, Graham reported on a 3-year programme that has delivered dementia education to over 800 carers in Northern Ireland (Alzheimer’s Society, 2000); Bruce & Gallagher (Alzheimer’s Society, 2000) outlined a collaborative education programme.
between the University of Bradford and the Bradford branch of the Alzheimer’s Society; and Stevenson (Alzheimer’s Society, 2000), from Alzheimer’s Scotland – Action on Dementia, described a similar programme for Scotland, which has been in place since 1993.

**Recommendations**

Carers can benefit from education programmes, which should be more widely available through statutory and voluntary agencies.

**Advocacy**

The role of advocacy for those who are unable to put forward their views is increasingly being addressed within health service research. Advocacy has been described as ‘making the case for someone or for a group of people or helping them to defend their rights or promote their interests’ (Killeen, 1996).

Advocacy is differentiated from other forms of support, such as befriending services, mediation services, advice work and counselling, in that it involves development of relationships with regard to rights and representation.

The problems of having carers of people with dementia act as their advocates has been documented and the issue of appointing an independent advocate raised (Cohen, 1994; Evans, 1994; Killeen, 1996). Other reports highlight the need for people with dementia to have access to an advocate (Wertheimer, 1993; Askham, 1997).

**Recommendations**

Advocacy services should be available for people with dementia and their carers, and those providing such services should be aware of possible differences between the interests of patients and carers.

**Befriending**

Another recent development is the introduction of befriending schemes for people with dementia. Some brief reports are available, but there is no comprehensive evaluation. One study (British Psychological Society Special Interest Group for the Elderly, 1998) evaluated a 12-month pilot befriending scheme. The objective of the scheme was to improve the quality of life of a sample of older adults with dementia through participation, social contact and friendship with specially trained befrienders. The study produced some evidence that the scheme had improved the clients’ quality of life and had eased the strain on carers.

Another scheme (Nicholson, 2001) included 103 people with dementia who were referred to the project. Benefits were identified for: people with dementia by providing stimulation and maintaining social and intellectual skills; for
families and carers by reducing carer isolation and giving them some free time; and for volunteer befrienders by giving training and enhancing communication and caring skills.

Recommendations

Befriending schemes for people with dementia may have benefits for people with dementia and their carers. A randomised trial would be valuable and should be undertaken.

Counselling

There is little research that addresses and evaluates the effectiveness of counselling either for people with dementia or their carers. This may be because it is difficult in practice to define and systematise the terminology associated with counselling. Counselling carers and people with dementia takes many forms, but its main function appears to be to provide emotional support to the carer.

Counselling strategies as a means of intervention have been examined with carers (Toseland & Rossitter, 1989; Keizer & Feins, 1991; Mittelman et al, 1996). The American study by Mittelman et al (1996) found that a programme of counselling and support could ‘substantially increase the time spouse–caregivers are able to care for people with [Alzheimer’s disease], patients at home particularly, during the early to middle stages of dementia when nursing home placement is generally least appropriate’.

It has now been acknowledged that people with dementia can be receptive to psychotherapeutic techniques, and a growing body of research has identified possible areas in which counselling may be beneficial (Hausman, 1992; Greene & Ingram, 1993; Cheston, 1998). Such therapeutic techniques have included the use of counselling skills to encourage expressions of grief, sadness and other feelings (Stokes & Goudie, 1990; Mills & Coleman, 1994). Being able to express such feelings can be cathartic and the stories that people with dementia are able to tell can act as a means of ‘emotion-focused exploration’ (Cheston, 1998).

Recommendations

• Clinicians should be aware that imparting information to people with dementia and their carers undoubtedly includes elements of counselling.

• Clinicians should consider that although psychotherapeutic approaches to people with dementia may have benefits for both patients and their carers, the most effective use of such resources has not been shown empirically.

• Caregiver counselling and support programmes should be researched to see if they are effective in the UK.
Support groups

Support groups can be defined in any setting in which a number of carers come together to meet in a planned way, usually for 1–2 h at a time, with a professional or lay person as leader. They may be run on either a time-limited or an ongoing basis. The intention is that participants may learn together and gain mutually by sharing their experiences. In educational sessions, information is shared by means of talks and discussions as well as the provision of written material. Support groups may be organised by voluntary agencies or statutory services.

In general, carers express satisfaction with support groups. These groups seem to be better at providing social support than relieving psychological symptoms. Although carers’ depression and psychological symptoms may be reduced, there is little evidence that the subjective burden of care is diminished (Melzer et al, 1999).

Recommendations

Support groups are a useful adjunct to other services and are a valuable source of social support to carers, which clinicians should consider.

Respite care

Respite care has been defined in various ways, but most definitions tend to agree that it is a means of ‘providing temporary opportunities for caregivers to be away from the patient in order to reduce caregiver stress and to delay or prevent nursing home admission’ (Monahan, 1993).

There is no single type of respite to suit the needs of all carers of people suffering from dementia. The issue is more about what is the optimum mix of services to meet both the wide range of needs of carers and those cared for, as well as to respond to changing needs over time (Mountain, 1995). Respite care facilities fall broadly into three categories: short residential placements, day care and home care. The nature of delivery may be planned, offered on a crisis basis or offered on demand of the carer.

The effectiveness of respite care in providing a break and relieving overburdened carers has been increasingly investigated over the past decade, and various schemes have been set up to try to evaluate the most appropriate method of delivery. However, carers’ views about the role of respite care vary and need to be incorporated when considering the type of care offered. Thus, some studies have looked at carers’ use of and satisfaction with respite care provision; others have examined carers’ use of time when receiving a respite service. Some new forms of respite care have been evaluated, including night care (Watkins & Redfern, 1997) and video respite (Lund & Hill, 1995) – the latter consists of individually tailored videotapes, which can be played as necessary.

The views of carers suggest that respite provision needs to be accessible, responsive to their needs and provide good-quality care (Briggs & Askham, 1999).
Despite strong clinical impressions that respite care is helpful to many family caregivers and helps bridge the gap between community and residential care, the results of controlled trials have been generally inconclusive, failing to provide clear confirmation of its effectiveness in terms of direct benefits to patients, relief of carer burden or delay in institutional admission (Melzer et al, 1999). However, it may be possible to justify the continuance of providing respite care merely on the basis that ‘caregivers show discriminating judgement in deciding whether to use such services and the usual principles of consumer demand can probably be counted on to regulate the extent to which it is used and paid for by those who need it’ (Lawton et al, 1998).

**Recommendations**

- Despite the lack of evidence from randomised controlled trials for its effectiveness, respite care should be viewed as an important source of support for carers of people with dementia.
- A range of respite options need to be available, including home care (sitting services), day care and short-stay respite care.

**Acute hospital admission**

The high rates both of clinical dementia and of milder cognitive impairment found among elderly patients on acute medical and surgical wards call for recognition and action by hospital trusts. Old people admitted from long-term care homes are in particular need of skilful diagnosis and of patient, understanding care. Departments of geriatric medicine (clinical geratology, health care of the elderly) can play a crucial part in raising clinical standards, including better recognition of delirium and confusional states. For example, Standard 4 of the National Service Framework (Department of Health, 2001) relates to care in general hospitals, including mention of patients’ mental health needs.

Acute beds are often ‘blocked’ by care-dependent elderly patients awaiting nursing home placement. For resolution of this problem, medical and social care planning must be coordinated for defined area populations and greater emphasis placed on provision of long-term care within the area boundaries.

In the terminal stages of dementia, the patient’s family may understandably wish not to let him or her be subjected to any further acute hospital treatment, and in this situation hospice-style care aimed at relieving pain, reducing distress and improving the quality of remaining life may represent a better alternative (Melzer et al, 1999).

**Recommendations**

- People with dementia should only be admitted to acute hospital wards if they have a physical illness requiring such treatment.
There should be a range of alternatives to hospital admission, with services able to respond to out-of-hours social needs and emergency situations.

Standards of care in general hospitals must be appropriate for the needs of people with dementia, and staff looking after patients with dementia must be competent to assess their needs and provide proper person-centred care.

**Palliative and hospice care for people with dementia**

At present the availability of hospice-style care for people with dementia is limited in the UK. Some research has addressed the palliative care needs of adults with pre-existing severe mental health problems who developed life-threatening illness and required palliative care, but only a few of those adults had dementia (Addington-Hall, 2000). General practitioners have a crucial role for people with dementia living in the community; they can be the bridge between palliative care and mental health services, as well as the key provider of palliative care to people with dementia, either living at home or in residential or nursing homes.

Hospices and specialist palliative care services are in limited supply and often lack the expert skills in the behavioural and psychiatric management of patients with dementia. They are not therefore an alternative to appropriate care in nursing homes, continuing care wards or to supported care at home from old age psychiatry services and others. Instead, their major role will be to work with health and social work professionals currently providing care for people with dementia, to support them during the terminal phase and continuing into bereavement (if appropriate), and to educate them in the palliative care approach and help them implement it in their care setting.

Recent policy stresses the importance of supportive and palliative care, particularly in relation to dignity at the end of life (Department of Health, 2001).

**Recommendations**

All those working with people with dementia and their carers may need to provide supportive and palliative care, as the patient’s death approaches, and they must therefore have the competence to do so.

