14 Alzheimer's Disease and Other Dementias*

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1 Summary

Statement of the problem

Upwards of one in 20 of the population aged 65 and over in England and Wales suffer from a significant degree of dementia, and rates for dementia and cognitive impairment of up to 80% have been reported from institutional care settings for the elderly. Numbers of people in need of care over the coming decades are due to increase at a faster pace than the overall elderly population increases, due to the disproportionate rise in the number of people aged 85 and over.

Alzheimer's disease and the other dementias are characterised by progressive decline in memory and other cognitive functions, although the course of these conditions is highly variable. Severity varies from mild impairment with little impact on everyday life through to the severe, in which patients need help with activities such as dressing, washing, eating and toileting. In addition, supervision may be needed to guard against wandering or dangers, such as leaving gas taps on. Aggressive or 'challenging' behaviour can be a feature, with verbal abuse, shouting and hitting. Informal carers, who provide the mainstay of support, experience high rates of stress and depression.

Subgroups

Dementia can be subdivided into specific diagnostic entities (*see* pp. 245–6) by age of onset (early or late) or by place of care receipt (institutionalised, living alone, etc.). For organising supportive services, classification into mild, moderate and severe stages on the basis of dependency in daily living is probably the most helpful approach. At the clinical level, diagnostic classification is becoming important, with, for example, new drugs requiring identification of mild to moderate Alzheimer's disease, and dementia with Lewy bodies requiring avoidance of major tranquillisers.

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* This chapter was prepared in 1999 with some updates in 2000. Since then there have been many new research findings in the field of dementia, which are not incorporated here. The reader is advised to use this chapter as an initial reference source, but to check for more recent information where appropriate.

Prevalence and incidence

The prevalence of dementia rises rapidly with age, and as the population aged 85 and over is projected to increase fastest, the total number of people in need of care could rise dramatically over the coming decades.

Table 1: Prevalence of dementia by age and sex (%) (pooled results from five centres of the Medical Research Council Cognitive Function and Ageing Study).

Age group (years)	Men (%)	Women (%)
65–69	1.4	1.5
70–74	3.1	2.2
75–79	5.6	7.1
80–84	10.2	14.1
85+	19.6	27.5

Services available

Table 2 lists the principal services currently available to people with dementia.

Table 2: Principal services currently available to people with dementia.

Service provider	Service functions
Primary health care	Early recognition, assessment and treatment of coexisting illness, rationalising prescribed medication, specialist referral, monitoring, arranging support services, medical supervision in long-stay institutional settings, terminal care and bereavement counselling
Local authority social services departments	Social care assessment, including assessment of caregivers' needs, social care plan, appointment of a care manager. Care offered may involve carer support and practical assistance with caring tasks, including home help, meals on wheels, day and respite care, funding for residential or nursing home care depending on needs and financial entitlement
Old age psychiatry services	Specialist psychiatric service offering investigation and diagnosis, symptomatic treatment including management of behaviour problems, treatment of coexisting psychiatric illness, specialist day care and carer support/education
Geriatric medicine and other hospital specialties	Acute and follow-up care for physical illness in hospital and community settings

Residential and nursing homes provide the bulk of formal practical care to people with dementia, and rates of cognitive impairment in these institutions are very high. Voluntary organisations provide a great deal of information and support, as well as some direct services.

Enid Levin lists ten key requirements for good dementia care (*see* p. 259):

- early identification of dementia
- integrated medico-social assessment
- active medical treatment (of concurrent physical illness, serious behavioural disturbance, etc.)
- timely referral (for diagnostic or treatment problems, or for practical advice and help)
- 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.

This list reflects many of the current problems in the care system. Late recognition of dementia is not uncommon. Polypharmacy and drug interactions can contribute to confusion, and inappropriate use of psychotropic drugs is a problem, especially in institutional care. Insufficient practical support and information often result in unmet needs and contribute to high rates of emotional distress and depression in carers. Those with behavioural problems can find it particularly difficult to get access to respite, day and other care. Lack of community services can lead to unnecessary use of acute hospital beds and accelerate entry into long-stay institutional care. Specific skills are needed to cope with the many people with dementia who are admitted to acute hospitals, where some remain longer than they need to for lack of suitable alternatives. Residential and nursing care homes are of variable quality, and skills training and quality improvement programmes could improve the lives of many residents.

Evidence of effectiveness

The available evidence at the time of writing (2000) and implications for service provision are summarised below in relation to the stages of illness. Much of the experimental evidence is fragmentary and drawn from efficacy trials, mostly from the USA. Interventions can have consequences not only for the patient, but also for carers and the public purse.

Before clinical onset:

- no measures are proven to be effective for primary prevention of dementia, although steps to reduce the incidence of cerebrovascular disease and head trauma may be important and are justified in their own right (*see* p. 264)
- genetic testing is currently only indicated for families where several members have developed early dementia (*see* p. 264)
- general population screening for dementia is not indicated (*see* p. 265)
- clinical recognition of established dementia should be improved, in order to rationalise medication, allow family and patient to make financial and other arrangements, prepare advance directives and avoid inappropriate care.

In mild to moderate dementia:

- much of the diagnostic assessment and management can be carried out by the primary health care team, either alone or in collaboration with specialist services (*see* pp. 253–5). There is a consensus that the diagnosis is essentially a clinical one, with laboratory investigations being employed to identify the uncommon treatable forms and comorbid conditions
- currently licensed anticholinesterase symptomatic drug treatments for Alzheimer's disease offer between two- and four-point improvements on the 70-point ADAS-cog cognitive function scale in

six-month trials on selected patients with mild to moderate impairments. A large number of new drugs are currently under development and updated sources, especially the Cochrane Reviews and NICE, should be consulted for evidence of their efficacy
- available trials of neuroleptics show significant but small effects in the control of agitation, unco-operative behaviour and hallucinations in dementia. Side-effects and drug interactions are a significant problem, especially in the elderly. There is at present much inappropriate prescribing of psychoactive medication for this patient group, especially in long-term care homes (*see* p. 269)
- a number of psychosocial and behavioural therapies have shown promise in improving behaviour and patient comfort (*see* pp. 270–3). Unfortunately, good trials are scarce due to technical difficulties and lack of funding. Although these need more rigorous development, several may prove useful if they can be incorporated into quality-of-care programmes using existing staff. Reality orientation, behaviour modification, validation therapy and activity groups have all shown promise in at least one study in improving important outcomes. Environmental approaches in long-stay settings, e.g. providing circular walkways in homes, can also contribute
- organisational approaches (*see* pp. 273–4) to improving care co-ordination, such as case management, have reduced carer burdens and delayed institutionalisation. Studies of a multi-disciplinary community team in London suggest that non-medical team members can diagnose and plan care with good agreement with the research psychiatrists
- respite care programmes (*see* pp. 274–5) are much praised, especially by the carers using them, but trials have shown little impact on carer stress or time to institutional placement
- two methodologically sound randomised trials have shown that support groups can reduce or delay institutional admission of patients with dementia by a mean of 11 months or more (*see* pp. 278–9). These trials included provision of information, counselling and support on an individual or group basis, and some element of ongoing support over time.

In moderate to severe dementia:

- supportive and practical care needs predominate
- social care 'case management' with flexible budget holding and small case loads can be effective in supporting disabled old people, including many with dementia. Multi-disciplinary community teams with joint health and social care elements can provide a 'one-stop shop' for specialist support and management
- the quality of care in institutional settings (*see* pp. 280–1) needs improvement, through meeting physical care needs, rationalising medication, improving recognition and treatment of depression, and bridging gaps to community care. Also provision of hospice-style care in the terminal stages of dementia should be explored. A number of new forms of supported provision have emerged along the spectrum from own home to nursing home, but their effects and relevance to the UK are as yet unclear
- standards of care for older people with dementia and milder cognitive impairment admitted to acute hospitals are in great need of improvement.

Models of care

There is insufficient evidence on which to base a quantified model of resources and care for dementia. This is partly due to the many possible substitutions in role (between primary and secondary care, between informal, community and institutional care, etc.), and partly due to the lack of adequate evaluation of many of the elements in the care system. Nevertheless, there are a number of key elements that are needed to address the current problems.

These key elements include:

- a central role for primary care professionals in diagnosis, provision of information, management of medication and coexisting illness, referral and monitoring
- meeting informal caregivers' needs for information and practical support
- integrated secondary health and social care provision, preferably in multi-disciplinary teams, providing a 'one-stop shop' for specialist help
- specialist psychiatry of old age services, providing a hub for the network of required services, and special provision for those with complex problems, including challenging behaviour
- improved care of people with dementia in acute hospital settings, with geriatric medicine and psychiatry of old age departments able to play a crucial part in raising clinical standards, including better recognition of dementia, delirium and confusional states and establishing better discharge and aftercare planning
- active programmes to improve care in institutional settings, monitoring psychoactive drug use, actively managing coexisting illness and introducing behavioural, environmental and other approaches to improving quality of life
- adequate continuing-care provision within the NHS for dementia associated with severe behavioural disorder and/or physical illness, combined with an equitable system of cost coverage for both community support services and long-term residential care deemed to be outside the responsibility of the NHS.

Conclusion

Dementia poses one of the great care challenges of ageing societies. Its gradual progression results in a spectrum of care needs from early mild impairments in functionally independent people through to complete dependence in daily living in those with severe impairments. Coexisting illness and challenging behaviour pose special problems in care and supervision, with most of the burden of care falling on informal caregivers and residential and nursing homes.

Current provision, mostly targeted at moderate and severe dementia, has many shortcomings, but the evaluative literature points to a number of important interventions that could be made widely available and which could improve quality of life for patients, reduce behaviour disturbance, reduce stress for carers and avoid premature entry into long-term care. Well-coordinated community provision is probably also essential to avoid inappropriate and wasteful acute hospitalisation.

Research in dementia is a rapidly changing field in which substantial advances in knowledge can be anticipated for the next decade. Thus far, new drugs have targeted mild and moderate Alzheimer's disease, adding a new range of service needs rather than replacing the established ones. The advent of new, more effective therapies may call for programmes of diagnosis and treatment in the early stages of disease, before irreversible brain atrophy has occurred. It is, however, imperative that any resulting change in health service priorities should not be at the expense of supportive and long-term care for the moderately and severely demented elderly, whose numbers are bound to continue to increase in the years ahead.

2 Introduction and statement of the problem

Alzheimer's disease (AD) and the other dementias are characterised by progressive decline in memory and other cognitive functions. The spectrum of cognitive decline is broad, ranging from mild forgetfulness, which many would regard as 'normal', through to severe impairment and dependence on others. Just as the manifestations are variable, so are the requirements for care.

Those organising and funding health services need to view the care of people with dementia as part of their larger responsibility for the elderly dependent and mentally ill. As informal care, social support, practical assistance, and residential and nursing home care are major elements in the management of these conditions, care must be provided in partnership with local authority social services departments, voluntary organisations and the neighbours, friends and particularly the relatives of sufferers. Within the health service, people with dementia will be seen in a variety of settings, including acute hospitals and surgical wards. However, psychiatry of old age is the specialty with the most specific interest in the management of the majority of people with dementia. Around 40–50% of the case load of the specialty is made up of people with dementia,[1,2] with some targeting of the subgroup of patients with behavioural or psychiatric problems.

Since the last edition of this book, there have been a number of new developments in the care of people with AD and other dementias. These have included the appearance of symptomatic treatments for mild to moderate AD and the identification of genetic markers of risk, which are of particular importance in early-onset dementia. At the service level, the phasing out of much NHS long-term care, with the transfer of funds to social services, has effectively moved most direct responsibility for the medical care of institutionalised patients into the hands of general practitioners. At the same time, evidence has accumulated on the benefits of specific types of supportive interventions, especially structured carer education and support.

Since substantial increases in the numbers of very old people are projected over the coming decades and the highest rates of dementia are in old age, the public health importance of the dementias is likely to increase substantially.[3] Indeed, as individuals, we are likely to experience the impact of these conditions in a number of ways – as professional or 'informal' carers of those affected, as decision makers, through the challenges they pose for health and social care organisation and funding, and in many cases directly through their effects on our own mental and social functioning in the future.

Nature of needs and impact on caregivers

As outlined below, dementias generally progress from mild disturbances of recent memory and abstract thinking through to a late stage of loss of personal identity and of unintelligible speech, incontinence and gross impairment of mobility.[4] In moderate and severe dementia the sufferer becomes increasingly dependent on daily care and supervision. Care needs include support with daily activities, such as dressing, washing, eating and toileting. In addition, supervision might be needed to guard against wandering or dangers, such as leaving gas taps on. Aggressive or 'challenging' behaviour can be a feature, with verbal abuse, shouting and hitting.

Much of the burden of care falls to informal carers, frequently spouses or children.[5] Caregiving can result in social isolation and psychological stress, and high rates of depression have been detected.[6,7] The caregiver's psychological well-being is a key factor in admission into nursing or residential care.[8] There is evidence that carers' needs for support and help often go unmet.[9]

Concern with the problem of elder abuse by relatives and other informal caregivers has grown in recent years, but information on this subject is still fragmentary. According to Fisk,[10] findings of interview surveys in the USA and Canada suggest a prevalence of abuse of around 4% in the population over 65. Extrapolations of this estimate to the UK are uncertain as the concept is poorly defined and there may be important inter-country differences. Systematic research in this area is urgently needed in the UK.

Course and outcome

Institution-based studies using informant histories to define the point of onset of overt mental decline indicate that the mean duration of survival is currently of the order of seven to eight years,[11,12] though with a wide range of variation. Remaining life expectancy is lower for men than for women, and for people with an early disease onset than for those with a later onset, after correcting for age. A number of other possible factors have been noted in individual studies, including concomitant physical illness, severity of cognitive and behavioural disorder, and presence of neurological signs such as apraxia. Medical therapy for intercurrent infection or other physical illness probably increases survival, but the effect on survival of therapy for the dementing process itself is so far unclear.

AD and related dementias are associated with an increase in age-specific mortality which becomes less pronounced with advancing age. A UK study[13] of AD patients found that they were 3.5 times more likely to die than those not demented, with a decline from 5.0 times more likely for those aged 65–74 years to 2.8 times more likely for those aged over 85 years.

3 Sub-categories of dementia

The diverse population suffering from AD and other dementias can be subdivided into more homogenous subgroups in a number of ways, to suit different purposes. These include the following:

- specific diagnostic entities (including delirium which can be mistaken for dementia)
- age of onset – early or later
- global severity – mild, moderate or severe
- type of living situation and quality of social support (e.g. living in the community alone, with a carer or in an institutional setting).

Diagnostic classifications are based on underlying neuropathology, and in the context of needs assessment are most useful when discussing specific drug treatments or palliation. In practice, much of the care needed depends on the severity and degree of dependence, rather than the precise diagnosis.[14] Factors influencing the level of care required include severity of cognitive decline, nature of associated behavioural disturbance, presence or absence of other physical or sensory impairment, and the availability of informal caregivers.

Diagnostic definitions of the dementias

Dementia is defined in the *International Classification of Diseases* (10th revision)[15] as 'a syndrome due to disease of the brain, usually of a chronic and progressive nature, in which there is impairment of multiple higher cortical functions'. These cognitive impairments (of memory, thinking, orientation, learning, etc.) are commonly accompanied by deterioration in emotional control, social behaviour and motivation. The ICD-10 classification of dementias and relevant codes are set out in Appendix I. The medical features of the principal disorders are summarised below, but it is important to remember that mixed forms are frequent, and thus there is considerable overlapping of these stereotypes.

Alzheimer's disease

AD is a primary degenerative cerebral disease of unknown aetiology, with characteristic neuropathological and neurochemical features.

Clinical features include:

- insidious onset, usually in late life with gradual development over a period of years
- brain pathology with progressive loss of neurons leading to cerebral atrophy
- progression apparent as increasing impairment of memory storage and retrieval, going on to global disorder of cognition, orientation, linguistic ability and judgement
- clinical course accompanied by growing disability and dependency on care
- widely variable rate of progression.

Vascular dementia (VaD)

VaD (formerly referred to as arteriosclerotic or multi-infarct dementia) is distinguished from AD by its clinical features and course. Typically there is:

- a history of transient ischaemic attacks with brief impairment of consciousness, fleeting pareses or visual loss
- dementia following on a succession of acute cerebrovascular accidents or, less commonly, a single major stroke
- either abrupt onset, following a single major cerebral insult, or a more gradual, stepwise progression
- mental deterioration resulting from infarction of the brain due to cerebrovascular disease, the individual lesions usually being small but cumulative in their effect.

Mixed forms of vascular and Alzheimer-type dementia occur frequently, especially at older ages, and separation of the two is problematic and difficult in practice.

Dementia with Lewy bodies

This form of dementia is not listed in ICD-10, but on the grounds of its symptomatology and specific neuropathological changes has since gained wide recognition, although it overlaps on the one hand with AD and on the other hand with Parkinson's disease.[16]

The condition is characterised by five clinical features:

- fluctuation in the level of cognitive impairment
- visual and auditory hallucinations
- paranoid delusions
- depressive symptoms
- falls or unexplained episodes of loss of consciousness.

Here again the aetiology is unknown and onset is usually in late life.

