Guidelines for the Support and Management of People with Dementia

Introduction

Dementia is the clinical syndrome characterised by acquired losses of cognitive and emotional abilities severe enough to interfere with daily functioning and quality of life. It is not a specific diagnosis but includes more than 55 illnesses, some of which are non-progressive.

Dementia is not a specific disease but a syndrome with many possible causes. Dementia describes the loss of cognitive abilities in someone who was previously cognitively intact. New Zealand's population is ageing. The prevalence of the dementias increases markedly with increasing age so the number of affected people is projected to rise rapidly in the next few decades. This is a worldwide trend. Whilst the ageing population will contribute the large majority of new cases the issues of those younger people with dementia should not be neglected. Most Crown Health Enterprises in New Zealand have specialised services for the elderly and a number of these employ psychiatrists for the elderly. The particularly poignant issues that arise in the case of a younger person with dementia should not be neglected simply because they do not fit neatly into traditional service boundaries.

Awareness of Alzheimer's Disease and the other conditions that cause dementia has improved significantly in the last 12 years primarily due to the Alzheimers Society (formerly ADARDS) and departments of Psychiatry for the Elderly. The Alzheimers Society has also been responsible for advocacy for carers and identifying gaps in services and education. They have emphasised the need for a National Dementia Plan and an increase in resources for a group that arguably has been overlooked in health service planning.[1] During the same time an increasing number of information booklets and resource materials have been developed both locally and overseas. Several of these are recommended to families, other carers and health professionals.[1-5] Dementia research has also blossomed in the last 20 years. From the original epidemiological studies of the 1960s has developed a rapidly increasing knowledge of the genetic, histological and chemical changes that accompany the dementias. Potential treatments that may improve the quality of life of patients and their families are now being developed. The need for continuing research and education is paramount. The 'dementia dividend', or the money that could be released for other purposes if the dementias could be treated or delayed, is huge. The impetus for further research and increased understanding of these conditions must be maintained even at a time of health funding restraints. The costs of ignoring the dementias may well outweigh the costs of improved services, public education and understanding. A number of overseas studies have identified the considerable costs associated with caring for people with dementia, much of which is borne by families as unpaid contributions.[6-8] New Zealand data on the costs of dementia care are urgently needed.

Carers of those with dementia have also expressed criticism of attitudes of staff within hospitals, particularly those in secondary care units. The bewildered person with a dementia is all too often treated as an unwelcome guest in busy acute care settings. Often they are seen as less worthy than those with more 'exciting' medical conditions. This is reinforced in a culture of high technology and where inability to cure is seen as failure. The design of acute facilities may be particularly dementia-unfriendly. Indeed the environment often contributes to an increase in confusion and difficulties in management. A constant plea from carers is for better staff education and more enlightened and humane attitudes.

The authors of this report were asked to develop guidelines for the management of Alzheimer's Disease and the other dementias. Key elements to be considered were how to improve and foster nationwide consistency of management. We were asked to outline:

1. The processes by which clinical decisions should be made.
2. The boundaries for competent practice.
3. Which services should be publicly funded (within a climate of resource constraint).

At the same time the authors have felt unable to ignore the implications of an ageing population on dementia prevalence, the major contribution of carers and the underprovision of specialised services for dementia care that have existed to date.

We have recognised the crucial role of the General Practitioner in early diagnosis, specialist referral where indicated and as an ongoing support for patients and families. The central role of support groups such as the Alzheimers Society (ADARDS) is similarly acknowledged.

The following topics are discussed:

1. Diagnosis of dementia with special reference to early diagnosis and difficulties encountered in general practice.
2. Comprehensive assessment and review including co-morbidity, psychosocial problems and carer strain.
3. Management of intercurrent events.
4. Initiation of changes of therapy including potential drug treatments and rehabilitation.
5. Help and support for carers including home help, respite care, information on service and advice.
6. Change to a different care setting.
7. The need for better education at both undergraduate and postgraduate level for those in all health disciplines.

The guidelines have been developed to particularly assist and improve the management of dementia in primary care, however we appreciate that they will be used by a wider readership.

Incidence and prevalence of dementia in New Zealand

There is wide variation worldwide in the estimates of the prevalence and incidence of dementia. This is probably because of variations in the criteria used to define the syndrome.[9] An over-reliance on tests of mental status (eg, the Folstein Mini Mental Status Examination or MMSE[10]) can also be misleading (see Figure 1).[11] In general, Alzheimer's Disease accounts for 50–70% of all cases of dementia and vascular dementia for 10–20%.[13] There has only been one study looking at the prevalence of dementia in New Zealand,[13] which has shown prevalence rates which are similar to other countries (Table 1).