**Long-term care**

Long-term care should seek to maintain people’s independence and promote interventions that enable them to exert maximum control over their own lives (Alzheimer’s Society, 2000).

The organisation, provision and financing of long-term care continue to be the subject of heated debate in the UK and the availability of such care varies widely. Access is further complicated by the introduction of the National Health Service (NHS) ‘free nursing care’ – and by its different availability in the devolved
administrations. The components of long-term care should include NHS continuing care, residential and nursing home care.

Carers need to be given good information about the options for long-term care in their area, yet an Audit Commission survey reported that fewer than half of the carers surveyed said that they knew of a residential or nursing home providing good-quality care, or how to explore the possibility of a place for their relative (Audit Commission, 2000).

**Recommendations**

- Carers of people with dementia require information about long-term care at an early stage, including details of homes available locally, the process for seeking a placement, and information about the likely financial and other consequences.
- Carers of people with dementia often require ongoing support from services after a person with dementia has moved into long-term care, as there are often practical problems and emotional issues (including feelings of bereavement and guilt) to address.

**Carers and service development**

Carer involvement in dementia care services can be of several kinds, at different levels of the health and social care system (Dening & Lawton, 1998; Killeen, 2001). These include carer organisations such as the Alzheimer’s Society, carer input into policy and commissioning, involvement in planning new services and involvement in existing services.

The form of the input may vary, including public meetings and consultation exercises, surveys, carers panels or research studies with individual interviews. To ensure that such participation is genuine and effective requires attention to detail, for example with regard to timing of meetings, transport and payment of expenses.

**Recommendations**

Carers of people with dementia should be routinely involved in service planning and evaluation. This requires the provision of adequate resources, including transport, for the purpose.

**Working with people with dementia**

**Imparting the diagnosis**

In general, there is a consensus towards an obligation to inform people of their diagnosis (Pinner, 2000; McKeith & Fairbairn, 2001). This becomes more imperative when drug treatments are being considered and consent is needed. There may be circumstances in which this is less desirable or is resisted, although
evidence from empirical studies is lacking. Imparting a diagnosis requires time for the recipient to assimilate information and ask questions. Most people with dementia appear to prefer to be informed of their diagnosis, across a wide range of dementia severity, although those who are also depressed may find the diagnosis particularly distressing (Jha et al, 2001).

There is a discrepancy between what people with dementia appear to want and the views of general practitioners, around half of whom did not think the diagnosis of dementia was worth actively pursuing (Audit Commission, 2000).

Carers may have different perspectives and wish to protect people with dementia from the knowledge of their condition. Maguire et al (1996) found that 71% of carers (of patients attending a memory clinic) would wish to be told of their own diagnosis, but only 17% wanted the person with dementia to be informed.

**Recommendations**

People with dementia should be informed of their diagnosis whenever possible. This requires careful explanation using appropriate terms, and time, both when the information is being imparted and subsequently, for reflection and to answer questions that arise. Information about prognosis needs to imparted with similar care and sensitivity.

**User involvement in care and treatment**

Subsequent to the work of Tom Kitwood, several accounts have emphasised the importance of obtaining views from people with dementia (e.g. Goldsmith, 1996). Examples of obtaining user views to influence service developments are given by Bamford & Bruce (2000) and Cox (2001). Stalker et al (1999) examined similarities and differences in a comparison of user involvement in learning disabilities services. Different approaches may be needed to obtain views from people with different degrees of impairment (Killeen, 2001).

There are discrepancies between the views of users and carers in relation to treatment choices in chronic conditions such as dementia. Carers often rate the person with dementia’s quality of life as lower than they think that person would have wished, especially if the carers are themselves depressed (Karlawish et al, 2001). Carers often choose a lower intensity of treatment for those they care for than do the patients themselves (O’Neill, 1997), so it is vital to be careful when taking decisions on behalf of people with dementia, and to take a broad view of the whole situation.

**Recommendations**

- The views of people with dementia regarding the care and services offered to them should be routinely sought. People with dementia have a valuable part to play in the design and evaluation of services.
• With regard to treatment, the views of people with dementia should be sought wherever possible. In all cases, the possibility that their perspective may differ from that of their carers should be borne in mind, although it is also vital to consider the carers’ views when making treatment decisions.

Training implications
The purpose of training is to assess and meet the needs of people with dementia and those of their carers. Training across a wide range of settings is relevant to the care of older people and people with dementia – for example, care assistants in residential homes; medical and other health care students; and specialist workers, including psychiatrists, in mental health teams. In general, increased attention should be paid to dementia and related topics, such as ageing, in training curricula. This should be in proportion to the growing importance of dementia as a health and social care issue, with its consequent massive economic impact.

However, the evidence base for simply providing ‘training’ is both patchy and at times equivocal. Evaluating the direct effects of training initiatives upon the care of people with dementia can be difficult; and results are not always positive, and can even be negative (Lintern et al, 2000). There is more to raising standards than simply providing training packages – also needed are good management structures, positive support and an overall commitment to improving quality (Cox et al, 1998; Alzheimer’s Society, 2001; Cox, 2001).

Furthermore, carers and people with dementia have an important part to play in shaping the training that is provided (Killeen, 2001). Initiatives that draw directly upon the experiences of people with dementia and their carers are to be welcomed, as their impact can be powerful in raising awareness and conveying the most important messages.

Recommendations
• Training in dementia and its care is needed at many levels, but to be successful it must be integrated with a general approach to improving quality.
• Coverage accorded to dementia in health care curricula should be in proportion to its health, social and economic importance.
5. Capacity, legal, financial and risk issues in people with dementia

Capacity, legal and financial issues

The legal jurisdictions making up the UK and Ireland differ and are likely to do so even more in the future. For example, the Adults with Incapacity (Scotland) Act 2000 is now in force (Scottish Executive, 1999, 2000), whereas there is no equivalent legislation as yet in England and Wales (Law Commission, 1995). This statement attempts to consider the principles of good practice rather than the specifics in each jurisdiction. Where any specific legal detail is quoted, as an example, this relates to the law of England and Wales.

There is no evidence from randomised controlled trials published in English on the usefulness of services giving or not giving guidance on capacity, legal and financial matters. There is significant evidence that carers benefit from an educational intervention (Brodaty & Peters, 1991; Brodaty et al, 1997), and it seems sensible that such an intervention should include advice about these areas, as appropriate. There is significant evidence that carers would like services to address such areas (Twigg & Atkin, 1990; Coyne, 1991; Kohner, 1992; Keady & Nolan, 1995; Mudge, 1995; Nolan & Keady, 2001). This section therefore addresses the areas that it is thought patients and carers would find helpful and which it would seem good practice to cover.

Although this section is concerned with legal and financial issues, it is important to keep in mind the ethical perspective. The four major medical ethical principles (Beauchamp & Childress, 1989; Bloch & Chodoff, 1991) are autonomy, beneficence, non-maleficence and equity (or justice). The ethical task of the good doctor is to find the right balance for the patient between frequently competing themes, using these principles (Gillon, 1995; Jones, 2001). Additionally, the interests of carers and other societal implications have to be considered (with a similar ethical balance), although the doctor’s prime ethical relationship has always been with the patient (Evans, 1987; Jones, 1987). Conflicts may arise, for example between the need (and legal obligation) to protect the public from an impaired person with dementia who is a danger when driving, and the ethical obligation to preserve medical confidentiality (Driver and Vehicle Licensing Authority, 1999).

Achieving a proper ethical balance can be particularly taxing in people with dementia. Further discussion and guidance is available (Gillon, 1994; Shah & Dickenson, 1999; Hughes, 2000; Jones, 2001) and the British Medical Association periodically produces useful works broadly addressing such areas (British Medical Association & Law Society, 1995; British Medical Association, 2001). Clinicians should ensure they have sufficient familiarity with the ethical concepts, how these concepts might be applied, and familiarity with how to balance the
competing principles (or the ability, as necessary, to seek helpful discussion with appropriate colleagues, ethicists or local ethics committees).

Legal areas relate to these considerations, but otherwise, with people with dementia, tend to be dominated by the concepts of capacity, best interests, promoting the exercise of autonomy despite incapacity, and the use of compulsion under mental health legislation.

Only the briefest account of these aspects is given here, and, in difficult cases, recourse should be had to the more detailed reference sources noted.

**Capacity**

Responsibility for assessing capacity lies with the treating doctor. The Law Commission (1993) proposals have elaborated on the earlier common-law test of capacity: understanding in broad terms what is proposed to be done and why. Accepting this, the Lord Chancellor (Lord Chancellor’s Department, 1999) proposed that incapacity exists when a person is ‘unable by reason of mental disability to make a decision on the matter in question; or unable to communicate a decision on that matter because…unconscious…or for any other reasons.’

Further, a person is ‘unable to make a decision by reason of mental disability’ if the disability is such that the person is ‘unable to understand or retain the information relevant to the decision’ at the time when the decision is to be made, for example in relation to health or welfare matters, or ‘unable to make a decision based on that information’ (Lord Chancellor’s Department, 1999).

The common-law test for capacity to consent to treatment, as paraphrased by Michael Gunn (Gunn, 1994), included specific reference, regarding the necessary information, to the individual ‘believing it’. This is incorporated into the present Mental Health Act Code of Practice (for England and Wales) (Department of Health & Welsh Office, 1999).