Other dementias

A number of other dementing disorders are clinically important but, because they are infrequent in the elderly population, contribute less to the public health problem of dementia as a whole. Among these are fronto-temporal degeneration (including Pick's disease), Huntington's disease, Creutzfeldt–Jakob disease and dementia associated with acquired immunodeficiency syndrome (AIDS).

Health resource groups

The National Casemix Office has developed broad classifications covering dementia. In the health resource groupings (version 3), dementia is divided simply into T01 ('senile dementia') and T08 ('presenile dementia'). This classification appears to include many conditions that are not normally included under the diagnosis of dementia, especially under the T08 grouping.

Delirium

Delirium, while distinct from dementia, is commonly associated with it. It is a state characterised by:

- fluctuating mental confusion, with reduced alertness and attention
- disorders of perception, misinterpretation of one's surroundings and, in many cases, fearfulness and agitation
- accompanying tremor, sweating and tachycardia
- lapse into coma in severe cases.

Provoking causes include infections (e.g. pneumonia), cardiac failure and rapid withdrawal of alcohol or drugs, but an underlying predisposition in terms of old age and cognitive decline is common. Although most episodes of acute or subacute delirium are responsive to medical treatment, the presence of an underlying dementing process, even in its early stages, spells a continuing vulnerability to further episodes of delirium.

Early-onset dementia

Dementias affecting those under the age of 65 are known as 'early onset'. While AD does account for some of these, a number of rare genetic conditions are also important. People with Down's syndrome are at greatly increased risk for AD. A survey of the Cambridge Health District[17] estimated prevalence rates rising from 3.4% at 30–39 years to 40% at 50–59 years, suggesting a prevalence curve similar to that for the general population but brought forward 30 to 40 years. The present chapter cannot provide detailed guidance on needs assessment for early-onset dementia. Recent guides to this area include *Young Onset Dementia*[18] and *Mental Health Services: heading for better care – commissioning and providing mental health services for people with Huntington's disease, acquired brain injury and early-onset dementia.*[19]

Severity and relation to normal ageing

Mild, moderate and severe degrees of dementia can be distinguished, though the dividing lines between these are not clearly defined. A fourth group, on the borderline between mild dementia and normal ageing, is now sometimes differentiated in research projects, and has been variously designated 'ageing-associated cognitive decline', 'benign senescent forgetfulness', 'mild cognitive disorder', 'minimal dementia', 'cognitive impairment, no dementia (CIND)' or simply 'query dementia'.

Following the CAMDEX guidelines[20] the four categories can be briefly characterised as follows.

- Minimal dementia: difficulty in recalling recent events and in unfamiliar situations; a tendency to mislay and lose things; increasing errors in activities of daily living (ADL), but without loss of ability for self-care.

- Mild dementia: manifest impairment of attention and memory; forgetting of recent information; occasional confusion or disorientation; some help or guidance needed with any activities outside the daily routine.
- Moderate dementia: amnesia for recent events; some disorientation for time and place; severe impairment of reasoning and ability to understand events, resulting in dependency on others in personal care and routine daily tasks.
- Severe dementia: incoherent speech; disorientation for time, place and person; failure to recognise close relatives; incontinence of urine and faeces; complete dependence on others for basic personal care.

These categories correspond roughly to those provided by the 'interval of need for care' classification,[21] which divides old people into the following groups:

- independent of care
- long interval – care needed at least once a week
- short interval – care needed at least once daily
- critical interval – care or supervision needed continually or at brief irregular intervals each day.

Sub-categories for planning: a pragmatic approach

Of the systems of classification outlined above, the system based on severity provides the most useful guidance for planners and providers of care, since it is essentially in the stages of moderate and severe dementia that individuals are dependent on continuing care and supervision on a daily (and nightly) basis, whether provided by family or other informal caregivers or by professional staff. Indeed the presence of dementia-related disability for self-care and routine daily activities to an extent requiring help or care within each 24-hour period is a practical indication that the stage of moderate severity has been reached, and the probability of admission to long-stay residential care will increase steeply once this threshold is crossed.

Severity grade alone is, however, only a crude indicator of need because:

- it represents a stage in the disease progression, not a permanent state
- care requirements at each stage are strongly influenced by (a) type of residence and (b) availability of family and social support
- they may also be influenced by particular features of the dementing process, e.g. wandering or aggression.

Thus assessment of care needs in a defined population area calls for an estimate of the current numbers of moderate and severe cases according to the above criteria, broken down by type of residence and, for those in private households, presence or absence of informal caregivers.

4 Incidence and prevalence of dementia

Dementia is a complex syndrome and its definition includes three major dimensions: cognition, behaviour and function. Studies of dementia in populations have used a variety of approaches to identify the condition, from simple measurement of cognitive function to detailed examination including observational and clinical techniques. Different methods inevitably lead to different estimates. Needs assessment requires identifying modifiable factors and needs for care or formal services, yet few epidemiological studies have addressed these issues directly.

Epidemiological measures include prevalence (the frequency of dementia in a population at a set point in time), incidence (the rate of occurrence of new cases in a population over a specific time period) and survival (the remaining life expectancy from time of onset). Although decline in cognitive function is the central criterion for the diagnosis of dementia, some decline is observed in most old people. Abnormally steep decline combined with behavioural changes is particularly important in establishing the diagnosis.

Sources of information

Death certification is a poor indicator of the prevalence of dementia since its presence is recorded in only a small proportion of cases.[22] It is becoming more acceptable to record AD in Part II of the death certificate, but reliance on such reporting is unlikely to provide reliable or complete figures for comparison between places or over time. Routine hospital statistics only identify the selected subset of patients referred during the recording time period, and many community services provide care for patients who have had no formal hospital diagnosis. Even at the primary care level dementia is not always recognised or recorded. A complete picture can thus only emerge from systematic population surveys.

Prevalence studies

The most satisfactory compilation of prevalence data for dementia comes from the work of EURODEM (European Commission Concerted Action on the Epidemiology and Prevention of Dementia). Hofman *et al.*[23] have published age- and sex-specific prevalence estimates for dementia (defined as DSM-III[24] or equivalent) derived from 12 European population-based studies conducted or published since 1980 (*see* Table 3). These studies all had sample sizes sufficiently large to enable stable age- and sex-specific estimates of prevalence to be calculated (at least 300 subjects aged 65 years or over). They all employed an individual examination of subjects and included both institutionalised and non-institutionalised cases.

Table 3: Prevalence (%) of dementia by age and sex (pooled results from 12 European studies).

Age group (years)	**Prevalence of dementia (%)**	
	Men	**Women**
60–64	1.6	0.5
65–69	2.2	1.1
70–74	4.6	3.9
75–79	5.0	6.7
80–84	12.1	13.5
85–89	18.5	22.8
90+	31.8	34.1

Source: Hofman *et al.*[23]
The 12 studies included by Hofman *et al.* were carried out in Germany, Finland, Italy, The Netherlands (two studies), Norway, Spain, Sweden and the UK (four studies).

The most recent relevant source of UK data from population samples is the Medical Research Council's Cognitive Function and Ageing Study (MRC CFAS).[25] This study involved a longitudinal examination of population samples of people aged 65 and over in six sites across England and Wales. Table 4 summarises the prevalence estimates for dementia (indicated by '03' and above on the Geriatric Mental State computerised algorithm for organicity) in five of the six sites. The overall estimate at age 65 and over, weighted to the 1991 population, is 6.6% (95% CI: 5.7–7.3).

Table 4: Prevalence (%) of dementia by age and sex (pooled results from five centres of CFAS study).

Age group (years)	Men (%)	Women (%)
65–69	1.4	1.5
70–74	3.1	2.2
75–79	5.6	7.1
80–84	10.2	14.1
85+	19.6	27.5

The overall estimates from the MRC study vary slightly but not consistently from the estimates in Table 3, but the overall pattern is similar. No significant differences in prevalence were found between sites in the MRC CFAS study.

Harvey *et al.*[18] report the following prevalence rates for early-onset dementia, based on a study of all cases aged up to 65 in two London boroughs ($n = 185$). Estimated prevalence was 67.2 cases per 100 000 at risk in the 30–64 age group. The prevalence rates for specific dementias included AD (21.7/100 000 [15.6–29.3]), VaD (10.9/100 000 [6.7–16.5]) and fronto-temporal dementia (9.3/100 000 [5.5–14.7]). It is notable that AD accounted for fewer than half of the cases of dementia. Non-cognitive and behavioural symptoms were common in the patients, 53% experiencing delusions and 44% hallucinations.

Incidence studies

Launer *et al.*[26] have provided pooled estimates of the incidence of all dementia and AD derived from four European studies. They give the incidence rate for dementia as 2.5 per 1000 person-years (95% CI: 1.6–4.1) at age 65, rising to 85.6 (95% CI: 70.4–104) at age 90. These rates are inclusive of mild dementia, however, and may not reflect the numbers of new cases needing care.

Numbers potentially in need of care

Of more relevance to primary care trusts than the predicted numbers of individuals with dementia are the numbers likely to require formal supporting services. For any given individual, dependency will vary with time and be influenced by a variety of factors. These include the degree of intellectual decline but also, perhaps more importantly, the degree of behaviour disturbance, the presence of coexisting physical illness or disability, and the presence or absence of willing carers (*see* p. 244 and pp. 259–60).

Systematic information on the nature and extent of different forms of need is still sparse, but evidence is now available which enables the broad outlines of the problem to be discerned.

Epidemiological estimates of numbers by setting and severity

The MRC CFAS study provides data covering impairments and informal support for all respondents, and service data were collected from records for those classified as frail. Set out below are estimates derived from the four sites covered by the service data collection.

Subjects were classified as having 'dementia' if they scored 3 or above on the organicity scale of the Automated Geriatric Examination Computer Assisted Taxonomy (AGECAT) and physically disabled if they scored 11 or more on the modified Townsend disability scale.[27] The population surveyed included 10 377 people aged 65 or over. Service data were collected for 1391 of the 1446 people classified as having dementia or disability. All estimates have been weighted to reflect the population structure of England and Wales in 1996.

Table 5 provides estimates of the numbers of people with dementia and physical disability per 10 000 population in each age group. Estimates here are lower than those in Table 4 because people with Mini-Mental State scores above 23 (indicating minimal impairment) have been excluded from this table.

Table 5: Numbers of people with mild to severe dementia or physical disability per 10 000 population in each age group, by type of residence.

	Community		**Institutions**		**All***	
	65–84	**85+**	**65–84**	**85+**	**65–84**	**85+**
Dementia†						
Mild (MMSE‡ 18–23)	116	397	7	92	124	486
Moderate (MMSE 10–17)	98	601	43	360	142	967
Severe (MMSE 9)	36	168	45	540	82	739
Physical disability only	633	2,027	93	804	726	2,839
Total	883	3,193	189	1,797	1,074	5,031

* The numbers in the 'All' columns do not equal the sum of the numbers in the Community and Institutions columns because 0.2% of the original CFAS sample who had missing information on accommodation have been included. Those mentally frail people with missing MMSE scores (1.5%) were distributed in the same proportions as those with these scores.

† Based on screen, not full AGECAT diagnosis.

‡ Mini Mental State Examination.[100]

An alternative way of subdividing the group with dementia is on the basis of the frequency with which care or supervision is needed – the so-called 'Interval of need for care'.[21] Of those with mild to severe dementia, 6% were classified as independent (not needing care), 11% as long interval (care needed some time during the week), 48% as short interval (care needed at some time daily) and 34% as critical interval (constant care or supervision needed daily).

The MRC CFAS study also provided mortality data, the percentage dying during the two-year follow-up being 10% of all elderly compared to 25% of mild, 35% of moderate and 54% of severe cases of dementia.

Specific needs in groups with moderate or severe cognitive impairment

A re-analysis of data collected in the OPCS National Survey of Disability, 1985–86, found evidence of 'cognitive disability' (a rough approximation to moderate and severe dementia) in 5.5% of people aged 65 or over.[28,29] Thirty-four per cent of those affected were in institutional care and, as Table 6 demonstrates, members of this group were, on average, more severely handicapped than the remaining 66% still living in private households. Nonetheless, the profile of disabilities among affected elderly community residents points to a considerable burden of care on their families. Of this group (of whom 27% were living alone), daily assistance was required with toileting by 50%, basic self-care generally by 61%, mobility by 61%, and control of disturbed behaviour (aggression, wandering, shouting, etc.) by 17%.

Table 6: Associated disabilities and impairments in people with cognitive disability, based on OPCS national disability survey, 1985–86.*

Medium or high level of disability/impairment†	Community residents (%)	In institutional care (%)
Basic self-care	61 [40]	95 [32]
Continence	50 [33]	64 [22]
Unassisted mobility	61 [40]	92 [31]
Aggressive behaviour	17 [11]	29 [10]
Vision	28 [18]	23 [8]
Hearing	26 [17]	5 [2]

Source: Ely *et al.*[28]

* Figures in brackets = proportions of total sample (community + institutional).

† Medium or high level of disability defined as follows: self-care – unable to wash, dress, feed, toilet or get up from chair or bed unassisted; continence – bladder incontinence at least daily and/or bowel incontinence at least weekly; unassisted mobility – bedfast, chairbound, or restricted to within house or establishment; aggressive behaviour – injures self, hits other people, breaks things and/or has frequent temper outbursts; vision – unable to recognise friend close up, or to read large print or headlines; hearing – unable to recognise friend's voice close up, or to hear doorbell or telephone.

Assessing numbers in contact with services

In a study of people in contact with services in an area of central Scotland with 40 000 elderly inhabitants, Gordon *et al.* [30,31] identified around 2000 people suffering from dementia and assessed the total number of those affected at 2700, of whom 45% were in some form of institutional care and 55% were resident in the community. Estimates of the need for care are summarised in Table 7. Here again, while the levels of

Table 7: Proportions of elderly people with dementia in contact with services and needing different forms of help and supervision on a daily basis: Forth Valley survey.

Help required at least once daily with	Community residents (%)	In institutional care (%)
Basic self-care	63.7	93.8
During the night	28.6	82.2
Mobility	22.6	68.8
Domestic tasks	73.6	83.6
Control of behavioural disorder	47.3	73.5
During the night	29.7	72.4
Estimated number of cases	893	1,217

Source: Adapted from Gordon *et al.*[32]

need were generally higher among institutional cases, those in private households (of whom 38% were living alone) also represented a heavy burden. Daily help was judged necessary with basic self-care for 64%, with mobility for 23%, with domestic tasks for 74% and with control of disturbed behaviour for 47%.

There are, however, some quite large disparities in estimated frequencies between the various surveys, which are unlikely to reflect true population differences, and hence serve to underline the importance of having a clear-cut operational definition of each type of disability and a valid, reliable method for assessing it. Over the past few years a number of techniques of this kind have been developed and tested, including the Care Needs Assessment Pack for Dementia (CARENAP)[33] and an old-age version of the Camberwell Assessment of Need (CAN),[34] developed at the Institute of Psychiatry and UCL Medical School Department of Psychiatry, London. These are in addition to a number of more general standardised medico-social assessment schedules for use with the elderly.[35] These various research tools offer the prospect of more accurate needs assessment and greater comparability between area survey findings in the future. But in the mean time much valuable information can be gathered by local service audits and formative evaluation studies, making use of very simple descriptive data, as the recent Scottish surveys have demonstrated.

5 Services and resources currently available

This section reviews services for dementia available in the UK at the time of writing (2000). Although for convenience these are summarised in terms of the different service agencies concerned, it should be stressed that for most people with dementia, a package of care with contributions from a number of services will be necessary. Many patients have coexisting medical or surgical conditions and require a wide range of provision. An older person with dementia and a fractured neck of femur, for example, may need orthopaedic surgery, geriatric assessment, liaison psychiatry, rehabilitation services, and eventually residential placement and long-term care. Effective co-ordination of specialist medical, general medical, community nursing and social welfare services is therefore a basic prerequisite. This point is emphasised by Table 8, which sets out the principal forms of care provision called for during the course of a dementing illness, according to the different service providers, service functions and professional groups involved.

The following subsections are set out according to the different service needs and functions, rather than according to the individual agencies which, singly or in combination, supply these.

The primary health care services

Most old people in the community depend for their medical care on GP teams and this applies in large measure to dementia sufferers.[36] Together with health visitor and district nursing services (many of which have attachments in general practice) and social service fieldworkers, these constitute the front-line services by whom the onset of dementing illness must be detected and much of its care be provided. In the Forth Valley survey, 235 (29%) of the ascertained cases in private households were notified by GPs, while the primary care team as a whole, including attached district nurses and health visitors, notified 437 community cases (55%).[31]

Population ageing has made GPs and their co-workers increasingly aware of the importance of old-age mental disorders, though their skills in diagnosis and management in this field still vary widely,[37,38] and there is some evidence that as a body they remain sceptical about the value of early diagnosis and specialist

Table 8: List of principal services currently available to people with dementia.