Table 1: Prevalence of dementia in New Zealand[13]

Age group	Prevalence
All people aged over 65 years	7.7%
65–74 years	3.8%
75–79 years	6.4%
80–84 years	11%
85–89 years	23.6%
90+ years	40.4%

Information regarding the prevalence of the various subtypes of dementia in New Zealand is lacking. Further studies on rates of dementia in New Zealand are required to ensure that there is accurate information to enable planning of services. There is also a need to determine prevalence rates in Maori because New Zealand's Maori population is ageing faster than the population as a whole. There were only 400 Maori aged 85 years or more in 1991 but this is projected to increase to 5010 by the year 2031.[14]

Based on data accumulated from a number of studies, it has been estimated that the prevalence of dementia doubles each 5.1 years between the ages of 60 and 90 years but this exponential increase possibly does not continue over 95 years. The prevalence in men is similar to women.[9]

It has been estimated that between 1992 and 2016, the prevalence of dementia will increase in New Zealand by 96–100%, compared with a rise in the general population of 18–26%.[15]

The incidence of dementia is also difficult to estimate but is probably approximately 1% per year for people aged over the age of 65.[9]

Dementia sub-types

There are over 55 illnesses which can cause dementia.[16] The majority of cases are caused by either Alzheimer's Disease or vascular dementia.

Alzheimer's Disease

In addition to progressive memory impairment (especially recently acquired memories), language impairment is an important sign of Alzheimer's Disease. The earliest difficulties may be in finding words in spontaneous speech and by the increased use of automatic phrases and clichés (eg, social speech such as "how are you?, I'm fine" etc). The ability to repeat phrases is usually preserved. Other deficits occur with visual and spatial abilities such that there may be difficulties in recognising familiar faces or objects. Apraxias (or difficulty completing complex motor tasks) may interfere with abilities to carry out activities of daily living. Impairment in arithmetic (acalculia) may interfere with managing accounts and/or a cheque book.

Non-cognitive symptoms are covered elsewhere but might include decreased emotional expression, increased stubbornness, diminished initiative and greater suspiciousness. Delusions may occur in about 30%. Depression may be difficult to distinguish from apathetic states related to the dementia itself. Delirium (organic confusional state) may highlight underlying Alzheimer's Disease.

Vascular dementia

In up to 90% of pathologically verified cases of vascular dementia, there is history of acute unilateral motor or sensory dysfunction consistent with a stroke. Vascular dementia, however, can occur in the absence of overt strokes. Urinary dysfunction and gait disturbance are possible early markers. Parkinsonian motor features, asymmetric reflexes and/or extensor plantar responses are useful signs. Periventricular white matter lesions on imaging studies can occur in normal ageing, and have not been shown to be consistently related to cognitive impairment. Cognitive decline tends to be discontinuous and deficits are often patchy.

Dementia of the frontal lobe type

This syndrome probably accounts for 1–5% of all cases of dementia. Dementia of the frontal lobe type describes the syndrome of disordered executive function (impairment of initiation, goal setting, and planning) and disinhibited behaviour with only mild abnormalities on cognitive testing. Lack of insight into difficulties (anosognosia) is often seen but does not distinguish this syndrome from Alzheimer's Disease. These people are prone to angry catastrophic reactions. The apathy may be difficult to distinguish from depression. The apraxias of Alzheimer's Disease are usually absent and the language deficits are more characterised by abundant unfocused speech (logorrhoea), echo like spontaneous repetition of words or phrases (echolalia) or compulsive repetition of phrases (palilalia). One common cause of this syndrome is Pick's Disease which is associated with focal atrophy of one or both frontal and/or temporal lobes.

Dementia with Parkinsonism

These two syndromes can often co-exist. Rigidity and postural instability develop in approximately 30% of people with Alzheimer's Disease. Similarly people with Parkinson's Disease can develop dementia due to co-existent Alzheimer's Disease, cerebrovascular disease or other causes.

Lewy-body dementia is recognised as a separate syndrome and is characterised by fluctuating cognitive impairment which affects both memory and ability to carry out complex tasks. This fluctuation can be confused with delirium. In addition, however, at least one of the following is seen:

- visual or auditory hallucinations
- extra-pyramidal features such as sensitivity to neuroleptics or a Parkinsonian appearance and/or
- repeated unexplained falls, transient clouding or loss of consciousness.

Creutzfeldt-Jakob Disease

This is a rare cause of progressive dementia caused by a proteinaceous agent (prion) which is potentially transmissible. It is usually of short duration (1–2 years) and the early stages may be characterised by irritability or unusual somatic sensations. Motor signs such as myoclonus, Parkinsonism and motor neurone dysfunction may be prominent. Visual impairment or symptoms may occur. An electroencephalograph (EEG) can be diagnostic.