Under the Lord Chancellor’s proposals (Lord Chancellor’s Department, 1999), the individual must actually have the ability to make a decision. Similarly, to prove incapacity, an inability to make the decision in question must be proved. There ‘will be a statutory presumption against lack of capacity’. Great efforts should be made to communicate appropriately with such individuals.

‘Mental disability’ will mean ‘any disability or disorder of the mind or brain, whether permanent or temporary, which results in an impairment or disturbance of mental functioning’ (Lord Chancellor’s Department, 1999): it should be the reason for the incapacity mentioned above, although inability to communicate could be through unconsciousness, ‘or for any other reason’ (Lord Chancellor’s Department, 1999).

**Best interests**

The Lord Chancellor (Lord Chancellor’s Department, 1999) in making proposals for an Incapacity Act, and following on from the Law Commission works, has codified the various best interest factors to be considered. They include the following:
• The ascertainable past and present wishes of the person concerned, and the factors that person would consider if able to do so;
• The need to permit and encourage the person to participate, or improve his or her ability to participate, as fully as possible, in anything done for, and any decisions affecting, him or her;
• The views of other people whom it is appropriate and practicable to consult about the person’s wishes and feelings, and what would be in his or her best interests;
• Whether the purposes for which any action or decision is required can be as effectively achieved in a manner less restrictive on the person’s freedom of action (Lord Chancellor’s Department, 1999).

Promoting the exercise of autonomy despite incapacity

In England and Wales legal mechanisms only relate to control of property and affairs through an enduring power of attorney (Public Trust Office, 1996). However, an advance directive (‘living will’, advance refusal of treatment, etc.) is held to have legal validity and should be respected in so far as it is properly executed and applies in all the circumstances: see Re C (1994). Doctors should respect these mechanisms but cannot be forced to commit illegal acts such as euthanasia.

The Lord Chancellor’s original proposals (Lord Chancellor’s Department, 1999), if enacted, would introduce a continuing power of attorney, which would operate in a similar manner to an enduring power of attorney, but would additionally require a doctor’s certificate to attest that capacity was present when it was executed. This continuing power of attorney would be able to cover all health, personal welfare and financial matters. Similarly, a reformed Court of Protection would be able to rule on or appoint managers to act on such issues, acting in the patient’s best interests; this is seen to address the need to respect what is thought the person’s wishes would have been if the person were capable. Similarly, a General Authority to Act Reasonably will enable carers and professionals to act in an incapable person’s best interest (as outlined above), although it will not allow the use of force.

Until any such legislation in England appears, the present Court of Protection, Public Trust Office, Appointeeship and Agency arrangements (Law Commission, 1995) remain operative.

Other jurisdictions vary but address the same principles, and in Scotland this broad approach has been enacted with the Adults with Incapacity (Scotland) Act 2000.

Compulsion under mental health law

It is important to be clear that mental health law can be used with people with dementia, because it is a mental disorder. It should be used, when applicable, if
the patient is resisting necessary assessment, treatment or care, or if the mental disorder involves significant risk to the individual’s health or safety or that of other persons.

Outwith mental health law in England, the National Assistance Act, Section 47 remains available but is little used (Muir Gray, 1991).

**Recommendations for good practice**

Points to consider:

- Whether the patient has the capacity to consent to treatment:
  - if there is capacity, the patient’s wishes must be respected, unless there is a serious mental health problem for which the use of the Mental Health Act would be appropriate;
  - if there is incapacity, it is good practice to seek the support of the next of kin and/or carer for giving treatment for serious physical illness in the patient’s best interest, as appropriate;
  - if a patient is incapable and in need of treatment for mental disorder, consideration should be given to the use of compulsion under Mental Health Legislation.

- Whether financial incapacity issues arise and there is a need to advise the patient and/or carer about them:
  - whether there is a need for an enduring power of attorney or the Court of Protection;
  - whether the Public Trust Office should be approached to authorise a suitable person to manage finances on behalf of an incapable patient with less than £5000;
  - whether an arrangement is needed with a social security office for a person to deal with these payments on behalf of an incapable patient (Appointeeship);
  - whether Agency (collecting pension on behalf of the individual) is needed.

- The possibility that testamentary capacity may be impaired, with a consequent need for advice.

- Whether guardianship (under the Mental Health Act 1983 in England and Wales) could usefully legitimise necessary access to the patient’s home to provide supportive care.

- Driving – in the UK, patients who drive and are diagnosed with dementia must be informed of the diagnosis by the specialist and of the necessity for them to report this diagnosis to the Driver and Vehicle Licensing Authority (DVLA). Clinicians should keep themselves updated with respect to the DVLA standards. Other measures may be necessary (see below).

- When a firearms licence (e.g. for a shotgun) is held, consideration should be given to whether capacity issues or mental ill-health (and consequent
safety/dangerousness) issues arise, which may necessitate a report by the doctor to licensing authorities as a result of serious public safety concerns.

- Resuscitation – the specialist needs to consider the appropriateness of cardiopulmonary resuscitation for in-patients with dementia, and whether the patient is capable of taking part appropriately in discussion of this; involvement of the carer also is essential, all the more so if incapacity is present.
- Advance directives should be given appropriate consideration, and may well have full legal validity in all the circumstances.

A contentious area is the covert administration of medication to incapable patients who resist it when it is given openly (incapacitated patients who do not comply). Treloar et al (2000) found that staff in most long-term care settings resort to this at times, mixing medication in food or drink. These authors argued that such actions, although a last resort, are ethically legitimate in exceptional circumstances. Common law has to be invoked when the provisions of the Mental Health Act do not apply. Treloar et al argue that it is important to balance ease of access to good clinical care against restrictions which aim to prevent abuse:

‘If medication is given covertly, then it should be discussed between the doctor, nurse, pharmacist and relative or advocate, and recorded, so that legal redress is possible. The opportunity for legal redress is, of course, a key element of the UK Human Rights Act 1998’ (Treloar et al, 2001).

Although there is no consensus in this area yet, it is important that the responsible consultant addresses the issues and does not simply collude with unexamined, unregulated and poor practice. For nurses, the UK Central Council has issued guidance (UKCC, 2001). Similar considerations arise with what may amount to de facto detention.

**Risk issues**

**Autonomy and risk**

Assessment of risk in relation to a person with dementia is part of the core clinical assessment by members of the multidisciplinary team and is best regarded as a continuous clinical process rather than a one-off assessment. People with dementia are likely to have diminished ability to manage their affairs as the illness progresses, and those around them may become concerned about various risks. There are many tools for risk assessment in general psychiatry but they are often oriented towards danger to others and potential self-harm; they are not appropriate for assessing risk in people with dementia for whom many other risks may enter the picture, including wandering, neglect, fire risk and vulnerability to exploitation. Consideration of risk in people with dementia must be balanced against their right, within their capacity to choose, to lead the lifestyle of their choice, as far as they are able to. People with dementia must be helped to make decisions for themselves as far as they can, for as long as they are able to, and this should be reflected in care plans.
Recommendations

- People with dementia should be involved in all decisions affecting their care and assisted to make whatever decisions they can for themselves.
- Staff who become aware of potential risks should share that information with others involved in the person’s care.
- Concerns about risk and actions taken or recommended to minimise risk should be documented.

Risk

It is important to recognise that the assessment and prediction of risk is not an exact science. Dementia involves potential reduction or loss of the person’s capacity to look after his or her own affairs. Such reduction or loss of judgement and insight often mean that new elements of risk enter into the picture – elements that mean different things to those involved in the care package. The assessment of the perceived risk, and its place in the overall care situation, is an aspect that runs throughout the assessment process, and is a central tenet in developing a care programme with which everybody involved in the care can agree.

The many published tools for risk assessment in general psychiatry are chiefly oriented towards forensic issues, such as dangerousness and self-harm, and attempts to eradicate such behaviours. For people with dementia, more often the risk concerns incapacity, and the potential for abuse and neglect. The task is to identify and understand the risk, and to place it in context. Although attempts should be made to minimise risk, the principle must remain that people with dementia, in so far as they retain capacity, retain the right to choose how they lead their lives; and care plans should assist them to do this rather than limit their activity. This approach does not always sit well with family and other carers, but, at all times, the patient’s best interests must remain the focus; otherwise services can attempt to treat too many conflicting needs.

Currently no published risk assessment tool has been evaluated and validated for exclusive use in older people.

Risk screening

Many short screening tests are used by different services – often based on the principles expressed here. No validated scale is available. Some make use of a scoring system, others do not. Any recording method or instrument used should cover four principal areas: neglect, abuse, deliberate self-harm and aggression (violence to others).

Recommendations

- Risk should always be considered during assessment of the patient and documented in a standard way (perhaps using a simple instrument).
- The responsibility to record this rests with the initial assessor and subsequently the care manager.
• It is useful for such records to show whether risks were identified:
  • as part of the assessment
  • as the care situation subsequently changed
  • at a later agreed review.

Risk management

Risk management, like risk assessment, is not an exact science. There is no evidence base to give definite guidance on appropriate procedures, documentation and strategies, and good clinical practice is the mainstay. The management of risk should be a continuous process, as usually needs change over time, and any procedures or documentation should reflect this.

In the absence of a suitable evidence base the Working Group adopted the following discussion as the basis for good practice. Individual situations and specific services might require more specific responses.