Service provider	Service functions
Primary health care agencies	Screening, early recognition, assessment and treatment of coexisting illness, rationalising prescribed medication, arranging support services, specialist referral, monitoring, medical supervision in long-stay institutional settings, terminal care and bereavement counselling Staff include GPs and practice nurses, health visitors, district nurses and nurses with specific roles, such as incontinence advisers
Local authority social services departments	Social care assessment, including assessment of caregivers' needs, social care plan, appointment of a care manager. Care offered may involve carer support and practical assistance with caring tasks, including home help, meals on wheels, day and respite care, residential or nursing home care, depending on needs and financial entitlement Staff include social workers, home-care assistants, day-care workers
Old-age psychiatry services	Specialist psychiatric service offering investigation and diagnosis, symptomatic treatment, including management of behaviour problems, and monitoring Usually work in a multi-disciplinary team. Staff include psychiatrist and community psychiatric nurses. May have access to specialists, including psychologists, physiotherapists and occupational therapists. May have joint team with social services
Geriatric medicine and other hospital specialties	Acute and follow-up care for physical illness in hospital and community settings
Voluntary agencies	Advice, carer support, provision of services
Private care agencies	Provide nursing and home help in people's own homes
Long-term institutional care	Local authority, voluntary and private residential care, private and voluntary nursing homes, and NHS continuing inpatient care
Social security	Financial assistance, including attendance allowance

referral for dementia.[39] Nevertheless, there is a strong case for early diagnosis of established dementia, and this could be best achieved in primary care.

The GP, as leader of the primary health care team, is responsible for co-ordinating and directing long-term management.[40] GP knowledge of the availability and limitations of local community services is important. In the care of those with dementia, this role would be shared with community psychiatric nurses (CPNs), particularly where the latter are linked to individual practices. Involvement of the district nurse from the outset, whether the patient lives alone or with carers, can promote a joint approach in identifying needs for care. As yet, however, neither district nurses nor health visitors have realised their potential in case detection or management of dementia – district nurses because they have been trained and accustomed to focus exclusively on physical illness and disability, and health visitors because of their overwhelming commitment to families with young children. Designation of specialist health visitors for the elderly could be an important step in redressing the balance,[41,42] but has thus far been on an experimental scale only.

The health of family caregivers is crucial for successful maintenance of community care. Since patient and carer are often registered with the same practice, the GP may assume a pivotal role in support for the latter. By gauging the family's capacities, knowing which of its members can contribute and giving them the information they need about services and benefits,[43] the practice team can play a decisive part. Regular home visits provide the best means of reviewing each case, encouraging caregivers and monitoring the need for further action. The GP also acts as gatekeeper to specialist medical services, a function that has gained importance in recent years as restructuring of the NHS has brought a shift of resources from hospital to community. In parallel with this trend there has been a growth in general practice of psychiatric consultation and liaison schemes,[44,45] which are now extending to old-age psychiatry.

Social and community support services

These services extend from information and counselling to 'substitution' services (e.g. home help, bathing and dressing, meals on wheels, transport), to respite care, which itself ranges from sitter services in people's own homes to day care and intermittent short stays in residential or nursing homes.

A number of objectives stated in the 1990 Community Care Act were intended to improve the quality and delivery of such support:

- assessment of need and appropriate care management
- definition of agency responsibilities and accountability
- development of domiciliary, day care and respite care
- practical help for family and professional caregivers.[46]

While this strengthening of the legislative infrastructure has been welcomed, progress on the ground has generally proved disappointing. Because local authorities have not been given adequate resources to maintain and develop the services for which they are responsible under the Act, for many families the perceived effect has been a worsening of their situation.[47]

Moreover, support services are provided by local authority departments independently of the NHS, and standards of liaison and co-operation between the two administrations vary widely. Assessment of a dementing old person's needs must pay regard not only to his or her current capacity for self-care, but to the presence of emotional or behavioural disturbance, the likely progress of the condition, and the co-existence of physical or sensory impairments. Care managers and 'approved social workers' under the 1983 Mental Health Act are trained in this work, but in practice much individual casework has to be dealt with by less well-trained and experienced personnel.

Specialist old-age psychiatry

Old-age psychiatry as a service-based discipline has its UK origins within the NHS, where the number of clinicians specialising in this field increased from a handful in 1969 to over 400 in 1996.[48] In order to meet the needs of the elderly, service teams are population based and accept responsibility for defined geographic areas. The average over-65-year-old population served by a team appears to have fallen from 36 000 in 1981 to around 22 000 in 1996.[48]

The team normally includes a consultant and one or more psychiatrists in training, trained nursing staff, a clinical psychologist and an occupational therapist, and should have ready access to physiotherapy and other remedial services, as well as a close liaison with social services. Though teams are usually based on hospital units, much of their work is located in the surrounding community. Their tasks and activities are summarised in Table 9.

Table 9: What does an old-age psychiatry service do?

- Home visits and community 'outreach'
- Hospital assessment, diagnosis, treatment and rehabilitation
- Outpatient and day care
- Consultation/liaison in relation to other hospital clinical departments and primary health care services
- Liaison with statutory social services, voluntary agencies and other care professionals
- Supervision of continuing and respite care; consultation in long-term residential care
- Information, counselling (including legal and financial advice) and support for informal caregivers
- Participation in training and further education courses
- Participation in health education and public relations
- Research activities and service auditing

Source: Adapted from Jolley & Arie.[49]

Hospital units for psychiatry of old age

Acute inpatient units are now often located in general hospitals, where they are linked with outpatient and often also day hospital facilities. Here mentally ill old people are treated in the same setting as the physically ill, with the resources of modern medical technology to hand. Some modification of the acute hospital regime is, however, required for patients who, because of confusion and disorientation, cannot adapt to new and strange surroundings, and an effective placement service must be provided to ensure that those who require long-stay care do not block urgently needed acute beds. Day hospital facilities can help both to relieve the pressure on beds and to act as a link between hospital and community. The special requirements of dementia patients are most readily met where day care is located, together with the corresponding inpatient and respite care facilities in combined units, permitting easy transfer of patients as the need arises.

No distinctive model of hospital-based outpatient care for dementia patients has yet emerged, though home-based assessment by psychiatrists or other members of the team plays a crucial part. Innovative schemes tried out in different regions include consultation in the general practice setting,[45] 'memory clinics',[50] open hospital referral[51] and mobile units.[52] Further evaluative research is required to assess the respective importance of these different approaches.

Memory clinics deserve special mention because of their possible significance for early case detection. The first such units were set up in the USA in the 1970s, and aimed to identify people in the early stages of the disorder, before it would present to the ordinary medical agencies. Since 1983 there has been a similar development in the UK. Wright and Lindesay[50] identified 20 memory clinics in the British Isles (14 in England, two in Wales, three in Scotland and one in Eire), 12 of which had started up within the preceding three years. Most patients were referred by physicians (GPs, psychiatrists or geriatricians), but some clinics accepted family or self-referrals, and nearly all took patients from outside their own areas. All provided a multi-disciplinary assessment (psychiatric, psychological and geriatric) and most shared a common core of tests and investigations (physical examination; Mini Mental State Examination [MMSE]; full blood count; urea and electrolytes; thyroid and liver function tests; vitamin B_{12} and folate levels; serum glucose). The proportion of patients found to be suffering from dementia varied from under 20% to nearly 100%, indicating major differences in patient selection and clinic function.

The conclusions of this study were that memory clinics were still at an exploratory stage of development and had not yet been integrated into a population-based system of provision, but that maintenance of a national network would be valuable both for research purposes and for the testing and evaluation of innovative approaches to early case detection and diagnosis – a need likely to increase with the advent of new pharmacological or other modes of therapy.

Psychogeriatric care in the community

The consultant domiciliary visit, widely employed in cases where the patient is unable or unwilling to attend as an outpatient, has strong advantages for initial assessment of the elderly patient.[53] In addition to history-taking and brief clinical examination, it provides an opportunity to assess the patient's home environment and capacity for self-care, and to observe family interaction and quality of caregiving, all in a highly practical and economic way. Beyond that it can be used to plan care management and establish an understanding with regard to hospital or long-stay care. The tradition of domiciliary visiting and home assessment of the elderly represents a largely undocumented success of the British NHS.

Tasks involved in care management include co-ordination of medical treatment with the patient's GP, explanation to caregivers concerning the patient's medication and other matters, eliciting of caregivers' emotional problems and avoidance as far as possible of family crises. Admission to hospital or long-stay residential care may have to be arranged. Help and guidance may also be needed if, for example, a driving licence must be withdrawn or an enduring power of attorney arranged.

CPNs specialising in care of the elderly have become key members of the old-age psychiatry team. It has been reported that around 60% of all CPNs are engaged in this field of activity,[54] and that a large part of their work deals with dementing old people and their informal caregivers.[55] The standard of provision of two CPNs for an area population of 10 000 elderly, recommended by the Royal College of Psychiatrists (*see* Table 11), is probably attainable as a national average, but there appears to be wide variation in current levels, even within single districts.[56] It has long been argued that, while national provision of CPNs is the result of a basically haphazard development, there is now a need for systematic auditing and controlled evaluative studies in order to establish firmer guidelines as a basis for future provision.[57] This general point applies with particular force to the field of dementia care, where the match between the needs of patients and informal caregivers on the one hand, and the functions of the specialist CPN on the other, remains ill-defined.

Other hospital specialist care

Rates of cognitive impairment are raised among elderly patients admitted to acute hospital beds compared with the background elderly population. A high case-frequency has been found in geriatric units in particular,[58] but extends to medical inpatients more generally,[59,60] and applies to some extent to all general hospital wards.[61]

Cognitively impaired patients are prone to be admitted with delirium, or to become delirious while in hospital. They have, on average, a significantly longer hospital stay than other patients of the same age[61] and also a less favourable prognosis in terms of illness outcome, admission to long-stay care and mortality.[62] Despite the high prevalence of cognitive disorder, medical and nursing staff on the wards often appear unaware of the problem, unless the patient's behaviour is disturbed.[58]

It is important that the condition should be recognised and correctly diagnosed, because of its implications for future treatment and care.[63] The routine use of standardised dementia screening tests could, however, lead to harmful consequences because of the high proportions of false positives they yield and the consequent unnecessary 'labelling' of elderly patients that might ensue. More pressing, therefore, is the need for better training of hospital doctors and nurses in awareness and recognition of confusion and memory disorders.

Long-stay care and sheltered housing

Rates of admission to long-stay residential care increase steeply with severity, but vary between populations, according to their age structures, the proportions of old people living alone and the availability of long-stay beds, as well as according to the prevalence of dementing illness. Findings of dementia case registers and cohort studies in urban societies suggest that about half the cases known to services will be in residential care within two to two and a half years of referral and up to three-quarters before death, and that the mean duration of such care – as a rule terminating only with death – is from two to three years.[64–66]

Long-stay residential care for the elderly includes old people's homes, for those who are still relatively independent, and geriatric nursing homes and designated NHS 'continuing-care' units, both intended for those in need of long-term nursing care and supervision. While numbers in local authority old people's homes have declined, there has been a steep increase in numbers in independent (mostly privately owned) nursing and residential homes catering for the growing numbers of old people who can no longer benefit from intensive medical investigation or treatment but who, because of chronic disablement, cannot lead independent lives.[67]

An underlying problem is the division between NHS care, free at the point of consumption, and social care provision outside the NHS (whether by local authorities, independent charities or the private sector), for which charges apply, often with means tests. Formerly this was resolved by the availability of long-stay hospital beds (geriatric and psychiatric), and guidelines on care requirements were used to limit the pressure of demand upon them. In the mid-1980s old-age psychiatry services had on average 3.4 long-stay beds per 1000 population aged over 65.[68] A change in national policy at that time resulted over the following decade in a halving of this level of provision to an average of 1.7 per 1000, and a large-scale shift to nursing and residential homes.

Only 8% of nursing homes cater explicitly for the elderly mentally ill. However, the prevalence of dementia in both residential and nursing homes is high. Darton[69] reported that 67% of admissions have significant cognitive impairment (on the 'US-MDS CPS' score), although only 39% had been diagnosed as having dementia. Thirty-four per cent of all admissions displayed behaviour problems.

Wattis and Fairbairn,[70] reporting on an expert group consensus, concluded that NHS continuing care units, medically supervised by a specialist consultant, are an essential part of the service. Characteristics of patients who need to be cared for in such units are:

- sustained or frequently recurrent difficult behaviour arising from dementia or other major mental disorder
- associated physical illness and sensory impairments, if the patient's needs cannot be better met elsewhere
- dementia or other major mental illness, with failure to cope or more rapid deterioration in other care settings.

Equitable and transparent (non-financial) criteria are necessary to decide who needs NHS continuing care and who can be adequately served by social care and support alone. In view of continued population ageing, the previously recognised guideline for NHS continuing-care beds of three per 1000 people aged over 65 is unlikely to be an overestimate of true need.

Surveys of geriatric homes in the UK continue to report wide variation in the quality of care.[71,72] Criticism of the less satisfactory units has focused on structural inadequacies and reliance on untrained caregivers (both of which may result in overuse of sedatives and tranquillisers), the lack of properly structured activity programmes for residents, the inadequacy of residents' documentation (medical and personal) and the absence of bridges to the surrounding communities. Efforts are being made to improve standards in the homes. A code of practice, with guidelines for home managers and inspectors, has been circulated,[73] and the Department of Health (DoH) has set up a number of projects to promote staff training, encourage self-assessment and performance review, strengthen links between homes and their local communities, ensure better information and choice for 'consumers', and facilitate complaints procedures. It remains to be seen what impact this action will have. Implementation will depend on the resources local authorities can devote to the required tasks.

Mounting professional disquiet regarding the haphazard arrangements that currently characterise long-term residential care led to the setting up of a joint working party of the Royal College of Physicians, the Royal College of Nursing and the British Geriatrics Society. Their report[22] sets out a number of specific recommendations, including:

- adoption of an agreed comprehensive assessment tool
- a population-based approach to the planning and provision of residential services
- development of specialist nurses as the lead practitioners in care homes
- re-engagement of geriatric medicine and old-age psychiatry in the field of long-term residential care
- introduction of a special pharmacy service for care-home residents.

Although these recommendations are not focused explicitly on the problems of dementia, they have implications for the severely cognitively impaired elderly who now make up a high proportion of the care-home population.

Sheltered housing, which has undergone a large expansion in the past 15 years, offers for many old people a pleasant alternative to residential home admission[74,75] but is less suitable for those who require any degree of nursing care. Warden supervision is more useful for alerting support agencies when necessary than as a direct care resource. In practice, most personal care must still be provided by families or by community support agencies based outside the housing development. In general, therefore, it is inadvisable for people with serious mental health problems – and especially with dementia – to be moved into sheltered housing unless sufficient support is available from other sources.[47] Schemes for 'very sheltered' or 'extra-care' housing offered by some local authorities and housing associations are more suitable for old people with progressive disabilities, including dementia.[74]

Meeting the needs of informal caregivers

There is growing awareness of the need to give help and support to the informal caregivers – usually, though not always, family relatives – who carry out most of the nursing and supervision of people with dementia in the community.[76] Providing support is not the sole responsibility of any one professional agency, but should be seen rather as an integral part of the package of care for each individual sufferer, to which a number of services may contribute. The voluntary sector, including the Alzheimer's Disease Society, provides a range of direct services, including much practical information.

A list of ten key requirements set out by Levin[77] serves as a useful framework, both for identifying the current contributions of the various agencies and for locating weak points in the existing provision.

1. *Early identification of dementia*: health screening of patients over 75 years of age in general practice should include simple testing of cognitive function.
2. *Integrated medico-social assessment*: recognising the presence of cognitive impairment and decline needs to be combined with an informant account and an overall appraisal of the domestic situation.
3. *Active medical treatment*: medical and home nursing care may be required for concurrent physical illness, as well as for serious behavioural disturbance. District nurses must often deal with cognitive disorder in old people they visit, and need both additional training and reduced case loads to be able to cope adequately with the resulting problems.
4. *Timely referral*: whether indicated because of diagnostic or treatment problems, or for practical advice and help in management.
5. *Information, advice and counselling*: a survey undertaken by the Alzheimer's Disease Society (1995) found that 50% of respondents were dissatisfied with their GPs on this score, though the Alzheimer's

Disease Society membership is not necessarily representative of carers in general. In many areas these functions are now shared either by local branches of national voluntary bodies (Alzheimer's Disease Society, Age Concern, etc.) or by small neighbourhood and mutual-help groups. A proportion of family caregivers, however, require professional mental health counselling because of the psychological distress they suffer.[7,78]

6 *Continuing back-up and review:* because episodes of NHS specialist care tend to be fairly brief, responsibility here often devolves to primary care professionals, together with CPNs working in the community mental health teams.

7 *Regular help with household and personal care tasks*: under the Chronically Sick and Disabled Persons Act, local authorities have a duty to assess disabilities and to provide aids and adaptations for the physically disabled, as well as (at a charge) support services such as meals on wheels and incontinence laundry. At the same time, they often lack the resources to provide regular home help for the growing numbers of very elderly people who suffer from combined physical and mental impairment.

8 *Regular breaks from caring*: this broad category extends from 'sitting' services, through day-care attendance (as a rule involving daily transport) to spells of 'respite care', in which the affected old person is admitted to continuing care for a week or so because the main caregiver is ill, or so that he or she can take a holiday. Responsibility may therefore be shared between the specialist team and the local authority, and calls for a co-ordinated approach.

9 *Regular financial support*: attendance allowance is a benefit for people aged over 65 who have needed help with personal care for six months, a higher rate being payable where help is required both day and night. Invalid care allowance (ICA) is a benefit intended for carers who cannot work full time because they are looking after someone who needs a great deal of care. To be eligible, the affected old person must be receiving attendance allowance, and the caregiver must initially be under 65 years and providing care for at least 35 hours a week.