Hydrocephalus

Normal pressure hydrocephalus is characterised by the triad of gait disorder, urinary incontinence and cognitive decline. As each of these elements is common in elderly people, their occurrence together does not necessarily signify a diagnosis of normal pressure hydrocephalus. The condition is sometimes responsive to shunting, but the likelihood of cognitive improvement is highest when the dementia is of short duration.

Alcohol dementia

Characteristically this presents with amnestic deficits. Other cognitive deficits may be seen which often include frontal lobe features.

Subcortical dementia syndrome

This refers to a clinical syndrome characterised by slowing of cognition, memory disturbances, difficulty with complex intellectual tasks such as strategy generation and problem solving, visuospatial abnormalities and disturbance of mood and affect. Unlike Alzheimer's Disease there is relative preservation of language, calculation and tasks requiring co-ordinated motor function. This syndrome may be seen in conditions such as Parkinson's disease, Huntington's disease, progressive supra-nuclear palsy, Wilson's disease and other disorders affecting predominantly the basal ganglia and/or thalamus.

Potentially reversible dementia

This refers to syndromes which are, at least partly, reversible following early recognition and treatment of the underlying condition. Although this is encountered rarely, potentially reversible components of dementia are important to detect as they have enormous implications for the patient and his/her carer. This has led to the development of the so-called 'dementia screen' or a list of tests which should be undertaken in any person with dementia, to ensure that reversible causes will not be overlooked.

The use of such tests often reveals abnormalities which can be corrected. Unfortunately, this is not always translated into an improvement in cognition. Regrettably, many studies purporting to show reversibility of dementia have had methodologic flaws and are not always able to be extrapolated to the community setting.[16]

Nevertheless, there is often considerable comorbidity found in people with dementia. Treatment of this can often offer substantial improvement to a person's quality of life. An evaluation of elderly people with progressive cognitive impairment must be undertaken with the goal of improving patient wellbeing rather than simply identifying disease. The concept of 'excess disability' is useful and it reminds us that even the most severely demented (or otherwise impaired) person may still benefit from a methodical examination in search of treatable conditions, including medical illness, drug toxic effects, and functional impairment.

The most common causes of 'confusion' which can be reversed include:[17]

- depression
- drugs
- thyroid disorders
- subdural haematoma
- neoplasms
- alcohol
- normal pressure hydrocephalus
- vitamin B12 deficiency
- other metabolic disorders.

Differentiating depression from early dementia can sometimes be difficult and a trial of antidepressants may be worthwhile. It is important to emphasise that people who gain an improvement in cognition following antidepressant therapy are at greater risk of developing overt dementia in the future.[18] This is because 'subclinical dementia' may be unmasked by a depressive illness. Follow-up is therefore important.

Many reversible causes of confusion may therefore not be dementia at all. They can be detected following a full medical evaluation and judicious use of investigations such as:[17]

- thyroid function tests
- vitamin B12
- full blood count
- ESR
- CT scan of the brain [see Appendix 7[2]]
- plasma electrolytes, calcium and glucose.

Early diagnosis

The key questions to ask when considering the possibility of a dementia are "Does this person really have dementia rather than some other problem?" and "if so, what is the cause?".[21] The question of whether a person's mental state is deteriorating must be judged in context. The primary care physician who has known a person for years and is familiar with his/her background is often in an ideal position to identify dementia. The chief diagnostic criteria for Alzheimer's Disease in a person between the ages of 40 and 90 years are slowly progressive memory loss and deterioration in at least two cognitive functions such as language use, perception, motor skills, learning ability, problem solving, abstract thought and judgement.[22] Because people with dementia are often unaware of their problems, history from others is essential particularly so that declines in function, potential risks to safety, and any family history of dementia, stroke or related conditions can be assessed.[22] People with Alzheimer's Disease and other dementias and their families require ongoing counselling from their primary care doctor or appropriate professional when the diagnosis is first suspected and continuing as the reality of progressive dementia and increased dependence touches the family. Families who choose to provide care for patients throughout the course of the illness require access to support groups, good clinical information about the probable course of the disease, effective management strategies, and non-judgmental recommendations as to when to seek outside help and a move to continuing care.[21] (Refer to Algorithm 1: Early diagnosis of dementia is important for the following reasons.)

1. Treatment issues

Effective therapy, including drugs and behavioural therapy, is more likely to be effective in the early stages of the condition (eg, treatment of hypothyroidism, vitamin B12 deficiency or alcoholism).