Regular review of risk should occur, for example at care management meetings or when circumstances alter. Staff who identify potentially serious risks are responsible for sharing that information with the multidisciplinary team, in order to share their concerns and to help collectively to determine what action is appropriate to reduce and manage such risk. A more thorough assessment of risk may be needed if there is greater concern, and this could document identified problems in more detail, including factors that might seem likely to make the problems worse and what might reduce them. When there is significant concern it can be helpful for all key providers of care, together with the patient and family, to formulate what is the level of risk, ensuring thereby that this is explicit, understood and consequently acceptable to all, or at least to the majority. Documenting such a process should greatly help avoid misunderstandings, but a review time is important, to retest the assumptions made. Consequent interventions would be allocated to named individuals, with a specified time scale and a mechanism for reporting back at a set review.

Useful information sources for carers

The Alzheimer’s Society publishes a number of fact sheets which address many of these areas most usefully. They are well worth bringing to the attention of carers and sufferers. The most relevant include the following:

• Financial and Legal Tips (2003), which covers Agency, Appointeeship, enduring power of attorney, the Court of Protection and the Public Trust Office, wills, guardianship and where to go for help;
• Driving and Dementia (January 2000);
• Welfare Benefits (2001);
• Council Tax (1996);
• Care on a General Hospital Ward (2000), which mentions consideration of resuscitation issues.
They are available online from the Alzheimer’s Society (http://www.alzheimers.org.uk).

**General Medical Council guidance on driving and dementia**

The General Medical Council’s position on breach of confidentiality, and obligations under law, suggests that the doctor should take direct action to inform the DVLA if it is believed that there is a serious risk to the public and that driving is continuing despite advice to the contrary (Driver and Vehicle Licensing Authority, 2001). It seems prudent to ensure that there is a documentary record to show that advice of an appropriate nature has been given to an older person diagnosed with dementia: this should cover driving and legal obligations to inform the DVLA. This is important in relation to subsequent legal action, such as from a fellow road user accidentally injured by a driver with dementia.

The 1999 version of the DVLA’s guidance emphasised explicitly that the ‘DVLA must be notified as soon as a diagnosis [of dementia] is made’ (Driver and Vehicle Licensing Authority, 1999). The same document advises that when a patient cannot be persuaded to stop driving, or when the doctor is given or finds evidence that a patient is continuing to drive contrary to advice, the doctor should disclose relevant medical information immediately, in confidence, to the Medical Adviser at the DVLA. Before taking this action, the doctor should inform the patient of the decision to do so. Once the DVLA has been informed, the doctor should also write to the patient to confirm that disclosure has been made. Guidance also suggests that every reasonable effort to deter patients from driving should be made, and that this may include telling their next of kin of the situation. This guidance quotes stipulations directly from the clear GMC guidelines: these refer to driving licence holders having ‘a condition which may, now or in the future, affect their safety as a driver’.
6. Treatment of cognitive symptoms in people with dementia

Pharmacological treatment of cognitive symptoms in dementia has become possible since cholinesterase inhibitors were licensed for use in the UK for the symptomatic treatment of mild to moderate Alzheimer’s disease. The National Institute for Clinical Excellence reported upon the use of these drugs in clinical practice in January 2001 and their guidance forms the basis for this report (National Institute for Clinical Excellence, 2001). Preliminary data are available about the efficacy of cholinesterase inhibitors in non-Alzheimer’s dementia, and reference is also made to this. Other classes of medication have also been proposed as effective in the treatment of the cognitive symptoms of dementia, either in improving symptoms or delaying disease progression. Limited epidemiological data or results of randomised controlled trials are available to support these claims, which have been made for non-steroidal anti-inflammatory drugs (NSAIDs), vitamin E and *Ginkgo biloba* extract.

Since the overwhelming majority of evidence about efficacy of treatments has been established in Alzheimer’s disease rather than in other dementias, it should be assumed that the recommendations below apply to patients with Alzheimer’s disease unless otherwise specified.

**Cholinesterase inhibitors**

Donepezil, rivastigmine and galantamine have all been shown in placebo-controlled randomised trials to improve cognition above baseline values, although treatment has generally been assessed over periods of 6 months or less and the effect size is modest. There is no evidence that the three available drugs differ significantly in degree of efficacy or side-effects.

Clinicians should be fully familiar with details of the NICE guidance first issued in January 2001 (National Institute for Clinical Excellence, 2001).

**General recommendation**

The prescription of a cholinesterase inhibitor should be considered as one component of the management of Alzheimer’s disease.

**Selected aspects of NICE guidance and the College view**

The recommendations below represent the College view on selected aspects of the NICE guidance (which are also quoted, with the appropriate paragraph numbers), and should be read in conjunction with the source document which is freely available online (National Institute for Clinical Excellence, 2001).
NICE guidance
‘Diagnosis that the form of dementia is [Alzheimer’s disease] must be made in a specialist clinic according to standard diagnostic criteria’ (NICE: 1.1.1).

‘Only specialists (including old age psychiatrists, neurologists, and care of the elderly physicians) should initiate treatment’ (NICE: 1.1.4).

Recommendation
No particular set of diagnostic criteria was proposed by NICE. One of the standard operationalised schemes, such as ICD–10, DSM–IV or NINCDS–ADRDA criteria should be adopted for consistent use within a given service.

NICE guidance
‘Tests of cognitive, global and behavioural functioning and of activities of daily living, should be made before the drug is prescribed’ (NICE: 1.1.2).

Recommendation
The importance of accurate baseline assessment is emphasised, since it is against this that subsequent judgements about response will be made. Details of the precise tests to be used were not given in the NICE guidance and thus may vary according to local practice. The MMSE, which will be performed at baseline, should suffice as a cognitive outcome measure. Other more detailed tests may be added if desired.

NICE guidance
‘The three drugs donepezil, rivastigmine and galantamine should be made available [for people] whose MMSE score is above 12 points’ (NICE: 1.1)

Recommendation
The NICE absolute requirement for an MMSE score over 12 at baseline is likely to mean difficult clinical decisions in patients with scores at or below this threshold. Due allowance should be made in patients unable to complete the MMSE because of dysphasia or having a first language other than English.

NICE guidance
‘Carers’ views of the patient’s condition at baseline and follow-up should be sought’ (NICE: 1.1.3, 1.1.4).

Recommendation
The views of the patient, carer and clinician should be recorded separately in case notes and a consensus view about global change documented as the basis for management decisions.
**NICE guidance**

‘A further assessment should be made, usually two to four months after reaching maintenance dose of the drug. Following this assessment the drug should be continued only where there has been an improvement or no deterioration in MMSE score, together with evidence of global improvement on the basis of behavioural and/or functional assessment’ (NICE: 1.1.5).

**Recommendation**

Since it may take 3–4 months to achieve a maintenance dosage with some cholinesterase inhibitors, the guidance suggests that the first follow-up assessment visit might be 6–8 months after baseline assessment. The Working Group considers that, in practice, more regular contact will be required for dose titration and side-effect monitoring. Visits by a community psychiatric nurse and/or telephone contact might be useful.

**NICE guidance**

‘Patients who continue on the drug should be reviewed by MMSE score and global, functional and behavioural assessment every 6 months. The drug should normally only be continued while their MMSE score remains above 12 points and their global, functional and behavioural condition remains at a level where the drug is considered to be having a worthwhile effect. When the MMSE falls below 12 points, patients should not normally be prescribed [a cholinesterase inhibitor]’ (NICE: 1.1.6).

This is likely to be a problematic area. The latter guidance is based upon a lack of evidence about efficacy of cholinesterase inhibitors in severe dementia rather than upon actual evidence of such a lack of efficacy. Trials in severe dementia are in progress.

---

This guidance is based upon information in two evidence-based reviews of the diagnosis and management of dementia (Waldemar et al, 2000; Doody et al, 2001), supplemented by the UK NICE Appraisal Technology Report No. 19 (National Institute for Clinical Excellence, 2001), the report of the Wessex Institute for Health Research and Development (2000), and a Web of Science review of papers published since January 2001, using keywords including DEMENTIA, ALZHEIMER’S DISEASE and TREATMENT. Evidence has been coded as being provided by:

(I) well-designed randomised controlled trials, meta-analyses or systematic review;
(II) well-designed case–control or cohort studies;
(III) uncontrolled studies or consensus statements.
Recommendation

If patients show clinically significant deterioration following cholinesterase inhibitor withdrawal that was initiated solely on the grounds of their MMSE score having fallen below 12, reinstatement of medication should be considered.

NICE guidance

‘The benefits of [cholinesterase inhibitors] for patients with other forms of dementia…have not been assessed in this [NICE] guidance’ (NICE: 1.2).

One placebo-controlled randomised trial (McKeith et al, 2001) with rivastigmine\(^\text{(I)}\) and several published case reports\(^\text{(III)}\) suggest efficacy of cholinesterase inhibitors in dementia with Lewy bodies with benefits in cognition and behaviour of a greater magnitude than seen in Alzheimer’s disease. A placebo-controlled randomised trial of galantamine, only published in abstract form (Erkinjuntti et al, 2001), reported cognitive improvement in patients with a diagnosis of mixed vascular and Alzheimer dementia.\(^{\text{(I)}}\) Patients with pure vascular dementia showed limited treatment response. No trial or systematic case report of cholinesterase inhibitor treatment of frontal lobe dementia has been published, but expert opinion is that these drugs generally are not beneficial and may cause increased agitation and behavioural disturbance.\(^\text{(III)}\)

Recommendation

The Working Group suggests that clinicians may choose to treat patients with dementia with Lewy bodies or with mixed vascular and Alzheimer’s dementia with cholinesterase inhibitors, particularly patients who have behavioural symptoms or global disturbance that have proved refractory to other interventions. Such treatment will be outside the licensed indication. There is no evidence to support the use of cholinesterase inhibitors in frontal lobe or pure vascular dementia.