10 *Permanent residential care*: families confronted by the prospect of long-term care for an old person may need support and guidance for a number of reasons – to reach their decision that the time has come, to help them come to terms with this and deal with any emotional conflicts, to know how to gauge the quality of care on offer and find a place in a well-run home, to avoid unwise actions, such as buying unsuitable sheltered accommodation, and to take full advantage of any financial provisions made by the state.

Norms, averages and recommended levels for service provision

A high proportion of people with dementia are in contact with formal health and social services. Table 10 summarises the numbers of disabled older people living outside institutions and using various services, as measured in the MRC's CFAS study (*see* p. 251).

In a study sample of 700 people aged 65 or over in a district of London, the 5.6% of people with dementia consumed 15.6% of community care.[79]

At a local level there is considerable variation in provision of health and social services, in terms of both type and level. However, routine data accurately identifying this patient group are scarce. The available data in social services performance indicators cover either the elderly as a group or all those with mental illness, and are not specific to people with dementia. Even hospital diagnostic or health care resource group data should be treated with caution, as many people with dementia will be admitted with coexisting illness and the presence of dementia may not be recorded.

Recommended levels of provision of old-age psychiatry services

Quantitative guidelines for the provision of old-age psychiatry services appear in the Royal College of Psychiatrists model job descriptions for consultants[1] and are summarised in Table 11 (*see* p. 262).

In addition, 8 to 18 beds and 8 to 16 day places are recommended as needed for younger people with dementia per 1 000 000 population.

In the 1998 report of a joint working party[80] these target figures are extrapolated to a service planning population of 250 000, with 37 500 people aged over 65, the recommended levels of provision remaining basically the same.

Table 10: Percentage (estimated number in England and Wales) of disability groups aged 65 or over (living outside institutions) using hospital and community services during a two-year follow-up period.*

	Physical† impairment only		**Dementia‡**					
			Mild (MMSE 18–23)		**Moderate (MMSE 10–17)**		**Severe (MMSE ⩽ 9)**	
	%	**Thousand**	**%**	**Thousand**	**%**	**Thousand**	**%**	**Thousand**
Any hospital contact (short-term)	71	392.4	61	64.6	63	70.2	60	18.3
Acute inpatient	49	269.6	39	42.1	48	53.1	51	15.6
Outpatient	58	319.8	41	43.5	38	42.5	29	9.0
Day hospital	8	44.4	15	16.0	10	10.8	12	3.6
Community nursing services§	57	312.3	41	43.5	52	58.2	54	16.6
Social worker	10	53.8	13	13.5	15	16.4	26	7.9
Specialist community services¶	60	327.1	39	41.1	52	57.6	45	13.9
Day centre	13	70.1	16	16.6	19	21.6	27	8.2
Home care services**	55	303.4	32	33.7	51	56.9	45	13.8
Meals on wheels	22	122.6	10	11.2	25	28.0	13	3.9
Home help	47	258.6	28	30.0	41	45.9	32	9.8
Any of the above community services	87	475.7	63	67.5	77	85.8	82	25.1
Total people (thousand)		549.6		106.8		111.8		30.7

* Sample data weighted to 1996 England and Wales population by age and sex.

† Includes sensory impairment.

‡ Diagnosis based on screen positive caseness, not full AGECAT.

§ GP and community nurses, including psychiatric and Marie Curie nurses, health visitors and continence advisers.

¶ Chiropodists, physiotherapists, audiologists and occupational therapists.

** Meals on wheels, laundry, home help, private domestic help and incontinence service.

These recommended targets are substantially higher than average existing provision. For example, in 1996 there were 328 whole-time equivalent (wte) consultant posts (across 418 posts) in England, corresponding to a rate of 0.42 wte posts per 10 000 population aged 65 plus,[81] less than half the target figure.

Costs of dementia care

The dementias are responsible for large amounts of care spending, but cost estimates are hampered by difficulties in obtaining representative and accurate service data and in the costing of informal care.

Gray and Fenn,[82,83] using mainly routine service data, estimated the total cost of AD alone for England as £1.04 billion at 1990–91 prices, excluding the costs of informal care. Sixty-six per cent of these costs were in residential and nursing homes and 17% in mental hospitals. However, the mental hospital estimate will have changed with the rundown of NHS long-stay facilities.

Table 11: Recommended Royal College of Psychiatrists minimum service levels: resources per 10 000 people aged 65 and over.

Resource	Numbers	Comment
Consultant in psychiatry of old age	1 wte	
Community psychiatric nurse	2 wte	
Occupational therapist	At least 1 wte	
Physiotherapist	0.5 wte	
Clinical psychologist	0.5 wte	
Secretary	1 wte	
Acute beds	15–20	Lower numbers if day hospital places available
Day hospital places	20–30	Two-thirds of places for people with dementia
Long-stay and respite beds	up to 30 beds	Lower numbers possible, depending on NHS eligibility criteria

wte = whole-time equivalent.

Kavanagh *et al.*,[84] applying a 'bottom-up' approach based on the total number of people with moderate and severe cognitive disabilities estimated from the Office for Population Censuses and Surveys (OPCS) disability survey, arrived at total costs of £5.1 billion at 1992–93 prices, mostly falling to social security and social services. NHS annual expenditure was estimated at £1.26 billion, or just under a quarter of the total. Estimated annual costs per person varied from around £11 000 per annum for those living alone at home (generally mild cases) through £17 000 per annum for those in private or voluntary residential homes, to £40 000 per annum in long-stay hospital wards, at 1992–93 prices. More recently Knapp *et al.*,[85] using data for 1992–93 from the NHS Executive, estimated the direct health and social services costs for dementia in England to be £850 million, or 3.2% of all public service expenditure on health and social services.

The large discrepancies between these basically comparable studies demonstrate the fragility of health-economic computations in a field where so many assumptions have to be made, especially when they deal with service structures undergoing transition. Some of the differences can be explained simply by the fact that Gray and Fenn restricted their analysis to AD, whereas Kavanagh *et al.* considered dementia as a whole. In addition, however, there were disparities in the estimation of numbers and expenditure for dementia sufferers in nursing home care and even more for those in private households. Kavanagh *et al.* emphasise that for a realistic costing, a monetary value must be placed on the opportunity costs of relatives and friends who give up their time and energy to act as informal caregivers. According to their calculations, these and other 'invisible costs' of dementia amount to around £1.8 billion annually.

Patients and their families are liable for only a small fraction of hospital care costs, but for much larger proportions of those for long-stay care and – partly for the reasons given above – for the total costs of community support. By 1991, so much of dementia care was already located outside the NHS that, as Table 12 demonstrates, half the total costs were borne either by patients and families or by social security funds. Since then the balance has continued to change.

Official policy from around 1980 onwards has led to a steep reduction in both NHS and local authority provision for long-stay care, while at the same time promoting a boom in the private care sector. Over a period of some 11 years (1982–83 to 1993–94), geriatric hospital bed numbers fell by 33%[86] and local

Table 12: Summary of average weekly care package costs, at 1992–93 prices.

Type of residence	Proportion of costs payable by:				
	DHA (%)	FHSA (%)	SSD (%)	Patients/ DSS (%)	Total costs
Hospital (long-stay)	95.7	0.0	2.8	1.5	773.1
Local authority residential home	2.3	2.3	92.0	3.4	354.5
Private or voluntary residential home	2.2	2.2	27.3	68.3	240.5
Private or voluntary nursing home	2.3	2.3	42.5	52.9	337.7
Private household, living alone	8.2	1.4	12.9	77.5	212.1
Private household, living with others	13.6	1.3	8.3	76.8	243.5

DHA = district health authority; FHSA = family health service authority; SSD = local authority social services department; DSS = Department of Social Security (government).
Source: Adapted from Kavanagh *et al.*[84]

authority home places by 41%, whereas 'independent' (chiefly private) nursing homes increased their capacity by over 700%.[87]

Although cost estimates for the same period, provided by the above studies, amount to very different totals, the ratio of NHS expenditure to direct social costs is similar in each, with a proportion of around 25% contributed by the NHS. Gray and Fenn[82] emphasise that this relative contribution to dementia treatment and care is disproportionately low when compared to the expenditures for other chronic disabling conditions, such as stroke, coronary artery disease, arthritis, diabetes, epilepsy or multiple sclerosis, due to the much higher proportion of long-term residential care associated with dementia. This is a point to be borne in mind when considering models of care and the development of local strategies (*see* pp. 287–8).

The Royal Commission on Long-Term Care Report (1999)[88] recommended that the costs of care for those individuals who need it should be split between living costs, housing costs and personal care. Personal care should be available after an assessment, according to need, and paid for from general taxation; the rest should be subject to co-payment according to means.

The Commission considered that the cost of this proposal to public health and social expenditure would be £800 million to £1.6 billion in the base year, rising (at 1995 prices) to £1.7 billion in the year 2010, £2.4 billion in 2021, £3.4 billion in 2031 and £6.0 billion in 2051. They pointed out that these sums would amount to around only a quarter of private expenditure on long-term care, under the existing system.

From the definition of personal care supplied in the report, it seems clear that people with severe or moderately severe dementia should normally be assessed as eligible, and hence that this proposal, had it been accepted, would have a large impact on the financing of dementia care in the UK. However, in the Government's response to the Royal Commission, now published as an addendum to the NHS Plan,[222] this recommendation is rejected on cost grounds, with the justification that making personal care universally free is not the best use of available resources. The task of differentiating NHS nursing care from personal care for dementing elderly residents is likely to prove a difficult one.

6 Effectiveness of treatments and services

The following section reviews evidence available at the time of writing (2000) of the effectiveness of specific treatments and care services for dementia. Each subsection summarises the evidence and conclusions. In some instances, good systematic reviews of evidence already exist, in which case their findings are cited. Where there is no evidence for or against a particular intervention, this has been stated. (A description of the search methods used to identify studies is contained in Appendix II.)

In each subsection we have reviewed the evidence in the light of favourable outcomes which may be expected from an intervention. Broadly these fall into three groups:

- effects for the patient
- effects for the carer
- effects for the service provider or funder, the NHS or the State.

Favourable outcomes for the patient include improvement in functional performance (particularly in the activities of everyday living) and cognitive function, and reduction in behavioural disturbance, dependency and risk of death. In addition, the safety or side-effects of interventions or treatments are important. Other central criteria such as reduction in distress and maintenance of quality of life are less well studied, perhaps because of difficulties in measurement.

Favourable outcomes for caregivers include improvement in both physical and mental health, reduction of burden (objective and subjective) and gains in social support. Outcomes for health services and the State tend to be considered primarily in terms of resource expenditure. From this perspective, avoidance of admission to hospital or to an institution has been seen by some authors as a desirable outcome in itself. However, for a true perspective these factors must also be seen in the context of patient and family functioning.

The importance of each type of outcome may vary in individual cases, but together they provide a framework within which to consider the evidence of effectiveness of services.

In addition to the measurement of outcomes, there are a number of other problems in assessing the available evidence. One important consideration is that while it is assumed that results of drug trials can be generalised across countries with different health and social care systems, this assumption is clearly less defensible when examining service and organisational studies.

Primary prevention

So far, there is no firm evidence that any form of intervention can prevent dementia, or that the tempo of cognitive decline in old age can be reduced. The clearest potential for primary prevention is to be found in those areas where there is high vascular risk, e.g. prevention of stroke and transient ischaemic attacks, prevention of type 2 diabetes and of vascular complications in those who have type 2 diabetes, and smoking reduction.[89] More general health measures, such as nutritional programmes, may prove important if they are shown to prevent certain diseases earlier in life and thus reduce the risk for dementia in old age. There is also growing inferential evidence that reduction in the risk of brain trauma in earlier life (e.g. by imposing speed limits, drink and drive legislation, seat belts and crash helmets) may help to prevent dementia in later life.[90]

Specific interventions, such as hormone replacement therapy in older women or sustained use of non-steroidal anti-inflammatory medication, must await the results of ongoing trials. The Cochrane Collaboration is preparing reports on these topics.

Genetics and prevention

A number of specific genetic mutations have been shown to be associated with AD in families where several members develop early-onset disease, and the pedigree indicates an autosomal dominant transmission. Such families are rare, and their individual members require services and counselling akin to those available for Huntington's disease (HD). Genetic testing in these families follows guidelines established for HD and is provided by genetics departments.[91]

The only genetic finding so far which is relevant to the common forms of dementia is that the allelic variations of the apolipoprotein E (ApoE) gene are associated with varying risk of dementia.[92] While research has been focused mainly on AD, the mutations may also be associated with other forms of dementia. The mechanism of effect is not yet understood, and more data are required from longitudinal population studies before any valid assessment of risk conferred by such genetic factors can be made. Genetic testing at the ApoE locus is not recommended at present, but may play a future role in aiding diagnosis. Testing of unaffected individuals, however, is unlikely to have a role in the foreseeable future.[93]

Population screening

As dementia is a serious and relatively common condition in which early symptoms are often overlooked, the issue of screening segments of the population, perhaps in certain age bands, has been considered. In a review of the literature undertaken by an independent panel of experts set up by the US Agency for Health Care Policy and Research[94] in 1992, conclusions were that:

- none of the available screening tests has a high sensitivity for early or mild dementia
- no evidence supports the efficacy of general screening for AD or related dementias, given the lack of unequivocally effective treatment and the difficulties of recognising early dementia.

In addition, genetic markers of increased risk of dementia, such as ApoE, are too unspecific to be recommended for use in screening.

Simple cognitive screening can already achieve some success in predicting the onset of clinical dementia within two to three years, but also generates a high proportion of 'false positives'.[95,96] The numbers of reversible cases are likely to prove small. Clarfield,[97] in a review of published studies, found an average of 13%, mostly related to faulty medication, metabolic disorders and depression, but stressed that the corresponding figure for an unselected case series might well be much lower than this. So far any potential gains from early detection probably have less to do with specific therapy than with more general measures of care management and family support, but this could change in future as new treatments emerge.

Clinical diagnosis and assessment

Quality of evidence: III C

Accurate diagnosis can reduce anxiety for patients and caregivers, identify treatable coexisting conditions and steer patients towards appropriate services. High sensitivity and specificity mark out superior diagnostic tests, together with evidence of improved management. For the NHS, cost-effectiveness of the test or investigation is an important criterion.

Important questions include the following.

1 Which tests should be used?
2 Is the accuracy of diagnosis or assessment influenced by who administers it?
3 Does accurate and timely diagnosis affect management?

Controlled trials are scarce, but much of the available evidence bearing on these questions is reviewed in two professional Consensus Statements – one from the Royal College of Psychiatrists in the UK[98] and one jointly from the American Association for Geriatric Psychiatry, the Alzheimer's Association and the American Geriatrics Society.[99] A citation search did not reveal any favourable or critical comments on either of these documents.

The Royal College of Psychiatrists in October 1995 published a Consensus Statement on the assessment and investigation of elderly people with suspected cognitive impairment. Consensus was apparently achieved by 'extensive and lengthy discussion within and without the RCPsych Specialist Section for Psychiatry of Old Age, and after a large nation-wide exercise'. The document was not clearly referenced.

The Consensus stated that to facilitate the referral process there should be collaboration between primary and secondary care, with information for GPs on the referral process, and an agreed timescale for responsiveness. Assessment should include assessment at home (usually) and medical assessment under the supervision of a consultant. A history should be obtained from the carer. Assessment of mental state should be made using, for example, the MMSE, the Abbreviated Mental Test Score or the Clifton Assessment Procedure for the Elderly. Physical examination should be performed to detect indications of aetiology or of aggravating factors. Regarding laboratory investigations, the paper concludes that there is insufficient firm evidence to allow authoritative recommendation of a definitive list of tests. Tests may include full blood count, ESR, vitamin B_{12} and folate levels, blood glucose, liver and thyroid function tests, and syphilis serology. Computerised tomography (CT) scanning should be performed 'if practicable' unless the illness has a duration of more than a year and the picture is typical. In summary, the diagnosis is mainly clinical; further tests should aim to exclude coexisting or aggravating comorbid pathology.

The US joint Consensus Statement published in October 1997 was based on a conference at which presenters summarised and presented data from the world literature to a panel of experts. The resulting statement emphasises that the most important diagnostic tools are the informant interview and a clinical assessment. Physicians should conduct a comprehensive physical examination, including a brief neurological and mental state examination. The MMSE,[100] as a quantitative measure of cognitive function, and laboratory tests including full blood count, blood chemistry, liver function, serological test for syphilis, thyroid function and vitamin B_{12} level were recommended. Other investigations as suggested by the history or physical examination should be undertaken. Though brain imaging was considered optional, the value of functional imaging, by means of positron emission tomography (PET) or the more economic photon emission tomography (SPECT), in resolving diagnostic difficulties was stressed. Consensus was also reached that the diagnosis of dementia is usually a clinical one, and laboratory or other specific investigations are performed to identify uncommon treatable causes and comorbid conditions.

In summary, the two consensus documents are in agreement that the diagnosis of dementia is essentially a clinical one, laboratory and other investigations being employed in differential diagnosis. Diagnosis and assessment should include an informant interview and attention to both cognitive performance and abilities in everyday activity. Much of the assessment can be undertaken in the community or the primary care setting, though diagnostic uncertainty may necessitate hospital admission.