Other pharmacological treatments

The use of non-steroidal anti-inflammatory drugs has been associated in epidemiological studies with a reduced incidence of dementia.\(^\text{(I)}\) The postulated mode of effect is a suppression of inflammatory responses. A placebo-controlled randomised trial with the anti-inflammatory hydroxychloroquine (Van Gool et al, 2001) did not, however, show any cognitive benefits in patients with established Alzheimer’s disease.\(^\text{(I)}\) A large epidemiological study (‘t Veld et al, 2001) suggested that NSAIDs do have a protective effect against Alzheimer’s disease but not against vascular dementia.\(^\text{(I)}\) This effect is dose-dependent and manifest only if medication has been taken over a long period (>2 years). There appears, therefore, to be no evidence to support the use of NSAIDs in the symptomatic treatment of cognitive symptoms in Alzheimer’s disease, particularly since this class of drugs has the potential to cause significant adverse effects.
One placebo-controlled randomised trial showed modest cognitive improvements with *Ginkgo biloba* extract, which is an over-the-counter preparation widely used by older people and people with dementia in the UK. A mixed dementia population was tested and outcome measures fell short of those expected (a psychometric measure plus clinician’s global impression). Vitamin E was shown to delay the progression of moderately severe Alzheimer's disease to an end-point of severe disability in a placebo-controlled randomised trial (Sano *et al*, 1997). No improvement in cognition was, however, observed. Similar outcomes were observed for the type B monoamine-oxidase inhibitor selegiline within the same trial. Epidemiological studies suggest that oestrogens might have a therapeutic effect in Alzheimer's disease, but although there are case reports of cognitive improvements following oestrogen administration, there are negative findings from two placebo-controlled randomised trials. Other potential treatments for dementia, including vaccine therapy, ampakines and beta-secretase inhibitors, remain at an early stage of development and are available only within approved clinical trials in specialist centres.

**Recommendation**

There is insufficient evidence to support the use of any medications other than cholinesterase inhibitors for treating the cognitive symptoms of dementia. Some patients with dementia may benefit from *Ginkgo biloba* extract but sufficient evidence-based efficacy data are lacking. Vitamin E (1000 IU twice daily) may be considered in an attempt to slow progression of Alzheimer's disease but its use for this purpose has not been licensed. Non-steroidal anti-inflammatory drugs and oestrogens have not been shown to have symptomatic effects on cognition in Alzheimer's disease and should not be prescribed for the treatment of dementia.

**Non-pharmacological treatment of cognition in dementia**

Non-pharmacological treatment of dementia forms the major part of multidisciplinary case management and the effects of such interventions should be considered. Psychosocial interventions specifically directed towards cognition include reality orientation treatment, reminiscence therapy and validation therapy. The Cochrane Library holds updated systematic reviews on each of these, and concludes that:

'[there is] some evidence that reality orientation treatment has benefits on cognition for dementia sufferers. It is unclear how far the benefits of [this therapy] extend after the end of treatment, but it appears that a continued programme may be needed to sustain potential benefits' (Spector *et al*, 2001b).

No firm conclusion could be reached regarding the effectiveness of reminiscence or validation therapy.
Recommendation

Psychosocial interventions and particularly cognitive-oriented treatment may be helpful to some patients and carers, but do have potential to precipitate or worsen depression, anxiety or frustration. In the absence of clear evidence of efficacy, treatment programmes must be designed in the light of the cognitive capacity and level of tolerance of the patient, and possible adverse effects of the treatment must be monitored.
7. Treatment of non-cognitive symptoms in people with dementia

In addition to the cognitive symptoms and problems with activities of daily living that result from dementia, a range of psychiatric symptoms and behavioural disturbances are a consistent expression of the syndrome. The most common and distressing features are agitation, psychosis (e.g. delusions, hallucinations and misidentifications), depression, apathy, wandering and pacing, sexual disinhibition, aggression, sleep disturbance and eating disorders. A number of names have been given to this cluster of symptoms, including ‘non-cognitive features’ (Burns et al, 1990a–d), ‘neuropsychiatric features’ (Cummings et al, 1994) and ‘behavioural and psychological symptoms of dementia’ (Finkel & Burns, 2000). These features are important because they cause particular distress to patients, place burden on carers, are associated with more rapid cognitive decline and promote institutionalisation of patients.


Pharmacological interventions
Management of behavioural disturbances

Probably the most common clinical situation is where a clinician is asked to see a person suffering from dementia who has become agitated and/or aggressive. A thorough assessment of the patient’s physical health, mental state and the environment is essential. It is important to rule out a physical cause for the aggression (such as a urinary tract or chest infection, or other physical illness) and to investigate whether there is any clear precipitant in the environment. It is also important to review the medication that the person is taking, to check if it – or a combination of drugs – might be the precipitant of agitation. Pain can also be a potent precipitant of agitation and aggression. Non-pharmacological management should always be the treatment of first choice, examining the antecedents of the behaviour, the behaviours themselves, and the consequences (ABC). Staff education in homes, carer education and behaviour management techniques have all had some success in alleviating agitation and aggression.

If pharmacological intervention is considered appropriate (where non-pharmacological treatments have failed, and where the disturbance is acute, severe and/or life-threatening), Howard et al (2001) have noted the following points:

- a lack of evidence from controlled trials to support using benzodiazepines;
• using antipsychotics should only follow full consideration of risks as well as benefits;
• older people are especially sensitive to the common side-effects of antipsychotics;
• there may be accelerated cognitive decline in Alzheimer’s disease associated with antipsychotic use;
• neuroleptic sensitivity particularly occurs in patients with dementia with Lewy bodies;
• there is good evidence of a modest level of efficacy for antipsychotic drugs.
• there is no demonstrated difference in efficacy, but atypical agents seemed to have ‘a better side-effect profile’;
• start at the lowest dosage and carefully monitor for side-effects;
• only continue medication if there is evidence of efficacy;
• review the need for continuing treatment every 3 months;
• for patients in whom antipsychotics are ineffective or not tolerated, carbamazepine or trazodone may be efficacious;
• if agitation is severe or treatment-resistant, specialist referral is appropriate.

Agitation and aggression sometimes coexist with psychosis. Most studies concentrate on patients with agitation, but where psychosis is also present, antipsychotics are of benefit.

Three studies have demonstrated the efficacy of risperidone in the treatment of behavioural problems, agitation and aggression in people with dementia. A comparison of risperidone and haloperidol showed that risperidone achieved the same degree of reduction in agitation, with fewer side-effects. Olanzapine does reduce agitation and psychosis in patients with dementia. Selegiline (L-deprenyl) has not shown any consistent benefits over placebo. Carbamazepine and sodium valproate have shown benefits in the treatment of agitation associated with dementia. The anticholinesterase drugs are effective at reducing a number of psychiatric symptoms and behavioural disturbances in patients with dementia with Lewy bodies (McKeith et al, 2000), and are shown to delay the onset of the emergence of behavioural disturbances, as well as a reduction in extant behaviours in people with Alzheimer’s disease.

Management of depression

Several studies have examined the treatment of depression in people with Alzheimer’s disease. Comparisons of newer drugs with tricyclic antidepressants are difficult because there tends to be a larger number of withdrawals due to side-effects among those taking the older drugs. There has been demonstrated benefit of clomipramine, moclobemide, fluoxetine, citalopram, fluvoxamine and paroxetine in patients with Alzheimer’s disease and superadded depression.
Considerable work has been devoted to the usefulness of non-pharmacological interventions with the behavioural and psychological symptoms in dementia, and this is examined in Chapter 8.

Summary
In relation to pharmacotherapy in patients with dementia, Doody et al (2001) concluded that:

- antipsychotic therapy is appropriate in patients with dementia where environmental changes are not successful in improving agitation or psychosis;
- atypical antipsychotics may prove to be better tolerated than typical agents;
- for patients with depression, consider prescribing a selected tricyclic antidepressant, monoamine-oxidase type B inhibitor or selective serotonin reuptake inhibitor, with the side-effect profile guiding the choice of drug.

Recommendations for the treatment of behavioural and psychological symptoms
In the light of this evidence review, the Working Group makes the following recommendations:

- Proper and thorough assessment to establish the aetiology of the problems is the first essential.
- Neuroleptic (antipsychotic) agents are appropriate to treat agitation or psychosis in people with dementia where other approaches have failed.

The following recommendations from Howard et al (2001) are supported:

- Non-pharmacological management should always be the treatment of first choice, examining the antecedents of the behaviour, the behaviours themselves and the consequences.
- Staff education in homes, carer education and behaviour management techniques have all had some success in alleviating agitation and aggression, and should be considered.
- Consider that there is a lack of evidence from controlled trials to support using benzodiazepines.
- The use of neuroleptics (antipsychotics) should only follow full consideration of risks as well as benefits.
- Consider that older people are especially sensitive to the common side-effects of antipsychotics.
- Consider that there may be accelerated cognitive decline in Alzheimer’s disease associated with neuroleptic (antipsychotic) use.
- Consider that neuroleptic sensitivity can particularly occur in patients with Lewy body dementia.
Consider that the evidence shows a modest level of efficacy for neuroleptic (antipsychotic) drugs.
Consider that there is no demonstrated difference in efficacy.
Start at the lowest prescribable dosage and carefully monitor for side-effects.
Only continue medication if there is evidence of efficacy.
Review the need for continuing treatment every 3 months.
Consider that for patients in whom neuroleptics (antipsychotics) are ineffective or not tolerated, carbamazepine or trazodone may be efficacious.
Consider that if agitation is severe or treatment-resistant, specialist referral is merited.

Recommendations for the treatment of depression

We support the recommendation of Doody et al (2001) that depression in patients with dementia may be treated with a selected tricyclic antidepressant, monoamine-oxidase type B inhibitor or selective serotonin reuptake inhibitor, with the side-effect profile guiding the choice of drug.
8. Non-pharmacological approaches to treating people with dementia

It is only comparatively recently that effective pharmacological therapies have become available for the treatment of cognitive impairment in dementia. Even now, it is only in Alzheimer’s disease and, perhaps, dementia with Lewy bodies that cholinesterase inhibitors appear effective (McKeith et al, 2000; National Institute for Clinical Excellence, 2000). Pharmacological treatments are also prescribed for some non-cognitive symptoms occurring in patients with dementia, and may be helpful (Rosequist et al, 2000). Nevertheless, non-pharmacological approaches have been, and remain, the major resource available to help individuals with dementia and those caring for them. It is possible to classify such approaches as either designed to reduce the likelihood of developing dementia (preventive) or designed to limit progress of – or reduce – complications once the condition has become evident (ameliorative).

Preventive approaches encompass genetic counselling, which should only be undertaken by an expert in the field (Lovestone, 1999). Such specialist clinical genetics services, able to facilitate the education of health care professionals, as well as to support affected individuals and families, may be best organised on a regional basis. Hardship, poverty, and adverse life events and circumstances are associated with poor health, including poor mental health, and with reduced life expectancy (Whalley, 1998). These aspects probably affect the experience and expression of dementia. Heavy smoking is associated with the development of dementia in later life, perhaps mediated through cardiovascular or cerebrovascular disorder, and smoking may have direct effects on cerebral function (Ott et al, 1995). Excessive alcohol consumption over a period of years is associated with a number of organic brain syndromes, including dementia (Lishman, 1990). People with a high vitamin C intake have a reduced prevalence of dementia. High intake levels of vitamins C and E, and high serum levels of folic acid and vitamin B₁₂, are associated with lower plasma total homocysteine levels, and with a lower prevalence of dementia (Pitchumoni & Doraiswamy, 1998; Vatassery, 1998). High intake and high serum levels of thiamin are also associated with a lower prevalence of dementia (Mimori et al, 1996). Trauma to the head – whether singular and massive, or repetitive as in boxing – is associated with a risk of progressive dementia (Lishman, 1978). People with diabetes may suffer neuronal damage or loss as a consequence of either hyperglycaemic or hypoglycaemic episodes (Liebson et al, 1997). Continued use of long-acting sedatives and tranquillisers is a particular risk (Department of Health, 2001).

All this means that significant gains may be expected from the maintenance of good physical health throughout life, including into late life, aiming for the maintenance of good cerebral function, and from ensuring regular reviews of
the drug regimens of older people, particularly where the drugs affect brain function.

Apart from the non-drug aspects of these preventive approaches, and apart from the drug treatment (ameliorative) approaches established for those suffering from dementia, certain non-specific and specific non-pharmacological (ameliorative) approaches have been applied and evaluated to some extent. These include specific therapies, such as:

- reminiscence therapy
- validation therapy
- reality orientation
- exercise therapy
- pet therapy
- music therapy
- psychological techniques to cope with memory impairment or related symptoms.

Significant work (Alexopoulos et al, 1998; Burns et al, 1990a–d; Cummings et al, 1994; Scottish Intercollegiate Guidelines Network, 1998; Finkel & Burns, 2000; McKeith et al, 2000; Doody et al, 2001; Howard et al, 2001) has looked at the use of non-pharmacological interventions for the behavioural and psychological symptoms of dementia, and this merits further review.

**Interventions for behavioural and psychological symptoms**

**Caregiver interventions**

Several studies have compared the effects of an educational intervention for carers, compared with no treatment. Although there is no effect on severity of disease or cognitive function, these short-term interventions have been of proven benefit in decreasing burden and strain on carers and delayed admission of patients to institutional care (Brodaty & Gresham, 1989; Chiverton & Caine, 1989). The beneficial effects on carer morale and patients have been demonstrated by providing information to carers in nursing and residential homes (Ray et al, 1993).

**Other non-pharmacological approaches**

Various specific interventions have been used to try to improve functional performance in people with dementia, and practice and positive reinforcement have been shown to improve activities of daily living (Sixsmith et al, 1993). Scheduled toileting reduces urinary incontinence (Ouslander & Schnelle, 1993), and the benefits of memory training, manual and/or creative activities, improving sensory motor function and self-management therapy have all been found to be of benefit compared with traditional approaches (Bach et al, 1995). Reality orientation, re-motivation, sensory stimulation, reminiscence and exercise have all shown benefit in improving activities of daily living.
Music therapy (using the patient’s own choice) has reduced agitation, aggression and mood disturbances (Clark et al, 1998). One-to-one social interaction or videotapes of family members have reduced verbal outbursts, and there are preliminary studies suggesting that audiotapes of familiar voices can improve mood, aggression and agitation (Woods & Ashley, 1995). Bright light therapy can reduce behavioural disturbances (Koss & Gilmore, 1998).

In relation to non-pharmacological interventions, our consensus supports Doody et al (2001), who recommended that consideration should be given to the following:

- short-term programmes to educate carers about Alzheimer’s disease, to improve carer satisfaction;
- longer-term education and support services to carers, to prolong time to institutional placement;
- education of the staff of long-term care facilities about Alzheimer’s disease, to reduce the unnecessary use of neuroleptic medication;
- behaviour modification, scheduled toileting and prompted voiding should be helpful in reducing urinary incontinence;
- functional independence should be improved through the use of graded assistance, practice and positive reinforcement in activities of daily living;
- simulated sounds of nature, reduced lighting levels and music have been reported to improve eating behaviours in people with dementia, and intensive multimodal group training has been reported to improve activities of daily living, but there is no conclusive study supporting these approaches;
- people with dementia have been reported to show less problem behaviours with the following interventions: music (especially during meals and bathing) and walking or other forms of light exercise;
- there is suggestive evidence only that some patients may benefit from approaches such as simulated presence therapy (using videotapes or audiotapes of family members), massage, programmes of comprehensive psychosocial care, pet-facilitated therapy, the issuing of commands at the patient’s comprehension level, bright light, white noise and cognitive remediation;
- aspects of the care environment – definitive studies are lacking but some evidence suggests the following environments are worth considering for patients with dementia:
  - specialist care units within a continuing care facility
  - avoiding a traditional nursing home appearance and instead using home-like physical settings with small groups of patients
  - if hospitalising, using only short, planned admissions of 1–3 weeks
  - providing access to exterior space, making internal corridors more like natural home settings and similarly improving the bathing environment;
- interventions for carers: the following interventions may benefit carers of persons with dementia, and may delay permanent institutionalisation:
• comprehensive training to carers of a psychoeducational nature, and support groups
• further benefits to patients and carers may be obtained through using computer networks to provide education and support to carers, television support programmes, and the provision of day care for patients and other respite services.

However, in conclusion, of all the recommendations suggested by Doody et al (2001), only the following achieved the recommendation of ‘standard’ (i.e. achieves a high degree of clinical certainty from well-designed randomised controlled trials, or overwhelming evidence from well-designed observational studies with controls):

• behaviour modification, scheduled toileting and prompted voiding to reduce urinary incontinence.

It is worth devoting further consideration to some of the specific therapies that have been described.

Specific therapies

Reminiscence therapy

Reminiscence therapy is a loosely defined range of therapeutic activities involving recall of events in a person’s life, either alone, with another person or in a group. Although this therapy is often enjoyed by participants, a Cochrane Review (Spector et al, 2001a) found it impossible to be sure how and when it should be used, what benefits are to be expected and how it compares with other psychological approaches in dementia.

Validation therapy

Attributed to Naomi Feil and developed in the 1960s, validation therapy seeks to restore the patient’s self-worth, minimise withdrawal, promote interaction and communication, reduce stress, release retained skills and ability, facilitate progress with unfinished life tasks and maintain independent living. The Cochrane Review (Neal & Briggs, 2001) of this technique found descriptions of benefits, but findings from participant observers reflect improvements not seen by non-participant observers. As with validation therapy, the Cochrane reviewers suspected that benefits might derive from involvement in structured activities and additional attention rather than specific attributes of the particular therapy.