Pharmacological treatment of dementia

Therapeutic drugs are used for a variety of purposes in people with dementia, including:

- targeting the disease itself (although these are still experimental)
- providing symptomatic improvement in cognitive function
- controlling psychotic symptoms or treating coexisting depression
- managing aggressive and challenging behaviour, and sleep disorder
- treating coexisting physical conditions.

In this section we review the evidence related to the principal agents. As a large number of drugs are under development, it is likely that new agents will appear over the next decade. In theory, if new drugs are effective in reversing, arresting or slowing the disease process, benefits could include amelioration of all the symptoms of dementia. Patients might therefore be expected to show improved cognitive and functional performance, and caregivers would experience a reduction in the adverse consequences of caring. Ultimately, if effective, drugs could potentially reduce the resource requirement for dementia care, with a reduction in inpatient and residential admissions. However, no such consequences have been reliably documented so far.

*Acetylcholinesterase inhibitors**

Quality of evidence: I-1 C

At post-mortem, the brain tissue from patients with AD shows a loss of cholinergic neurons and a deficiency of the neurotransmitter acetylcholine. This has led to the hypothesis that the cholinergic system is involved in the pathophysiology of AD. Possible therapeutic options therefore include cholinesterase inhibitors and cholinergic agonists.

Thus far, two of these drugs have been the subject of most study: tetrahydroaminoacridine (Tacrine) and donepezil (Aricept), the latter being licensed for the symptomatic treatment of AD in the UK.

Although cumulative evidence from randomised trials has confirmed that there are at least short-term benefits to cognitive performance from the anticholinesterase inhibitors, so far there are few data on their long-term efficacy, effects on patients' quality of life, or the cost-effectiveness of treatment. More information on these questions will be forthcoming from research now under way, including a large 'real-life' trial of donepezil now being undertaken by the University of Birmingham/West Midlands Consortium AD2000 Trial Group. Meanwhile, however, we remain at a watershed in the use of these forms of treatment.[223]

Tetrahydroaminoacridine (Tacrine)

Quality of evidence: I (one meta-analysis and several randomised controlled trials)

The Cochrane Collaboration has published a review of 18 published trials of the efficacy of Tacrine in AD,[101] which met inclusion criteria. From a meta-analysis of five comparable included randomised controlled trials (RCTs),[102–106] they conclude that there is no significant difference between Tacrine and placebo in the effect on overall clinical status, behaviour disturbance or cognitive function as assessed by the MMSE. However, barely significant improvements in cognitive function were evident on a more sensitive cognitive function measure, the Alzheimer's Disease Assessment Scale, cognitive subscale (ADAS-cog).[107] Formal comparison of adverse events was difficult, but changes in liver function tests were a major reason for withdrawal from trials, followed by gastrointestinal side-effects.

In the USA it has been claimed that systematic prescribing of Tacrine for AD could result in a significant reduction of total care costs, mainly by reducing the mean duration of nursing home care for those affected.[108] This conclusion, however, was based on a non-blind, non-randomised follow-up of a six-month double-blind RCT, and must therefore be regarded with great caution.

In summary, a Cochrane Collaboration review of trials of Tacrine concluded that there is no convincing evidence currently that Tacrine is useful in AD.

Donepezil (Aricept)

Quality of evidence: I

The Development and Evaluation Committee in Wessex published a review in June 1997 of the likely benefits and financial implications of donepezil use.[109] The *Drug and Therapeutics Bulletin* in October 1997 likewise published a commentary on donepezil.[110]

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* Since this chapter was prepared, NICE has produced guidance on the use of donepezil, rivastigmine and galantamine for the treatment of mild and moderate Alzheimer's disease.

The first published RCT of donepezil[111] studied the effect of 1, 3 or 5 mg donepezil daily in 161 patients aged 55–85 years with mild to moderately severe AD. A more recent large-scale trial, published in January 1998,[112] examined the effect of donepezil on 473 patients aged over 50 with uncomplicated mild to moderate AD. Excluded from the trial were patients with insulin-dependent diabetes, other endocrine disease, asthma or obstructive pulmonary disease, or major gastrointestinal, hepatic or cardiovascular disease, or if taking anticholinergics, anticonvulsants, antidepressants or antipsychotics. A double-blind RCT of 24 weeks' treatment, followed by a six-week single-blind washout period, compared the effects of 5 mg or 10 mg donepezil daily with those of placebo. The principal outcome measures used were ADAS-cog and the Clinical Interview Based Impression of Change (CIBIC)[113] scores. At 24 weeks, the mean placebo–drug differences in the 70-point ADAS-cog score were –2.49 (5 mg) and –2.88 (10 mg), indicating a small benefit in the treated groups compared with the placebo group. The CIBIC ratings also indicated a beneficial effect in the treated groups. After the six-week washout period, neither the ADAS-cog nor the CIBIC scores showed a significant difference between treatment groups compared with placebo. No evidence was reported of adverse effects due to abrupt cessation of the drug.

These findings have since been substantially replicated in a large-scale multi-national clinical trial, likewise industry-supported, which employed the same research design and instruments.[114] A total of 818 patients, with a mean age of 72 years, were recruited at treatment sites in nine countries, and over three-quarters of these completed the trial. Donepezil vs. placebo differences in mean change from baseline ADAS-cog scores were –1.5 and –2.9 points for the 5 mg and 10 mg daily donepezil groups, respectively.

In a 12-week study of similar design, reported in the American prescribing information sheet, similar results emerged, indicating the effect of the drug as positive improvement on baseline function. Examination of the details of the CIBIC scores shows, however, that fewer than 8% of patients were rated by trial clinicians as either avoiding non-minimal worsening or achieving more than minimal improvement in global clinical assessments.[115]

In addition, an open-label, long-term cohort has been compared to an historical cohort and purports to show that gains on cognitive tests are maintained over longer periods.[116] Unfortunately, the estimate for the normal rate of cognitive decline is far larger than was reported for the control groups in the donepezil trials – linear extrapolations of the latter would suggest that the effects of donepezil disappear with time, but given the large numbers leaving treatment over the two years, only a good trial can settle the question.

In summary, short-term trial results show that donepezil has limited positive effects on cognitive function in selected patients with mild or moderate AD. The clinical significance of this effect is probably quite small although, given the numbers randomised, it was statistically significant. Both trials excluded patients with many coexisting diseases, which are common in the elderly population with AD. Longer-term effects are less clear and the NHS Research and Development programme is currently setting up a further trial of donepezil in the UK.

Rivastigmine (Exelon)

Quality of evidence: I

In a large-scale, multi-centre, randomised controlled trial,[117] the acetylcholinesterase drug rivastigmine at a dosage of 6–12 mg daily was reported to yield small but significant improvements over both the same drug at a low dosage (1–4 mg daily) and a placebo. Patients were aged 45–95 years (mean age 72 years) and had a diagnosis of mild to moderate dementia (MMSE scores 10–26). Outcome of the 26-week trial was measured using the ADAS-cog subtest, CIBIC ratings and the Progressive and Global Deterioration Scales. About a quarter of the high-dosage treatment group showed an improvement of four or more points on the ADAS-cog scale, compared with one-sixth of the placebo group. Relative improvement in ADL was indicated by the Progressive Deterioration Scale scores, but not further substantiated. As with other drugs of this type, it appears that a small subgroup of patients obtains at least temporary benefit, but the composition of this group cannot be predicted beforehand.

The Standing Medical Advisory Committee recommends at present that treatment with either donepezil or rivastigmine should be initiated and supervised only by a specialist in the management of dementia. Benefit should be assessed at 12 weeks, and treatment then continued only for those patients who show evidence of benefit.

Other pharmacological therapies

Quality of evidence: I-2 C

There are a number of trials in the literature of other drug therapies. A trial of selegiline and α-tocopherol (vitamin E) (both antioxidants) found a significant effect on survival.[118] A trial of ginkgo biloba (a plant extract) showed a small treatment:placebo benefit on the ADAS-cog scale similar in magnitude to the benefit seen with donepezil.[119] A meta-analysis of four trials meeting stated inclusion criteria[120] found a small but significant effect of three- to six-month treatment with 120–240 mg of ginkgo biloba extract, amounting to a 3% difference between treated and placebo groups on the ADAS-cog subtest. A review of 47 trials of the effects of Hydergine (a cerebral vasodilator) concluded that a modest consistent treatment effect was seen, especially in vascular dementia.[121]

The Cochrane Collaboration is shortly to publish reviews of the effectiveness of ginkgo biloba, selegiline, was vitamin E, Hydergine and naftidrofuryl (cerebral vasodilators), lecithin (a choline which may enhance acetylcholine synthesis), metrifonate (an antihelminthic which is a cholinesterase inhibitor), thiamine (vitamin B_1), thioridazine (an antipsychotic), donepezil and other drugs. A review of the treatment of depression in patients with dementia is also planned.

Many other drugs are under development, some of which will appear on the market over the next few years. Until such time as the results of evaluative trials are published, there is little point in speculating about the place of these substances in the treatment of patients with dementia.

Symptomatic treatment of psychotic and behavioural problems

Quality of evidence: I-1 C

For many years, psychotropic drugs have been administered to patients with dementia to control behavioural problems, particularly aggression and wandering. Studies of elderly nursing home patients in a number of countries show that high proportions of them are maintained on prolonged neuroleptic medication, although variations in prescribing bear little relation to the frequency of behavioural disorders. As the use of these drugs has become widespread, it is now logistically difficult to conduct new trials of their effects.

Schneider *et al.*[122] identified seven double-blind placebo-controlled trials of neuroleptics in inpatients with (mostly severe) primary dementia, in a meta-analysis published in 1990. Neuroleptics were significantly more effective overall than placebo, but the effect size was small, 18% of dementia patients deriving benefit from neuroleptics beyond that which would be derived from placebo. They also found that neither dose nor duration of treatment was correlated with effect size. Agitation, unco-operative behaviour and evidence of hallucinations were all reduced to some extent. In a separate analysis comparing different neuroleptics,[122] no evidence was found of greater improvement with any single drug.

A review by the same group of the effects of non-neuroleptic drug treatment on agitation in dementia[123] looked at a variety of drugs, including lithium, β-blockers, carbamazepine and antidepressants, and concluded that the available studies were few and small and that there was little evidence of effectiveness.

A Swedish health technology assessment report[124] concluded that the scientific literature does not support the use of neuroleptic therapy in elderly people, except for those with psychotic symptoms. Current evidence suggests a restrictive approach towards neuroleptics in elderly patients, mainly because they are more susceptible to side-effects from neuroleptics, but also because the effects of neuroleptics are enhanced by interactions with other drugs, and because drugs remain active longer in elderly people. Moreover, there is some evidence that continued use of neuroleptics may accelerate the pace of cognitive decline.[125] Guidelines to good practice in the prescribing of neuroleptics for home residents have been published by Age Concern.[126]

Psychosocial and behavioural therapies for dementia

Quality of evidence: I-2/II-2 C-D

There are a number of interrelated psychosocial therapies and strategies which aim to improve symptoms or enhance comfort and quality of life in patients with dementia. Strategies which have been used to try to manage the behavioural disturbances associated with the condition include:

- memory training
- psychotherapy and counselling
- reality orientation
- behaviour modification
- reminiscence therapy
- validation therapy
- activity groups
- remotivation and resocialisation therapies
- psychomotor therapy
- snoezelen
- modification of environment and living arrangements in long-stay facilities.

Published studies of most such approaches have shortcomings, including lack of clarity in defining therapies, the inclusion of small numbers of patients, the use of a variety of instruments to evaluate effectiveness and relatively brief follow-up periods.[127] Much of the available research does not focus on patients with dementia specifically, but rather studies broad groups of elderly mentally ill patients, and most of the work has been undertaken in long-stay institutions.

Dröes reviewed a number of these strategies in *Care Giving in Dementia*, published in 1997.[128] Although she does not make explicit her search or critique methods, 163 references are quoted. Dröes concluded that although in the past 20 years there has been an increase in the interest accorded to the experiences of the demented elderly, there have been few experimentally designed studies of effect of therapies, and little focus on specific diagnostic groups. The evidence from this review, and the evaluative studies cited in it, can be summarised as follows.

Memory training

The scope for techniques of memory training, or memory management, is still unclear. Psychologists in clinical practice employ mnemonic and other coping strategies to improve individual patients' ability to recall simple, important information, such as names of friends and neighbours,[129] but there have been few evaluative studies. Experimental research suggests that ability to benefit from memory training diminishes with increasing clinical severity.[130] As yet, however, the gains at any stage appear to be small and may not generalise to daily living. Brodaty and Gresham,[131] in a controlled trial based on already established cases of dementia, found that a combination of memory training for patients and instructions for family caregivers showed clear benefits when compared with memory training alone, and that the advantages were maintained over a follow-up period of 30 months. Zarit found that cognitively impaired patients who participated in memory training had improved cognitive functioning (recall), although they also had deterioration on a depression scale.[128]

Psychotherapy and counselling

Although formal psychotherapy is not indicated for dementia, psychotherapeutic skills can be of value in coping with problems of management. First, they can help in dealing with the early stages of a dementing process, when the patient's perception of his or her growing mental impairment may lead to distress and affective disturbance. Second, they may be called upon in informing the patient's partner and other family members, in helping them to come to terms with the situation and in gauging their likely responses and needs in confronting what lies ahead.

Reality orientation

Reality orientation is designed to make the demented person's physical and social orientation easier to comprehend and to cope with, by supplying three basic needs:

- constant explanation, encouragement and verbal re-enforcement by caregivers
- a simple, regular daily routine, making it as easy as possible for the patient to know what to expect
- simple auditory and visual cues to help his or her orientation for place and time: this extends, for example, to having clocks and calendars clearly visible, doors clearly labelled and, for patients still living at home, important telephone numbers and other reminders displayed.

These techniques have been used extensively, and the general findings are that they do improve cognitive functioning.[128] However, the extent of the effect and the groups for whom it is most beneficial have not been adequately defined.

Behaviour modification

Behaviour modification is based on rewards for appropriate behaviour, and a randomised trial of 72 patient/caregiver pairs in which the patient suffered from dementia and depression found an improvement in mood in both patients and caregivers among the treated group.[132] The approach has also been used to help reduce incontinence.[128]

Reminiscence therapy

Reminiscence therapy aims to improve intrapersonal and interpersonal functioning by means of reliving, structuring, integrating and exchanging memories. Basically, patients are encouraged with the help of photographs and other aides-mémoires to reminisce about their earlier lives and experiences. In practice, this approach can be helpful for patients who have not adjusted to group living in a home, by enhancing their perception of their own value and interest for others. A review published in 1987 cast doubt on its usefulness more generally, but it is not clear how studies were selected for inclusion in the review.[133] Baines *et al.* have shown that reminiscence therapy may be more useful if preceded in the confused or cognitively impaired by reality orientation.[134] Subsequently, a small study found that reminiscence therapy was helpful in improving communication between patients with dementia and staff, but it was only effective in an environment that had lacked psychological aspects to care.[135]

Validation therapy

Validation therapy is aimed at helping patients who have withdrawn into the past, by exploring their experiences in a group situation, and helping them to feel understood and accepted. Toseland, in a small RCT ($n = 66$), compared validation therapy with social contact or usual care.[136] The study found that validation therapy reduced physically and verbally aggressive behaviour, but had no effect on other behavioural disturbance or on the use of medication or physical restraints.

Activity groups

Activity groups focus on art and music therapies, and other activities designed to stimulate the senses. A systematic review of 30 studies of music therapy in AD concluded that this therapy could increase participation in group members over time, improve mood, and reduce behavioural problems, particularly agitation.[137] There was no evidence, however, that it had an effect on cognitive function.

Remotivation and resocialisation therapies

Remotivation and resocialisation therapies are aimed at getting patients who have withdrawn into themselves to become interested in their environment and surroundings again. One study showed that patients with dementia had more interest in group activities after a period of remotivation therapy and their verbal communication increased.[128]

Psychomotor therapy

Psychomotor therapy makes use of body movements and actions to sharpen awareness. For people with dementia, whose ability to participate becomes severely restricted, simple actions such as throwing and catching a soft ball or moving around a ring may be suitable. Some success with cognitively impaired people has been reported.[128]

Snoezelen

Snoezelen was created in the 1970s, as an approach combining relaxation and sensory stimulation for mentally disabled people.[138] It is an individually oriented approach that employs active sensory stimulation, using light and sound, and materials for touching, smelling and tasting, to share the experience of the demented person, in an attempt to increase their well-being. It is mainly used for severely demented patients. In *Care Giving in Dementia*, Achterberg *et al.* describe its use in dementia, including an observation period, a snoezelen plan and use in daily care.[138] In this chapter, Achterberg *et al.* report a number of benefits for patient and caregiver, including improving the relationship between patient and caregiver, improving communication, increasing empathy and reducing feelings of powerlessness for the carer. However, they conclude that very few research studies have been undertaken looking at the effectiveness of snoezelen in dementia. A search found an abstract of a Dutch paper[139] reporting a randomised cross-over trial looking at the effect of snoezelen in 16 severely demented people in a nursing home. During the experimental observation, a relatively low level of behavioural problems was observed. The authors conclude that more research is needed.