Reality orientation

Reality orientation has been widely supported for work with people with dementia. This technique derives from earlier initiatives to rehabilitate war veterans. It presents orientation information – time, place, person, etc. – in a
structured classroom style, and aims to help individuals gain and retain a better understanding of their circumstances, and thereby benefit in terms of self-control and self-esteem.

The Cochrane Review (Spector et al, 2001b) found clear benefits in the short run, with measurable gains in cognition and behaviour. Improvements have been demonstrated to continue for at least a month. The Cochrane reviewers recommended that reality orientation techniques be included in the wider dementia care programme for individuals, and that initial sessions be consolidated, and reinforced, by continuous ongoing programmes.

**Psychological techniques**

Approaches to coping with failing memory have been developed and found to be effective. With mild impairment, techniques used may include internal approaches or external techniques.

Internal approaches are used by the individuals themselves. These rely on using retained cognition to retrace steps to discover where things were last cogent and then move forwards, attempting to avoid false traces and discover the required pathway (Pelmanism). Techniques include focusing attention on important aspects of activities, adding meaning to events or activities by associations, and reducing the volume of materials to be remembered. Mnemonic techniques may be helpful but require considerable retained capacity for new learning, internal motivation and the provision of training. The gains seem specific to the topics addressed and included in the training programme.

External techniques provide cues and nudges to retained internal abilities, such as a notepad, diary, instructions, newspaper, radio, television, clock, calendar, things in the right place, dosette box and telephone codes. To these may be added cue calls (by telephone or by visiting), and novel electronic compensatory devices, epitomised in the ‘smart house’ concept.

As impairment becomes greater, dependence on external techniques organised and operated by others becomes greater. Maintaining a routine, minimising change and contact with people who know the patient well – or come to do so – are the basics. Carers are increasingly required to become flexible ‘prostheses’, identifying what can no longer be done, anticipating the need and providing the necessary supporting action, to avoid frustration and distress. It is at this stage that reality orientation may have significant benefit.

In the later stages, with advanced impairment, dependence upon others is almost absolute. Often these are professional carers if transfer to a nursing home or hospital has become necessary. Features of the environment have a profound impact and issues of design for people with advanced dementia are being explored (Judd, 1997). The availability of natural light and views of or contact with the outside world are important; they tell of the time of day and time of year.

Colours of decorations, and the nature, style and arrangement of furnishings, may add to or minimise distraction and confusion. Floor coverings and designs
upon the floor may be influential and some are being subjected to evaluation. Labelling of doors, equipment and people seems important. Words may be too difficult, and uniforms or diagrams may convey stronger, simpler messages more effectively.

Safety devices to identify movement into hazardous areas, or away from safe supervision, have advantages as complements to personal monitoring, which may be exhausting to the monitor and can be irritating and perceived as intrusive by those monitored. Increasingly, new technology is used in preference to locked doors, although these may still be necessary in some circumstances.

Perhaps the strongest safety device in institutional settings is the inclusion of families and other visitors into the life of this special world. Well-trained staff with proper attitudes encourage this, but it does require some appropriately designated physical space and facility to operate optimally.

A Cochrane review of cognitive rehabilitation did develop to the protocol stage (Clare et al, 2001) as did reviews of aromatherapy (Thorgrimson et al, 2001) and snoezelen (Chung et al, 2001). A previously available Cochrane review of music therapy was withdrawn, but a number of papers have been supportive of its effectiveness (Clarke et al, 1998).

Forbes’ review of studies of strategies for managing behavioural symptoms in dementia (Forbes, 1998) concluded that planned walking, pet therapy, an attention-focusing programme, functional skills training and music all showed benefits in reducing aggression, wandering and disruptive behaviour, while encouraging better self-care and more social interactions.

Godkin & Onyskiw (1999) reviewed articles which concluded that education of staff and withdrawal of restraint devices from long-term care facilities were beneficial to residents and staff.

Opie et al (1999) provided a systematic review of studies of psychosocial interventions in people with dementia (1989–1998) and concluded that many of these interventions had been shown to be useful. These included concealing exits, provision of activity programmes, supervised walking, music (best tailored to the known preferences of individuals), involvement of families, and extra bright light (for those who wander in the evenings). Education of professional and informal carers and involvement of family recur as useful approaches.

In the light of the available evidence, the Working Group supported the following recommendations.

**Recommendations**

The recommendations of the American Academy of Neurology (Doody et al, 2001) are supported, namely:

- Family caregivers of people with dementia should be offered educational programmes to improve satisfaction and to postpone institutional admission.
• Staff in nursing and residential homes should receive education about dementia, aiming to minimise the use of antipsychotic pharmacotherapy.
• Consider the use of behaviour modification, scheduled toileting and prompted voiding to improve urinary continence.
• Functional independence should be improved through the use of graded assistance, practice and positive reinforcement in activities of daily living.

Further, in relation to non-pharmacological approaches, we recommend the following:

• The various specific and non-specific therapies should continue to be developed and refined, and their place in the spectrum of care be clarified. Components of these approaches should be available within all services.
• There is a particular need to increase the availability of training for staff and carers in techniques for coping with memory impairment, and this need might best be met by incorporation in the routine activity of memory clinics.
• Services should also consider the need for training for staff and carers in coping better with the non-cognitive aspects of dementia.
Appendix: Position statement by the Faculty of the Psychiatry of Old Age on the use of neuroleptic (antipsychotic) agents in treating older people with dementia

Concern has been expressed that neuroleptic drugs may be used inappropriately in people with dementia. The Faculty of the Psychiatry of Old Age of the Royal College of Psychiatrists believes it is important that:

- such medication is used when it seems likely to be beneficial to the patient;
- that the use of such medication be regularly reviewed;
- that the use of such medication on a pro re nata basis should be minimised and regularly reviewed;
- that advice be available for clinicians treating people with dementia outwith specialist service settings or not currently receiving the support of such specialist services.

This statement largely comprises relevant extracts on the topic drawn together from Council Report CR119, *Forgetful But Not Forgotten*, including strategies to avoid or minimise the use of neuroleptic medication. The statement begins with guidance on working in primary care with behaviour disorders experienced by people with dementia, including the use of neuroleptics. It goes on to review the management of behavioural and psychological symptoms in people with dementia, followed by guidance for practice by a specialist service. The statement in itself constitutes the Faculty Consensus Statement (which on this topic was led by Professor Alistair Burns) and was approved by Council in 2002.

Advice on relevant aspects of working with people with dementia in primary care

This guidance leans heavily on that of others, especially the North of England evidence-based guidelines development project (Centre for Health Services Research, 1998), the New Zealand Guidelines Group (1997) and the work of the Scottish Intercollegiate Guidelines Network (1998), to which grateful acknowledgement is given.

Managing behavioural disorders in patients with dementia

- Physical causes or acute change in physical problems, particularly possible pain, should always be excluded as an underlying cause for behavioural disorder (Beck & Shue, 1994; Nilsson et al, 1998; Patterson et al, 1999).
• Consideration should be given to non-drug interventions before drug options are embarked upon (Allen-Burge et al, 1999; Proctor et al, 1999; Terri et al, 2000; Howard et al, 2001).

• The ‘psychological environment’ of the care setting and the attitudes of carers may be influential in behaviour problems (Kitwood & Bredin, 1992; Allen-Burge et al, 1999).

• As far as possible such causes should be treated before considering neuroleptic medication (Kitwood & Bredin, 1992; Allen-Burge et al, 1999; Proctor et al, 1999; Terri et al, 2000; Howard et al, 2001).

• Routine use of neuroleptics or other tranquillisers to control behaviour in dementia should be avoided (McKeith et al, 1992; McGrath & Jackson, 1996; McShane et al, 1997; Thacker & Jones, 1997; Howard et al, 2001).

• For crisis situations short-term use of neuroleptics (antipsychotics) may be justified but they should only be considered when there are serious problems, such as psychotic symptoms, severe emotional distress or dangerous behaviour (Centre for Health Services Research, 1998; Ballard & O’Brien, 1999; Doody et al, 2001; Howard et al, 2001).

• There is no clear evidence that one neuroleptic is superior to another, but atypical agents seem to be better tolerated (De Deyn et al, 1999; Katz et al, 1999; Street et al, 2000).

• ‘Start low and go slow’, aiming normally for short-term treatment with regular reviews (Howard et al, 2001).

• All involved with the care of the patient should be aware of potential side-effects (Centre for Health Services Research, 1998). The routine use of anti-Parkinsonian medication is not indicated (Centre for Health Services Research, 1998).

• Neuroleptics should be avoided in patients with dementia with Lewy bodies (McKeith et al, 1992).

**Lewy body dementia**

• It is important to consider the possibility of dementia with Lewy bodies because of possible therapeutic implications (McKeith et al, 2000).

• It is important to avoid using neuroleptic drugs in such patients, accepting that making this diagnosis may be difficult, and, therefore, to consider the need for specialist referral (McKeith et al, 1992).

**Consensus statement on the management of behavioural and psychological symptoms in people with dementia**

In addition to the cognitive symptoms and problems with activities of daily living that result from dementia, a range of psychiatric symptoms and behavioural disturbances are a consistent expression of the syndrome. The most common and distressing features are agitation, psychosis (e.g. delusions, hallucinations and
misidentifications), depression, apathy, wandering and pacing, sexual disinhibition, aggression, sleep disturbance and eating disorders. A number of names have been given to this cluster of symptoms, including non-cognitive features (Burns et al, 1990a–d), neuropsychiatric features (Cummings, 1994) and behavioural and psychological symptoms of dementia (Finkel & Burns, 2000). These features are important because they cause particular distress to patients, place burden on carers, are associated with more rapid cognitive decline and promote institutionalisation of patients.