Environmental strategies

Such strategies aim to make the environment in long-stay settings more homely, to minimise disruption and enable patients to keep functioning as independently as possible for as long as possible. They can include normal tea, coffee and meal provision, adjusting the furnishings or furniture arrangement, or allowing pets. In general, studies of these techniques in the institutionalised elderly have shown improvements in activity, happiness and sense of control. However, cognitive changes or ADL functioning have not improved.[128]

In summary, a number of the above-outlined approaches are relevant to psychogeriatric care. Some have been assessed specifically for patients with dementia, although most studies have been based on small numbers ($n < 30$) and few have been rigorous or controlled. One difficulty is that good trials of such measures are harder to conduct, and less popular candidates for funding than trials of pharmacological agents. The conclusions from the existing evidence are that some of these techniques may prove of value insofar as they can be incorporated into long-term care programmes, as part of a more general endeavour to improve quality of care and also the morale of nurses and other caregivers. So far there is no information on their cost-effectiveness. Whether any of them should be recognised as a distinct form of therapy is also an open question.

The Cochrane Collaboration is planning to publish reviews of some of these techniques, which may aid future decision making. As one editorial put it, 'neuropathology may set limits on performance, but psychological approaches could assist the person with dementia in functioning closer to these limits'.[127]

Supportive services in the community

Organisation and delivery of community care

Community care is here taken to mean treatment and management of dementia in people residing at home, and the support from health and social services that they and their families receive. Certain of its components (respite care, day care, support for informal carers) are dealt with separately because of the large body of published research.

The following questions are considered.

- How effective is the care of such patients by community teams?
- What is the evidence regarding 'case management' in dementia?
- What is the role of day hospitals and outpatient clinics?

Community mental health teams for the elderly

Several studies have looked at the case load and activities of multi-disciplinary teams, and the characteristics of patients cared for by them. Approximately half of a sample of new referrals to four community teams in Cambridgeshire were cases of dementia.[140] At six-month follow-up, such patients were more likely than those with functional mental illness to have social workers as their key workers. Brown *et al.*,[141] comparing a one-in-three sample of open cases on the case loads of two community teams with a cross-section of newly referred patients, found that the former group had relatively more diagnoses of affective disorder and fewer of dementia. The dementia patients also had shorter episodes of care by the teams than did those with affective disorders. The authors concluded that this could be due to the kinds of problem for which dementing patients were referred (e.g. behavioural difficulties) being amenable to swift resolution, and because such patients are more often disposed of to other services.

Can non-medical members of multi-disciplinary old-age teams diagnose and manage patients effectively? A multi-disciplinary approach need not be associated with greater risks of misdiagnosis.[142] Assessment and management plans formulated by multi-disciplinary teams for patients with a variety of conditions, including dementia, have been found to agree well with those assigned by research psychiatrists, though there was less agreement between the groups as to which patients should receive psychological treatment.[143] It should be noted, however, that the studies in question were focused on process measures rather than outcomes.

Case management

Case management can be defined most simply as a strategy for organising and co-ordinating care services for the individual patient or client, and the term has been applied both to health and social care. It can be put into effect most successfully where the different agencies are co-operating, not competing, and where service structures and cost-bearing modalities are flexible enough to permit effective continuity of care over the course of the illness. A series of geographically extensive UK studies of case management in the social care of the elderly has been reported,[144–146] in each of which a case manager was responsible for assessing and arranging services to meet the needs of individual patients within a budget. Service delivery appeared to be more flexible and responsive to patients' needs than the traditional social work approach. An application of this model to patients with clinical dementia living at home was undertaken as an RCT in the London Borough of Lewisham.[147] Case loads were kept low to allow individual packages of care to be developed. Outcome after two years was better for the experimental group, as gauged by proportions in institutional care, levels of carer stress and burden, and measures of patients' self-care and degree of stimulation. Estimated costs of care management were higher in the experimental than in the control group.

Hospital day-patient and outpatient services

Day hospitals for the elderly are intended to provide treatment, promote rehabilitation and help to avoid relapse, but hard evidence regarding their effectiveness is still scarce.[148,149] They have been criticised for encouraging chronicity and dependence, and being costly and inflexible in operation.[150] A report on these facilities by the Audit Commission noted that review and monitoring of patients' progress were often patchy.[151]

While outpatient assessment and management programmes have been found effective in geriatric medicine,[152,153] there are no corresponding studies for demented patients specifically. Hence the role of outpatient clinics in the management of dementia is still unclear. The rapid increase in demand for acetylcholinesterase inhibitors and other 'anti-dementia' drugs must, however, bring an increasing pressure on those services in the years ahead, so that the need for evaluative studies can be predicted to grow.

Routine inpatient admission for diagnostic assessment is wasteful and may distress elderly patients, yet special investigations calling for hospital resources are often required. Under these circumstances there are strong arguments for a flexible system of assessment based partly on domiciliary visits and partly on diagnostic evaluation in specialist departments, whether on a one-day or brief (24–48-hour) admission basis.

In summary, it appears that multi-disciplinary teams can work well, and that non-medical staff in them can contribute to diagnosis and appropriate management. Within the team, patients with dementia may be under the direct care of a social worker or CPN, but through this 'key worker' they should have access to the skills and services of other team members as the need arises. Social case management (with budget holding) has been shown to be effective for many elderly people in the community, and may be applicable in dementia.

Respite care

Respite care aims to provide informal caregivers with periodic or occasional breaks from the caring tasks, to reduce the physical and psychological burdens of care, and to provide an opportunity for other tasks and activities to be carried out (e.g. shopping, family and social contacts, holidays). The term is used here to include all spells of care in a clinical or residential facility for a (usually prearranged) period, ranging from a few days to two or three weeks.

The following questions are considered.

- Is there evidence that respite has a beneficial, or at least non-detrimental, effect on the patient?
- Does it in practice reduce carer burden?
- Are informal caregivers satisfied with respite care?
- Does it appear to reduce or delay admission to long-term care?

Flint,[154] who conducted a systematic review of the effects of respite care on patients with dementia and their carers, found four studies that met his inclusion criteria.[155–158] Our own more recent search identified four additional studies of varying size and rigour. All eight are summarised in Table 13 (*see* overleaf). They are comprised of two large RCTs,[158,159] together with several smaller RCTs and other studies.

The studies varied in methodology, and compared different forms of respite for different time periods, but their findings are fairly consistent. Of those listed in the table, Burdz *et al.*[155] reported that patients in a respite-care group manifested no change in cognitive performance, but improved in behaviour. Adler *et al.*,[161] in an observational study, found no deterioration in behaviour after two weeks' respite care, and although there was a slight deterioration in ADL capacity in the Alzheimer patients, they ascribed this to normal disease progression over the six-week study period. No difference in mean duration of patient survival has been observed between respite care and control groups.[158] Another study, not included in the table,[163] suggested that there may be hazards associated with respite care, and there is some anecdotal evidence that the upheaval of respite can lead to a worsening in the patient's condition.

All the studies in Table 13 assessed carer burden and stress, and in general found little or no difference resulting from respite care. One trial[159] did show a decrease in carer burden in the support groups, but the interventions in question included measures other than respite care. On the whole, carers seem to appreciate this facility. A survey by the National Institute of Social Work of 267 carers[8] concluded that respite care is valued by carers, and once commenced, rarely given up. Often, however, there is an initial reluctance to make use of it, partly because of guilt about sharing care tasks, and partly from uncertainty about the effects it will have on the patients, and partly because of practical difficulties in preparing them for the move.

Four of the studies looked at effects on institutional admission. Lawton *et al.*[158] estimated that respite-care group members remained in the community for a mean of 22 days longer than did controls during one year – a significant difference. Montgomery and Borgatta[159] found no overall difference in nursing home admissions with or without respite care. In their study, nursing home placement was delayed for patients cared for by younger adults, whereas when the carer was a spouse, placement actually occurred earlier in the respite care group. They concluded that respite care may make spouse caregivers more aware of their own need for help, as well as of the ability of others to care for their dependants, in some cases leading to longer-term admission. In contrast, younger adult carers can derive benefit from the rest afforded by respite and be enabled to carry on longer. The two smaller studies[156,157] found no difference in admission rates between experimental and control groups.

In summary, 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 benefit to patients, relief of carer burden, or delay in institutional admission. Brodaty and Gresham,[164] reviewing the evidence, concluded that attempts at formal evaluation had been hampered on the one hand by a lack of clear guidelines for respite care, and on the other by methodological weaknesses. They argued for matched control studies to be applied to well-defined respite care programmes with clear objectives.

Table 13: Studies of effectiveness of respite care.

First author	Publication year	Type of study (number of participants)	Intervention studied	Outcomes studied	Effect of respite
Burdz[155]	1988	Controlled trial ($n = 74$)	Institutional respite: mean 15.3 days	Patient behaviour; carer burden and perception of respite	Patient's behaviour improved; no difference in carer burden; attitude to patient worse post-respite
Conlin[156]	1992	Controlled trial ($n = 15$)	Respite over 10 weeks; day care or in home	Carer stress and mood; institutional admissions	No difference in carer stress or mood, or in admission rates
Mohide[157]	1990	RCT ($n = 60$)	In-home respite and support	Patient time in community; carer burden and depression	No difference in any outcome measure
Lawton[158]	1989	Randomised by support group ($n = 632$)	Respite care: institutional or day care	Patient survival (days) and time in community; carer burden and satisfaction	No difference in survival; respite group remained longer in community; carer satisfaction higher
Kosloski[160]	1993	Controlled trial ($n = 116$)	Day care or in-home respite, or both	Carer burden and morale	Carers' morale improved; decreased subjective burden, but no increase in time for themselves
Montgomery[159]	1989	RCT ($n = 541$)	Five groups with different combinations of respite and support, plus control group	Carer burden; nursing home placement	Decreased carer burden; delayed nursing home placement with adult carers, but earlier nursing home placement with spouse carers
Adler[161]	1993	Observational ($n = 37$)	Inpatient respite on geriatric medical ward	Patient behaviour; carer burden and depression	Patient's behaviour no different; carer burden decreased during respite, but no different two weeks post-respite
Larkin[162]	1993	Non-controlled observational ($n = 23$)	Inpatient respite	Patient's ADL; carer stress and satisfaction	ADL decreased (not quantified), high proportion admitted for long-term care; carer stress showed no change pre/post-respite, but 95% satisfied

Day care and other relief care

Similar questions have been posed in trying to evaluate other forms of relief care. Day care (as distinct from day-hospital treatment in a clinical setting) is normally provided in local centres, on a basis of up to five days weekly, and can be flexible within the constraints of available transport. Other relief facilities include night-sitting or day-sitting services, in which somebody – usually from a voluntary or charitable organisation – attends to sit with the patient for a few hours so that the carer can have a break.

Most control studies of day care have detected only limited effects. A number of them[165–168] have found no or only small benefit to patients. However, in one small inquiry,[169] day-centre staff noted improvement in over 50% of patients receiving day care. Wells *et al.*[166] reported a small reduction in carer stress after three months of day care, but a significantly greater improvement in this respect among others whose dependants had been admitted to long-term care.

Two Scandinavian studies have looked at the effects on institutional admission. Wimo *et al.*[165] found that at one year, 24% of a day-care sample had been admitted, compared with 44% of a control group. In a randomised trial by Engedal[168] there was no overall difference in frequency of long-term admission after 12 months, but the control group had more admissions to acute hospitals during the year (1171 days for the 38 day-care patients compared with 2078 days for the 39 control-group patients). In view of this difference, day care was considered to be cost-effective. Wimo *et al.*[169] estimated that the cost of day care each 'well year' (i.e. year spent in the community) was the equivalent of £4293, while the corresponding cost of care by relatives was £3922. This again suggests that day care is cost-effective, though one cannot assume that proportionate costs would be the same in the UK.

No trials of sitting services in dementia have been identified. A general survey of informal carers by the National Institute of Social Work[8] found that only one-third had received any sitting service, and that nearly all the sitters came from voluntary organisations. Those carers who had received sitting services valued them, but raised issues regarding the amount and timing of sitting, and the relationship with the sitter (in particular, whether there was any choice of person). For dementia patients especially, there appeared to be a lack of available provision.

Carer groups and counselling

Approaches to supporting informal carers, other than respite care, include support groups, information and education programmes, and individual counselling. Support groups are defined as any setting in which a number of carers come together to meet in a planned way, usually for one to two hours 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 should learn together and gain mutually by sharing their experiences. In educational sessions, information is shared by means of talks and discussions, as well as by provision of written material. Information and education of carers are aimed at enhancing their knowledge about the illness and their ability to cope with associated behaviour disorders and other symptoms.

Questions to be considered are as follows.

- What is the effect of support groups on carers?
- Do they affect the probability of institutional admission?
- Are peer-led or professionally led groups more effective?
- Do information and teaching enhance carers' understanding of the problems and, if so, what effect does this have on their ability to cope?
- How do support groups compare with individual counselling?
- Are any of these interventions best suited to particular groups of carers?

Toseland and Rossiter,[170] reviewing publications up to 1987, found nearly 30 studies that met their inclusion criteria. Knight *et al.*[171] conducted a meta-analysis of studies from 1980 to 1990 dealing with psychosocial interventions and respite care. In addition, our own search identified a number of more recent papers on this subject. Table 14, however, is restricted to reports of systematic controlled trials. Of these, two were relatively large RCTs, two were small RCTs, and one had alternate group allocation.

The two larger RCTs found that carer depression was reduced in the treated groups, whereas the smaller studies looking at subjective burden felt by carers found no difference. Carers in the small studies by Hebert *et al.*[177,178] and Sutcliffe and Larner[179] improved in knowledge about dementia. As regards institutional admission, the two larger studies both found a delay in the treated groups (by nearly 11 months in one[174] and by 20 months in the other[176]). None of these studies looked specifically at whether the groups enhanced carers' support networks.

The question of who is best placed to lead the groups has been studied in the field of carer support generally, though not specifically with respect to dementia patients' carers. Toseland *et al.*[181] found no difference between peer- or professionally led groups in terms of effects on carer burden, psychological symptoms or social support. Different types of group appeared equally effective in improving social support and coping, although there was no significant change in degree of burden or psychological symptoms.

Because most support groups provide information, it is hard to identify any specific effects of this component. In one study comparing an information-giving and an emotional support group,[179] participants in both showed gains in knowledge, but only those in the latter experienced a reduction in stress.

With respect to carer support, a comparison of group and individual support for carers of elderly people more generally found that improvement in psychological symptoms, coping and satisfaction were the same with both, but that social support networks were enhanced more by the group approach.[182] In this study, individual counselling by professionals was associated with improvement in subjective well-being and reduction in psychological symptoms, whereas mutual support by peers produced a reduction in symptoms only. Knight *et al.*[171] concluded from their meta-analysis that individual counselling was more effective than group interventions in reducing subjective burden and emotional dysphoria. Here again the effect sizes varied widely between individual studies, so that any conclusions drawn by combining them must be guarded.

Some authors have concluded that support group or individual interventions may be differentially beneficial for carers with different needs. Toseland and Rossiter[170] concluded that an individual approach may be better for carers with psychological symptoms or particular problems in their caring role, whereas group participation provides more social support. Studies to further identify which interventions work best with which kinds of caregiver could help to elucidate the value of carer support groups more precisely.[171]

To summarise, many studies have examined the effects of group or individual interventions to support carers. While early studies were largely descriptive and non-experimental, in the late 1980s and early 1990s there have been a number of controlled trials. Because of variation in the types of care offered, the outcomes measured and the instruments used, it is difficult to draw firm conclusions. However, in overview:

- two methodologically sound, randomised trials have shown that support groups can reduce or delay institutional admission of patients with dementia (by a mean of 11 months or more)
- in general, carers express satisfaction with support groups
- carers' depression and psychological symptoms are reduced, although there is little evidence that subjective burden of care is diminished
- it is unclear whether, or to what extent, participation in support groups is helpful in building up carers' social networks in the longer term
- individual counselling has been shown to improve well-being and reduce psychological symptoms among informal carers generally, though not specifically for carers of demented patients.

Table 14: Controlled trials of carer support and educational programmes.

First author	Publication year	Type of study (number in trial)	Intervention studied	Outcomes studied	Effects of support
Mittelman[172]	1993	RCT ($n = 206$)	Individual and family counselling, then support group attendance; control	Nursing home placement	Placements reduced (OR = 0.4)
Mittelman[173]	1995	..	..	Carer depression	Depression reduced
Mittelman[174]	1996	..	..	Nursing home placement at follow-up	Mean delay of 47 weeks in placement
Brodaty[131]	1989	RCT ($n = 96$)	Carer training programme; waiting list for respite (control)	Nursing home placement; carer depression	Mean delay of 5 months in placement; reduced carer depression
Brodaty[175]	1993	..	..	Nursing home placement; patient mortality	Reduced nursing home admissions; non-significantly reduced mortality
Brodaty[176]	1997	..	..	Nursing home admissions and survival at eight-year follow-up	Mean delay of 20 months in admission; non-significant increase in survival
Hebert[177]	1994	RCT ($n = 45$)	Support group; control	Carer burden, mood and knowledge	Non-significant change in burden or psychological symptoms; improved knowledge
Hebert[178]	1995	..	..	Admissions over two years	No significant difference in rates of admission
Sutcliffe[179]	1988	RCT ($n = 15$)	'Emotional' and 'information' support groups, plus control group	Carer depression, burden, knowledge and contact with services	'Emotional' support reduced depression and increased knowledge; information improved knowledge, but stress unchanged
Dellasega[180]	1990	Alternate group allocation ($n = 75$)	Stress management programme vs. 'normal' support group	Carer burden and coping	Stress management programme improved coping but no change in burden

Long-term care settings

This subsection is concerned with long-stay facilities caring for patients with dementia who can no longer be maintained in the community. In the UK, the well-established forms of institutional care consist of nursing and residential homes, together with NHS continuing care units and the remaining long-stay hospital wards (psychogeriatric and geriatric). Cognitive impairment is among the dominant medical conditions in these long-term care settings. A UK study[69] indicated that 67% of people admitted to residential and nursing homes have cognitive impairment. Prominent among the factors determining admission to long-term care are a number directly associated with dementia, namely behavioural disturbance, incontinence, wandering and aggression, lack of an informal carer, and carers' reluctance or inability to continue. The care of patients with dementia in long-term settings is therefore a major issue for providers and commissioners of care.