This guideline is based on a number of recent publications that have addressed this area (Alexopoulos et al, 1998; Scottish Intercollegiate Guidelines Network, 1998; Finkel & Burns, 2000; Doody et al, 2001; Howard et al, 2001; Knopman et al, 2001). The guideline includes mention of carer interventions for people with dementia.

Non-pharmacological interventions

Caregiver interventions

Several studies have compared the effects of an educational intervention for carers, compared with no treatment. Although there is no effect on severity of disease or cognitive function, these short-term interventions have been of proven benefit in decreasing burden and strain on carers, and delaying admission of patients to institutional care. Beneficial effects on carer morale and patients have been demonstrated through providing information to carers in nursing and residential homes. Intuitively, providing general psychological support to informal and formal carers seems likely to be helpful.

Other non-pharmacological approaches

Specific interventions have been used to improve functional performance in people with dementia, and practice and positive reinforcement have been shown to improve activities of daily living. Scheduled toileting reduces urinary incontinence, and the benefits of memory training, manual and creative activities, improving sensory motor function and self-management therapy have all been found to be of benefit compared with traditional approaches. Reality orientation, re-motivation sensory stimulation reminiscence and exercise have all shown benefit in improving activities of daily living.

Music therapy (using the patient’s own choice) has reduced agitation, aggression and mood disturbances (Clark et al, 1998). One-to-one social interaction or videotapes of family members have reduced verbal outbursts, and there are preliminary studies suggesting that audiotapes of familiar voices can improve mood, aggression and agitation (Woods & Ashley, 1995). Bright light therapy can reduce behavioural disturbances (Koss & Gilmore, 1998).

In relation to non-pharmacological interventions, our consensus supports Doody et al (2001), who recommended that consideration should be given to the following:
- short-term programmes to educate carers about Alzheimer’s disease, to improve carer satisfaction;
- longer-term education and support services to carers, to prolong time to institutional placement;
- education of the staff of long-term care facilities about Alzheimer’s disease, to reduce the unnecessary use of neuroleptic medication;
- behaviour modification, scheduled toileting and prompted voiding should be helpful in reducing urinary incontinence.
- functional independence should be improved through the use of graded assistance, practice and positive reinforcement in activities of daily living;
- simulated sounds of nature, reduced lighting levels and music have been reported to improve eating behaviours in people with dementia, and intensive multimodal group training has been reported to improve activities of daily living, but there is no conclusive study supporting these approaches;
- people with dementia have been reported to show less problem behaviours with the following interventions: music (especially during meals and bathing), walking, or other forms of light exercise;
- there is suggestive evidence only that some patients may benefit from approaches such as simulated presence therapy (using videotapes or audiotapes of family members), massage, programmes of comprehensive psychosocial care, pet-facilitated therapy, the issuing of commands at the patient’s comprehension level, bright light, white noise and cognitive remediation;
- aspects of the care environment – definitive studies are lacking but some evidence suggests the following environments are worth considering for patients with dementia:
  - specialist care units within a continuing care facility
  - avoiding a traditional nursing home appearance and instead using home-like physical settings with small groups of patients
  - if hospitalising, using only short, planned admissions of 1–3 weeks
  - providing access to exterior space, making internal corridors more like natural home settings and similarly improving the bathing environment;
- interventions for carers: the following interventions may benefit carers of persons with dementia, and may delay permanent institutionalisation:
  - comprehensive training to carers of a psychoeducational nature, and support groups
  - further benefits to patients and carers may be obtained through using computer networks to provide education and support to carers, television support programmes, and the provision of day care for patients and other respite services.
However, in conclusion, of all the recommendations suggested by Doody et al (2001), only the following achieved the recommendation of ‘standard’ (i.e. achieves a high degree of clinical certainty from well-designed randomised controlled trials, or overwhelming evidence from well-designed observational studies with controls):

- behaviour modification, scheduled toileting and prompted voiding to reduce urinary incontinence.

Additionally, it seems appropriate to recommend:

- that the various specific and non-specific therapies continue to be developed and refined and their place in the spectrum of care be clarified (components of these approaches should be available within all services);
- there is a particular need to increase the availability of training for staff and carers in techniques for coping with memory impairment, and this need might best be met by incorporation in the routine activity of memory clinics;
- services should also consider the need for training for staff and carers in coping better with the non-cognitive aspects of dementia.

**Pharmacological interventions**

**Management of behavioural disturbances**

Probably the most common clinical situation is one in which a clinician is asked to see a person suffering from dementia who has become agitated and/or aggressive. A thorough assessment of the patient’s physical health, mental state and the environment is essential. It is important to rule out any physical cause for the aggression (such as a urinary tract or chest infection, or other physical illness) and to investigate whether there is any clear precipitant in the environment. It is also important to review the medication that the person is taking, to check if it – or a combination of drugs – may be the cause of the agitation. Pain can also be a potent precipitant of agitation and aggression. Non-pharmacological management should always be the approach considered first, where appropriate, examining the antecedents of the behaviour, the behaviours themselves and the consequences (ABC). Staff education in homes, carer education and behaviour management techniques have all had some success in alleviating agitation and aggression.

If pharmacological intervention is considered appropriate (where non-pharmacological treatments have failed, and where the disturbance is acute, severe and/or life-threatening), Howard et al (2001) have noted the following points:

- a lack of evidence from controlled trials to support using benzodiazepines;
- using antipsychotics should only follow full consideration of risks as well as benefits;
- older people are especially sensitive to the common side-effects of antipsychotics;
- there may be accelerated cognitive decline in Alzheimer’s disease associated with antipsychotic use;
• neuroleptic sensitivity particularly occurs in patients with dementia with Lewy bodies;
• there is good evidence of a modest level of efficacy for antipsychotic drugs.
• there is no demonstrated difference in efficacy, but atypical agents seemed to have ‘a better side-effect profile’;
• start at the lowest dosage and carefully monitor for side-effects;
• only continue medication if there is evidence of efficacy;
• review the need for continuing treatment every 3 months;
• for patients in whom antipsychotics are ineffective or not tolerated, carbamazepine or trazodone may be efficacious;
• if agitation is severe or treatment-resistant, specialist referral is appropriate.

Agitation and aggression sometimes coexist with psychosis. Most studies concentrate on patients with agitation, but where psychosis is also present antipsychotics are of benefit.

Three studies have demonstrated the efficacy of risperidone in the treatment of behavioural problems, agitation and aggression in people with dementia. A comparison of risperidone and haloperidol showed that risperidone achieved the same degree of reduction in agitation, with fewer side-effects. Olanzapine does reduce agitation and psychosis in patients with dementia. Selegiline (L-deprenyl) has not shown any consistent benefit over placebo. Carbamazepine and sodium valproate have shown benefits in the treatment of agitation associated with dementia. Cholinesterase inhibiting drugs are effective at reducing a number of psychiatric symptoms and behavioural disturbances in patients with dementia with Lewy bodies (McKeith et al, 2000) and are shown to delay the onset of the emergence of behavioural disturbances, as well as a reduction in extant behaviours in people with Alzheimer’s disease.

Management of depression

Several studies have examined the treatment of depression in people with Alzheimer’s disease. Comparison of newer drugs with tricyclics is problematic because there tends to be a greater rate of patient withdrawal due to side-effects among those taking the older drugs. There has been demonstrated benefit of clomipramine, moclobemide, fluoxetine, citalopram, fluvoxamine and paroxetine in patients with Alzheimer’s disease and superadded depression.

Recommendations

The first recommendation must be for proper and thorough assessment to establish the aetiology of the problems. In relation to pharmacotherapy in patients with dementia, we support the recommendations of Doody et al (2001) that:
• antipsychotic therapy is appropriate in patients with dementia where environmental changes are not successful in improving agitation or psychosis;
• atypical antipsychotics may prove to be better tolerated than typical agents;
• for patients with depression, consider prescribing a selected tricyclic antidepressant, monoamine-oxidase type B inhibitor or selective serotonin reuptake inhibitor, with the side-effect profile guiding the choice of drug.

Additionally, our consensus work indicates that:
• multiple neuroleptic use is a practice to be avoided;
• familiarity with chlorpromazine equivalents is good practice.


British Medical Association (2001). *Decisions Relating to Cardiopulmonary Resuscitation*. A joint statement from the BMA, the Resuscitation Council (UK) and the RCN. London: BMA.


Driver and Vehicle Licensing Authority (1999) At A Glance Guide to the Current Medical Standards of Fitness to Drive. Swansea: Drivers’ Medical Unit, DVLA.

Driver and Vehicle Licensing Authority (2001) At a Glance Guide to the Current Medical Standards of Fitness to Drive, p. 2. Swansea: Drivers’ Medical Unit, DVLA.


US Department of Veterans Affairs & University Health System Consortium (1997) *Dementia Identification and Assessment: Guidelines for Primary Care Practitioners*. Oak Brook, IL: USDVA.


*Re C (Adult Refusal of Treatment) [1994]* I WLR 290.