Various new forms of care are developing, including:

- special care units – generally nursing homes or parts of homes specialising in dementia only
- adult foster care – perhaps broadly equivalent to small residential homes
- 'assisted-living' arrangements – with congregate housing and care facilities, including what in the UK are called residential homes, and also, for example, individual living units with control over personal space, furnishings and appointments, and specific support services brought in where needed
- group living facilities.

Two main questions are considered here.

1 What is the evidence on quality of care in long-term settings?
2 What is the relative effectiveness of care in different types of setting?

Quality of care in long-term care settings

A number of aspects of quality of long-term care, whether on hospital wards[183] or in geriatric nursing and residential homes,[184] have aroused concern. Prominent among these is the use and misuse of psychoactive medication.[185] A UK study of residential care[186] found that 19% of residents were on major tranquillisers, and that variation between homes in the use of both major tranquillisers (5–28%) and hypnotics (0–18%) could not be explained by differences in residents' health status. Nearly a quarter of old people with dementia were being prescribed major tranquillisers. The authors commented that prescribing sedative drugs for people with dementia appears to be used as a substitute for more labour-intensive psychosocial approaches.

Similar problems have been uncovered in surveys of long-term care in the USA and elsewhere,[187] and a number of innovative approaches have been used to try to overcome them. A randomised trial of withdrawal of neuroleptic medication[188] in demented nursing-home patients revealed no significant difference in behaviour problems between the comparison groups. Subsequently, over half the patients in the 'withdrawal' group stayed off their medication for an extended period. This trial, however, examined effects of withdrawal from relatively low-dosage neuroleptics, so the findings cannot be generalised to all settings. In a controlled trial of an education programme for nursing home staff,[189] antipsychotic medication was reduced in the experimental homes over a period of four months, with no corresponding increase in problem behaviours. A Swedish study[190] demonstrated that multi-disciplinary team meetings and enhanced teamwork could result in reduced prescribing of psychotropics. Furthermore, physical restraints on patients in long-term care can be discarded without any increase in psychotropic medication.[191]

In summary, there is widespread reporting of inappropriate and excessive reliance on tranquillising drugs in long-term care settings, despite all the evidence that these substances are of modest therapeutic benefit in dementia and have serious adverse effects. Overprescribing and inappropriate use of drugs provide important indications of an unsatisfactory quality of care. A systematic reduction in their use would be beneficial to elderly patients and residents, including many with dementia, and is most likely to be achieved where there are adequate trained staffing ratios and adequate opportunities for staff training and teamwork.

Effectiveness of different settings of care

In the 1980s, dissatisfaction with conditions on long-stay hospital wards led to the setting up and testing of new types of care unit within the NHS. Bond *et al.*[192] conducted an evaluation of a new nursing home scheme, randomly allocating 464 patients either to the experimental units or to long-stay hospital wards, and examining survival, well-being and other outcome measures after one year. They found no significant difference between the two types of setting on any of the measures apart from stated preferences, which favoured nursing home care. An observational study showed, however, that patients in the nursing homes had more activity and contacts, and were more stimulated by that environment. Bowling *et al.*,[193] in an RCT comparing a long-stay geriatric ward with two NHS nursing homes, randomly allocated 122 patients and studied functional and mental ability, depression, satisfaction and death after one year. They found a greater decline in functional and mental ability among the nursing home patients, but in a related observational study[194] concluded that these showed greater flexibility of response and had a better quality of life. A third project set out to evaluate the 'Domus' style of residential care, which is based on four postulates:

1 that the Domus is the residents' home for life
2 that staff needs are as important as residents' needs
3 that the Domus should aim to correct avoidable consequences of dementia and accommodate those that are unavoidable
4 that residents' psychological and emotional needs may take precedence over their physical care.

The study compared care on a Domus unit with traditional psychogeriatric ward care, and found significantly higher levels of residents' activity and staff–resident interactions with the former.[195] However, costs were substantial – over £900 per week at 1992–93 prices.[196]

As a result of central Government policy effectively placing most long-term care for the elderly outside the NHS[197] and the ongoing closure of most long-stay hospital wards, these evaluative studies have lost much of their immediate relevance. In theory, their findings are to some extent applicable to the contemporary nursing and residential home scene, but here interest in scientific evaluation is so far very limited, and tends to be focused narrowly on cost–benefit issues. Hence progress in this field of health service research has become increasingly dependent on projects in North America and elsewhere.

Considerable attention in the USA has been focused on the so-called special care units (SCUs) for dementia.[198–200] A review of evaluative research undertaken by the Office of Technology Assessment (OTA)[201] found little evidence in their favour, but concluded that more research was needed. Since then, a cohort study of 77 000 elderly residents in the USA, including some 1200 in 48 SCUs, has shown no significant difference over one year between SCU residents and those in other types of facility, in terms of decline in locomotion, toileting, eating, dressing, urinary and bowel continence, ADL or body weight.[202] One difficulty is defining what is 'special' about SCUs. Maslow,[203] in reporting the OTA review, emphasised the underlying philosophy and principles, which constituted the core of what this is or should be. But as in the case of Domus units and other types of residential setting, in practice it is likely to be the day-to-day quality of care provision that influences measurable outcomes.

Issues of alternative care provision

For the reasons given above, evaluative research focused on comparisons between NHS hospital ward and nursing home environments has been overtaken by central policy changes and in consequence has declined in importance. By the same token, other issues have gained in topicality, in particular:

- the relative contribution that should be made by NHS continuing care units (a subject of heated debate within old-age psychiatry)
- the extent to which local authorities should continue to be involved in direct management of homes
- the scope for reduction (or at least containment) of demand for residential care, by dint of improved community support.

Systematic evaluation – including cost-effectiveness studies – is necessary to resolve these issues, but care providers must be induced to co-operate, and problems of patient allocation to the different facilities tackled to ensure that the comparisons are meaningful. The research findings outlined above indicate that geriatric home placement can be significantly delayed by improving community support. Research in the USA suggests that monetary saving from reduction in nursing home placements is unlikely to balance the additional costs of high-quality community care, but that such a shift could improve the quality of life of many affected old people, and the morale of their families.[204]

Overview of effectiveness and economic evaluation

There are a small number of reviews that have aimed to collate research results or report professional consensus on the operation of the whole care system for dementia or major sectors of it. Johnston and Reifler,[205] for example, come to essentially the same conclusions as are set out above, although they highlight studies of greater concern for American policy makers. These include the ability of day centres to pay for themselves in demonstration projects, and the development of social health maintenance organisations, providing integrated care to older people at risk in the community.

In the UK, the North of England Evidence-Based Guidelines Group has published a guideline for the primary care management of dementia.[206] This considered all aspects of primary care management, ranging from the prevalence and identification of people with dementia, to non-drug and drug therapies, and support for carers. The guideline is broadly in agreement with the conclusions presented in this review but there are areas in which their conclusions differ from our own.

Areas of disagreement relate mainly to the value of respite and day care, and of carer education groups. The guideline concludes that respite care may delay institutionalisation of patients. Our search did not support this conclusion, as three of the four studies we found examining institutionalisation reported no significant differences. The group's conclusion that respite care has not yet been demonstrated to improve carers' well-being is in agreement with our own. For day care, the only RCT we found likewise showed no significant difference in institutionalisation of patients. On the other hand, we concluded that groups providing support, training and information to carers, taken together (as many groups offer elements of all three), are of proven benefit in this respect. The two large, well-conducted studies we identified both gave evidence of reduced depression in carers and significant delays in institutionalisation of patients whose carers attended.

In terms of health economics of dementia, Wimo *et al.*[207] have provided a detailed multi-author review. Unfortunately, patterns of care and costs vary greatly between countries and the editors argue that economic studies from one country cannot be generalised: 'economic evaluation of dementia care is country specific'. They also argue that the subject is still in its infancy. Methodological difficulties, the use of different approaches to costing and the critical impact of assumptions in some economic models limit the usefulness of the current literature for the UK. Critical appraisal skills will be needed by policy makers in this area, as commercially funded studies accompany the licensing of the many new drugs under development.

In the next section, we attempt to integrate the studies we have reviewed above into a set of recommendations for an evidence-based system of care for dementia.

7 Models of care – towards rationally based services for dementia

In this section, we draw together the conclusions outlined above to delineate an integrated model of care for AD and other dementias.* For this purpose, the main components of such a model are discussed in a rough order of progression from specialised to generalist care, and from hospital and residential to community-based agencies. It must be stressed that this is simply a convenient schema, and no more represents a hierarchy of importance than do the hub, spokes and rim of a bicycle wheel.

Specialist mental health services must deal with the most difficult problems of diagnosis and treatment, but also have consultative functions. Because dementia so often occurs with major physical comorbidity, acute hospital departments are deeply involved in the medical care of patients with dementia. Given the large numbers of affected people in the elderly population, the primary health care team must be seen as a focal point, both for early detection and for case management. Because health and social needs are intertwined, joint provision with social service departments, perhaps even in a 'one-stop shop', may be a desirable goal, but needs to be more firmly tested. Patients' families carry most of the burden of care in the community and must be given help and support if this balance is to be maintained. Severe, late-stage dementia is a terminal condition, and new care modalities emphasising the comfort and quality of life at this stage need to be developed. At successive stages of dementia, different priorities will apply. As new pharmacological or other treatments become available, new service responses will be called for to test them in practice and to deliver those that are effective to the patients most likely to benefit.

Role and functions of specialist health services

Central to all the issues of specialist care is the requirement for integrated old-age psychiatry services with inpatient, day-care, outpatient and consultative functions, based on defined elderly populations and accepting responsibility for the mental health problems that arise within them. Attempts to define the general form of psychiatric services for older people across widely differing populations have been made at international level by the World Health Organization (WHO)[208]and at UK national level by the DoH[76] and the Royal Colleges of Psychiatrists and Physicians.[80] These suggest that services should be characterised by the following features:

- a strong primary and community care focus
- acceptance of referrals from a range of professionals
- a multi-disciplinary approach to assessing needs
- integral membership of a consultant in old-age psychiatry
- multi-agency liaison as an integral part of its working practices
- initial assessment in patients' own homes, followed by further assessment and case management in hospital or in the community as required

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* Since this chapter was prepared the National Service Framework (NSF) for Older People has been published. Standard seven in the NSF refers to mental health in older people.

- a systematic care-programme approach, with assignment of key workers to individual cases
- a close working liaison with specialist medical services for older people
- support for family carers, which is effective without subjecting them to attention from a variety of different agencies
- provision of continuing health care, based on accepted eligibility criteria.

In addition, local services should provide carer support, respite care and crisis intervention, as well as consultative services to long-term care homes.

The UK NHS model of old-age psychiatry has, on the whole, proved a success. It is being emulated in other countries, and should remain the central focus of specialist care for dementia. In many parts of the UK, however, stronger links to primary health care teams will be required as the role of the latter gains in importance. Moreover, old-age psychiatry has been increasingly restricted in scope by the withdrawal of NHS responsibility for long-term care, and its functions in this major area of care now need to be urgently revitalised. Philpot and Banerjee,[147] in their review of priorities for London, recommended development of multi-disciplinary teams along the lines of the Guy's model,[142] wider application of case management principles, and deployment of trained carers, appointed within the NHS, to assist in day-to-day care of mentally ill elderly people at home.

There is no firm consensus with regard to the logistics of specialist care. Even if the 'minimum' target of one consultant team for 10 000 people aged over 65, recommended by the Royal College of Psychiatrists (*see* Table 11), could be achieved, it would hardly be feasible to provide a full range of inpatient, continuing care, ambulatory and consultative services for each such population unit, quite apart from the fact that this would bear little if any relationship to local authority or other administrative boundaries. A more realistic basis for planning and provision may therefore be an area population served by two or three consultant teams working in co-ordination and with sharing of resources.

Care for dementia on acute hospital wards

The high rates of both clinical dementia and 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 patient understanding care. Departments of geriatric medicine (clinical gerontology, health care of the elderly) can play a crucial part in raising clinical standards, including better recognition of delirium and confusional states.

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 co-ordinated for defined area populations, and greater emphasis must be placed on provision of long-term care within the area boundaries.

In the terminal stages of dementia, the patient's family may understandably not wish 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. The location, staffing and funding of such units is a policy issue of growing importance.

Improving the quality of long-term residential care

A large majority of old people in nursing and residential homes today suffer from dementia, and the quality of care they receive can be improved substantially, often without extra cost. The Social Services

Inspectorate[73] has a list of features to be considered when inspecting for quality, and others can be added on the basis of existing knowledge.

- Psychoactive drugs should be prescribed only on clear clinical indications, for limited periods subject to regular review, and given by staff trained to detect adverse effects.
- All homes classed as suitable for dementia care should maintain a basic documentation and nursing record system, including information on previous medical history.
- Daily programmes of simple communal activities should be introduced and residents encouraged to help with any tasks of which they are still capable.
- Caregiving staff should be instructed in recognising depression, and encouraged in training and practice, under supervision, of simple psychosocial and behavioural techniques (*see* pp. 270–3).
- Visual cues should be used to assist residents' orientation for place and time (e.g. wall clocks, calendars, labelling and colours of doors).

Over and above such improvements within individual homes, national policies should be formulated to meet the growing challenge of dementia care in the decades ahead. The general principles of good care practice itemised by Murphy[209] should be adapted to the special problems of dementia.

- The design and location of new, purpose-built homes should meet specified criteria of suitability for dementia care, e.g. single-storey, open-plan layout with promenade, easy access to garden – as well as stringent safety regulations.
- Segregation of old people in long-term care needs to be broken down (a) by planning for such care to be located within or close to the local communities from which they are drawn, and (b) by establishing bridges between homes and communities (including respite and day care).
- The present imbalance in Government incentives, as between local authorities and independent providers, should be corrected.
- Eligibility criteria for continuing care within the NHS must be made compatible with the medical realities, and applied uniformly across the country.
- NHS continuing care units should be located within the area communities they serve, to facilitate visiting, and should provide respite as well as long-term care.[80]

The role of the primary health care team

Given the high and growing prevalence of dementing disorders in the general population, the contribution of primary health care teams must be seen as a major component of care provision. Most old people are registered with GPs and known to members of the practice team. Improvement in the services offered to affected patients and carers is likely to be reflected in changing public perceptions as well as in the overall standards of diagnosis and case management. The impact of the newly created primary care trusts on mental health care for the elderly will require careful monitoring.

While prescriptive screening programmes for dementia are not indicated, earlier recognition and diagnosis of the developing condition can bring real gains in avoiding misguided treatment and advice, giving patients and families time to prepare, and identifying those likely to benefit from the newly available medication. Regular over-75 health checks provide a useful framework for early case detection, particularly among infrequent attenders. In general, diagnosis depends predominantly on accurate history taking and simple investigations, most of which can be undertaken in primary care. Evidence of benefit from more precise differential diagnosis in late-onset cases is not strong, and the indications for special diagnostic investigations should be more clearly defined.

Firm guidelines will also be required for the prescribing of new acetylcholinesterase inhibitors and other anti-dementia drugs as these become available in the UK.* Auditing of the use of newly licensed substances seems desirable, both on cost grounds and to monitor their effects on relatively unselected patient populations.

Many GPs provide medical services to geriatric nursing and residential homes, where a number of specific measures are needed to improve quality of care (*see* pp. 280–1 and 284–5).

The contribution of social service departments

Social service departments are the lead agency for community care, residential placement and financial subvention for the disabled and dependent, codified in legislation.[210] In latter years, however, they have been handicapped by inadequate resources and the political downgrading of local government. Levels of care and practical help, e.g. home help, are now generally low, and evidence of unmet needs is everywhere apparent. Development of day care and respite care facilities (*see* pp. 274–7) is equally hindered. In addition, the massive shift of long-term care from NHS hospitals to nursing and residential homes has confronted social services with huge new problems. As Murphy[211] has stressed, money is supposed to follow the patient, but in this context often fails to do so. If standards of care are to be maintained – let alone improved – transfer of responsibility must be accompanied by transfer of resources.

Social service departments for their part should recognise that dementia and cognitive impairment are the dominant causes of old-age dependency, ensure that staff are alert to these conditions and equipped with the necessary skills, and strive for a closer co-operation with community mental health teams. There is scope too for the development, in collaboration with housing departments, of affordable, sheltered housing for the disabled and frail elderly, which for many could provide a suitable alternative to geriatric home placement. For progressive dementia, however, careful appraisal of the scope for 'very sheltered' housing will be required, since conventional warden-supervised accommodation can soon become inadequate.

There is evidence supporting the use of budget-holding care managers, with small case loads, helping to organise flexible packages of care for disabled old people, including those with dementia (*see* pp. 273–4). This should preferably be provided conjointly with health care, in multi-disciplinary teams. While budget holding has now, in principle, been accepted in community care, the degree to which the evaluated methods have been implemented in practice is so far unclear.

The statutory services should accord higher priority to development of liaison and co-operation with a number of voluntary bodies concerned with old-age disability and dependency. Prominent among these are area branches of national associations such as Age Concern and the Alzheimer's Disease Society, but local community and self-help groups should also be involved where possible, including in many areas those which support ethnic minorities.

Supporting informal carers

As emphasised above, it is informal caregivers – chiefly family members – who carry most of the burden in the community, especially for people suffering from mild to moderate dementia, and any serious breach of this line of defence would soon produce an acute crisis. Hence improving information, support and practical help for the carers must be accepted as a vital priority. Evaluative research into the effects of supportive care – respite and day care, support groups and counselling – has on the whole confirmed the value of these facilities, while at the same time underlining the need for clearer objectives and better auditing (*see* pp. 274–9). Skilled individual counselling is often necessary because the carer's ability to cope

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* NICE has produced guidance on the use of donepezil, rivastigmine and galantamine.

is so heavily influenced by the quality of his or her earlier relationship with the affected old person, and by family dynamics more generally.

Measures of practical help, in contrast, have seldom been included in evaluative research. Yet studies focused on family caregivers have repeatedly confirmed that the physical demands of personal care and household tasks – dressing and undressing, washing and bathing, toileting, cleaning, shopping, etc. – rank high as causes of burden and stress, and that help with these tasks is often a critical factor.[212] A reliable, well co-ordinated and affordable home-help service must therefore be seen as an integral component of supportive care.

Family care for dementia involves financial expenses and, in many instances, loss of income from paid employment. A diagnosis of moderate to severe dementia implies a need for caregiving at frequent intervals, day and night, and should be recognised as an adequate justification for both high-rate attendance allowance (for the affected person) and invalid care allowance (for the caregiver). Systematic auditing is required to ensure a high uptake, i.e. that family carers are informed about their entitlements, and that the diagnosis is regularly notified to, and accepted by, social security officers.

Services in need of closer scrutiny

Services which in recent years have been subjected to a good deal of criticism include, in particular, memory clinics, day hospitals for the elderly and respite care. Memory clinics established in teaching centres may serve useful functions in development and research (e.g. in recruitment to controlled clinical trials), and merit continuing support on these grounds. More generally, however, any memory clinics that are located outside teaching centres and not integrated into their area service networks stand in need of careful assessment.

Day hospitals for the elderly within the NHS also require some reappraisal, not because the basic need for this type of facility is in doubt, but rather to determine how it can most effectively be supplied, e.g. within inpatient and continuing care units or separately, jointly for demented and other EMI patients or with segregation, linked to non-clinical day-care centres or independently of them. Simple auditing methods, as against formal, controlled evaluative studies, might well provide answers to most of these questions.

Respite care differs in that it does not require separate buildings or staff, but is simply one facility offered as an adjunct to existing inpatient and long-term care, in the same units. As such, it should remain on offer, but the largely disappointing findings of research to date suggest a requirement for better-defined objectives and a careful assessment of the way respite care is working in practice.

It must be emphasised that those aspects of care provision which have been subjected to repeated critical appraisal are not necessarily the ones whose reform is most important or urgent. Indeed, the quality and effectiveness of care for dementing old people in acute general hospitals and geriatric nursing homes have been subjected to far fewer evaluative studies than have aspects of community care, although – as our review suggests – they are equally in need of scrutiny.

Allocating resources and developing local strategies

While quantification of such an integrated model of care in terms of skilled manpower and resources might be deemed ideal, it is hardly feasible at present to supply a blueprint for use by service managers. Levels of provision still vary widely across the country, and the existing service authorities (primary care trusts) administer widely varying budgets for populations of differing size. Moreover, there are major disparities in the available estimates of national care costs for dementia (summarised on pp. 261–3), and all such estimates tend to become outdated rapidly because of population ageing and cost inflation. Lastly, there is still no consensus as to what proportion of total costs should be borne by the NHS, as opposed to local authority social services, the Department of Social Security and the affected families themselves.

For all these reasons, the most that can be done here is to provide a rough orientation based on a notional 'average' health district (now a large PCT) with a population of about 250 000, and to give some indication as to how individual health authorities (now PCTs) might arrive at more accurate figures for their own areas. Kavanagh *et al.*,[84] on the basis of a careful, detailed analysis, estimated a total NHS expenditure of £1.26 billion annually at 1992–93 prices, corresponding to some £6.4 million (around £8 million at 2002 prices) for such an average health district (PCT).

The relative costs of different providers would, however, be affected by changes in the overall model of care. Kavanagh *et al.*[84] went on to list eight distinct policy options giving different priorities to NHS continuing care, community support systems and long-term nursing home placement. Of these alternatives, the one most immediately relevant is that combining a reduction of 50% in long-stay hospital beds (which in fact has since happened) with improved quality of both community and nursing home care. This option, according to the authors, would mean an increase in total expenditure of 7.6% over baseline, but while district health authority (now PCT) costs would rise by only 5.3% (because of the compensatory fall in long-stay beds), local authority social service departments would require an additional 27.4%. It is unrealistic, in short, to consider the burden of dementia on the NHS without setting this in the broader perspective of health and social costs as a whole. The inseparable nature of medical and social care for dementia makes joint service planning and provision essential.

The *Handbook on the Mental Health of Older People*[76] provides detailed advice on developing a local strategy for services, with a strong emphasis on formative evaluation and project planning. A central element in strategy development is the assessment of local needs. A picture of both the needs and the existing provision must be built up to inform policy for funding. Demographic structures will influence the numbers of cases to be expected in the area population.[75,213] While crude estimates can be made on the basis of published epidemiological findings and projections, service monitoring can reveal more specific local priorities. Gordon *et al.*[31] have shown that a census of agency users can locate a high proportion of the expected case numbers at fairly low cost. Deficiencies in care provision can be highlighted by relatively simple monitoring and assessment of unmet needs, based in part on interviewing of informal caregivers.[140] The views of caregiver groups and voluntary bodies should be taken into account in developing local care strategies.

8 Health information systems

A clear distinction must be drawn between management information, necessary to operate a service effectively and measure its 'outputs', and research aimed at comparing different care systems and testing innovations – bearing in mind, however, the need for an ongoing exchange between the two.[214] Recent attention to mental health information systems in the UK has been focused on efforts to standardise data collection and recording required for management, chiefly under three headings:

- minimum data sets (MDS) – basic data collected by service providers
- Health of the Nation outcome scales (HoNOS)[75] – standardised ratings intended to enable progress towards stated targets to be monitored; these are currently due to become part of the national MDS project

- health care resource groups (HRGs) – clinically meaningful groupings of different types of treatment/ care episode which appear to make similar demands on resources (essentially a way of simplifying and summarising disparate information for budgeting and related purposes).

To what extent these different systems will prove useful in relation to dementia care is so far unclear. Outcome scales for the elderly (HoNOS 65+) currently being tested would seem to meet the criteria proposed in Section 2 above, in that they include simple rating scales for severity of cognitive impairment, physical/sensory disability and behavioural disturbance, and are reported to be reliable.[215] They thus offer a potential framework within which defined targets could be set and progress monitored by individual primary care trusts. Their practical utility in this context, however, has yet to be demonstrated.

HRGs appear to be less useful in psychiatry as a whole than in some other clinical specialties because they are, in practice, poor predictors of duration of episode, which tends to be influenced by factors other than diagnosis.[216] This is likely to be the case with respect to dementia in particular, because of the chronic, progressive nature of the condition, and the fact that demand for supportive (including residential) care is determined largely by the patient's family situation.

More generally, meaningful targets can be set in this field only if it becomes possible to collect and collate relevant data over periods extending well beyond the single episodes of NHS specialist care, each of which typically provides only a small window on the course and outcome of the illness. For this purpose, communication and transfer of information becomes vital – between specialist and generalist health services, between each of these and local authority social service departments, and between all three and the providers of long-term residential care (now increasingly in the independent sector). A number of major obstacles will have to be overcome before systematic exchange of data can be achieved at this level, and the most urgent requirement at the present stage is for the mounting of pilot schemes in selected areas where conditions are particularly favourable.

9 Research and development (R&D)

The review of studies of service effectiveness (*see* Section 6) has highlighted the many gaps in present knowledge. The fast-moving nature of biomedical and drug development in dementia research makes it difficult to identify priorities for NHS R&D. However, a review of this field identified few currently funded projects dealing with models of service provision, and most of the research was based in specialist settings rather than in the community or long-term care facilities.[217]

Two main policy objectives, with corresponding research strategies, must be distinguished:

- in the longer term, through scientific advances to find ways of reducing the incidence of dementing conditions (primary prevention) and treating more effectively those that occur (secondary prevention)
- in the shorter term, to ameliorate distress and handicap among existing dementia sufferers, and to relieve the social and economic burdens which the illness imposes on their families and on society at large.

While the former objective is pursued internationally, the latter calls for research adapted to the populations and health service structures of individual countries, and hence is in large measure a responsibility of national Government. Given the massive and increasing costs of dementia care (*see* pp. 261–3), a large-scale Government-supported R&D programme for this field is now indicated. Aside from the input into biomedical research through the MRC, this should be concentrated in three areas:

- development of standardised medico-social assessment and outcome measures (*see* below)

- epidemiological studies to extend knowledge about the incidence, prevalence and distribution of dementing illness to cover:
  - presence of physical comorbidity
  - assessment of specific impairments and disabilities
  - family, social and caregiving situations
- controlled evaluation of local innovative developments, centred on:
  - early detection and diagnostic assessment
  - community care and support services
  - sheltered housing schemes
  - contributions of voluntary bodies.

Medico-social assessment and outcome measures

The importance of having standardised needs and outcome measures in dementia research is now widely recognised. Clancy and Cooper,[218] in a review of this field, point out that treatment-related physiological changes, even if robust in nature, have little meaning in the practical context of disablement and caregiving. Existing generic functional measures are better from this standpoint, but much confounded by the presence of physical and sensory impairments. Needs assessment scales of the kind currently being developed (*see* p. 253) come closer to the everyday realities of caregiving, but do not yet take sufficient account of housing and transport problems, financial burden, availability of services and other determinants of unmet needs. Dementia treatment studies rarely measure the strain on the household of patients' aggressiveness or the stress of inappropriate sexual behaviour. These authors argue that efforts to evaluate new treatments should take due account of family and social perspectives.

Ramsay *et al.*,[219] reviewing the literature on community support for dementia, enumerated the following measures of individual outcome.

For patients:

- cognitive performance, orientation and memory
- physical health, including mobility, sight and associated physical symptoms
- psychological well-being – evidence of depression, anxiety or other psychiatric symptoms
- personal self-care – getting in and out of bed, dressing and undressing, bathing and toileting, shopping, household chores and other activities of daily life
- behaviour patterns – aggression, wandering, sleep rhythm, confusion
- social functioning – quality of communication and social contacts
- treatment compliance, satisfaction with services and places of care.

For informal caregivers:

- physical symptoms resulting directly from caring activities
- psychological symptoms, including depression, guilt and anxiety
- social resources, including 'time to oneself'
- satisfaction with services received
- knowledge about and understanding of the condition.

The authors identified a large number of specific scales, developed mainly in research projects, some of which may prove useful in local service settings, either for case assessment or in formative evaluation.

In addition, measures are required to assess the standards and quality of available services, co-ordination between services and communication with informal caregivers. HAS2000 (the former Health Advisory Service) is developing a district and service level audit tool for old-age psychiatry services.

10 Future directions

Dementia research is a rapidly developing field, with a stream of new findings in biomedical research that offer promise of real advances in our understanding of the underlying processes, and perhaps of effective new interventions. The rapid pace of development of genetic and other markers, as well as of new pharmacological treatments, may well result in changes of priority in health care. Over the next generation, however, this group of conditions will inevitably continue to pose major public health, social and political challenges. Three requirements are likely to remain dominant:

- careful testing and appraisal of new research findings and emerging technologies
- improvement in the quality and provision of existing services for those with a clinical degree of dementia
- the need to develop methods of earlier detection, diagnosis and treatment so as to combat the underlying disease process at an early stage and prevent or delay its progression.

Striking the right balance between these requirements is likely to present the central challenge to a national health policy over the coming decades.

UK mental health policy for the elderly is part of the National Service Framework for Older People. A Government circular[220] required health and local authorities to work together, with special reference to joint investment planning for continuing and community care, multi-disciplinary assessment of old people and development of rehabilitation services. An audit of mental health services for older people is to be undertaken by the Audit Commission and DoH jointly (published in 2002), and an 'evaluation instrument' is being developed by HAS2000.

Opportunities to organise dementia research jointly with professional bodies, such as the Royal Colleges of Psychiatrists, General Practice and Nursing, will increase as these become increasingly aware of the challenge, and deserve to be pursued vigorously. Collaboration should also be promoted between the NHS and university centres with the necessary research capacity. The tendency, conspicuous in some countries, for central government to rely on health survey research commissioned from market research and similar commercial firms in general has been uneconomic and inimical to good-quality R&D, and should be avoided.

The tempo of change in the dementia field will call for a system of continuous monitoring by working groups, concentrating on:

- assessment of clinical trial results, and their implications for practice, in an international perspective
- implications of new scientific progress and also the emergence of new risk factors (e.g. AIDS, designer drugs).

Appendix I: Classification of dementia

The International Classification of Diseases, tenth revision (ICD-10),[15] provides the following classification of dementia.

Table 15: Classification of the dementias in ICD-10.

F00	Dementia in Alzheimer's disease (AD):
F00.0	Dementia in AD, with early onset
F00.1	Dementia in AD, with late onset
F00.2	Dementia in AD, atypical or mixed type
F00.9	Dementia in AD, unspecified
F01	Vascular dementia (VaD):
F01.0	VaD of acute onset
F01.1	Multi-infarct (predominantly cortical) dementia
F01.2	Subcortical VaD
F01.3	Mixed cortical and subcortical VaD
F01.8	VaD, other
F01.9	VaD, unspecified
F02	Dementia in diseases classified elsewhere:
F02.0	Dementia in Pick's disease
F02.1	Dementia in Creutzfeldt–Jakob disease
F02.2	Dementia in Huntington's disease
F02.3	Dementia in Parkinson's disease
F02.4	Dementia in human immunodeficiency virus (HIV) disease
F02.8	Dementia in other diseases classified elsewhere
F03	Unspecified dementia.

Appendix II: Search strategies and terms

The previous edition of this chapter was based on searches of the literature published up to the early 1990s. For this update the following databases have been searched:

- MEDLINE and Embase databases for the years 1987–97 for English-language papers
- the Cochrane database of trials, with related databases (Dare, ACP)
- NHS R&D database
- HSTAT (National Library of Medicine, Health Services/Technology Assessment Text)
- other guidelines – identified through TRIP and other sources.

For the MEDLINE and Embase searches, the terms 'dementia' and 'Alzheimer's disease' were used. For specific topic areas, the additional search terms used are stated. Searches were carried out looking for RCTs, controlled trials and review literature. Citation searches were conducted on key papers so discovered, and within each topic area, citation searches were also carried out on the names of key authors. The bibliographies of retrieved papers were searched and any additional references obtained. The Cochrane database of systematic reviews was searched for relevant reviews.

Internet sites relating to dementia or care of the elderly identified through the TRIP site were searched for additional relevant material. These included the National Institute on Aging, the US Agency for Health Care Policy and Research, Age Concern, the Alzheimer's Disease Society, the Royal College of Psychiatrists and the Department of Health. Lastly, experts in the field were consulted for their knowledge of additional work.

For all searches, the terms dementia and Alzheimer's disease were used. Additional search terms for specific therapies were as follows:

- diagnosis and assessment: diagnosis, assessment, recognition
- cholinesterase inhibitors: drug therapy, cholinesterase inhibitors, anticholinesterase, donepezil, Tacrine, meta-analysis, randomised controlled trials
- non-drug treatments for behavioural problems in dementia: therapy, behaviour therapy, cognitive therapy, reality orientation, reminiscence therapy, validation therapy, music therapy, psychotherapy, randomised controlled trial
- respite care and day care: respite care, day care, relief, controlled trial
- support groups, information and education, and individual counselling: support group, psychosocial intervention, information, education, counselling, therapy
- management of patients with dementia in the community: community team, community mental health team, community mental health services, community resource team, case management
- long-term settings: long-term care, nursing homes, residential homes, special care units.

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Acknowledgements

We thank the Medical Research Council Cognitive Function and Ageing Study management committee, as well as the respondents, RIS project team and fieldworkers for access to the data from that study. We also thank Dr Tom Dening for comments on earlier drafts and Brenda McWilliams for her careful work on the manuscript.