Also specific treatments for Alzheimer's Disease are being tested and the possibility for inclusion in drug trials can be discussed. Moreover optimal treatment of co-existent conditions can be undertaken with benefit.

2. Medico legal issues

a) An enduring power of attorney can be arranged.
b) Any advance directives can be discussed.
c) Car driving safety can be assessed (see related section).
d) Safety around the house can be assessed.

3. Education and support of carers

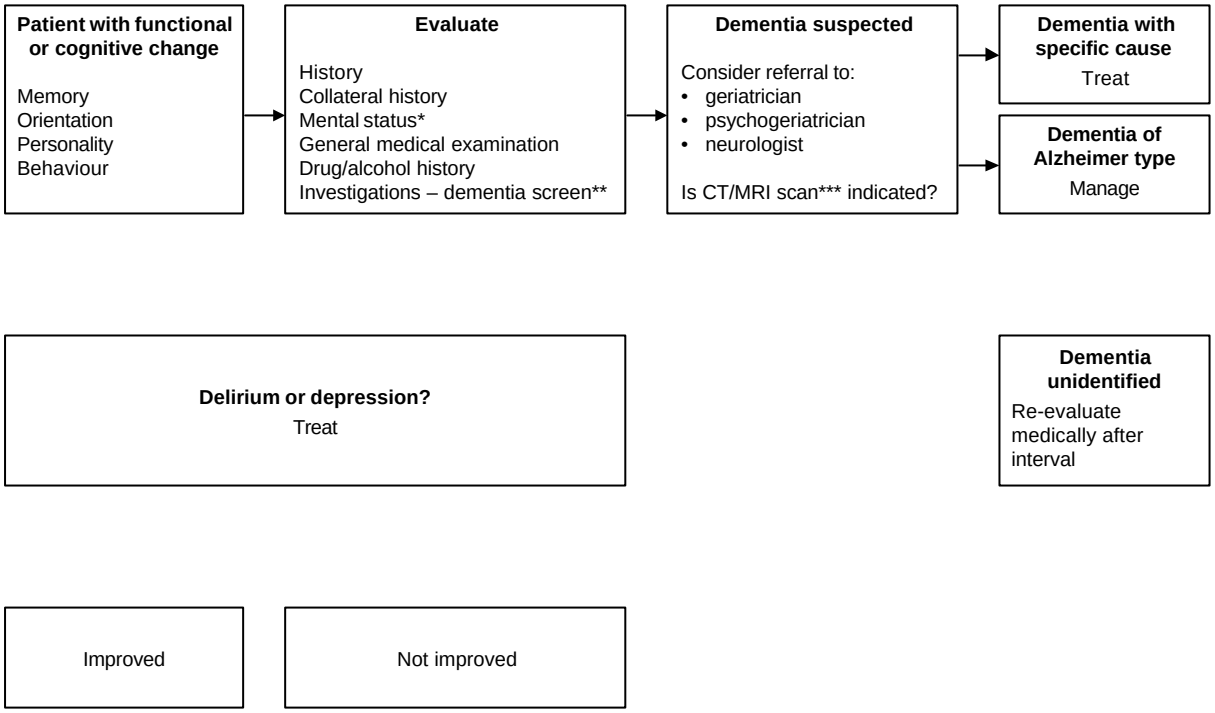
A good understanding of dementia by carers will assist in better management and lessen breakdown in relationships. Early diagnosis helps family and carers to make contact with support agencies that will help develop the support strategies and services that will be vital as the condition progresses. Forward planning is aided by access to accurate information and education.

Early diagnosis, however is not simple. There is no specific diagnostic test available at present. The implications are so potentially grave that accuracy in diagnosis is essential. Dementia is both over and underdiagnosed[23-24].

Accurate diagnosis can be aided by taking note of the following (see Algorithm 1):

1. The presence of cognitive loss or deterioration in functioning level, often reported by others. Because patients with dementia are often unaware of their problems, a history from family, carer or neighbour is essential. Reports of change in cognitive function or behaviour by those who know a person well should always be taken seriously.
2. A knowledge of specific tests of mental function (and their limitations) is important in determining the presence of cognitive loss, assessing severity and following progress. The 10 question mental status questionnaire (MSQ)[25] or the more sensitive 30 question mini-mental state examination of Folstein (MMSE)[26] are recommended. The clock drawing test is also useful in making a diagnosis.[27] Limitations in the interpretation of these tests include the presence of dysphasia, sight impairment, deafness, poor educational level or cultural factors. The Camdex scale[31] has been used by researchers and further editions of this scale are likely to be developed.
3. A thorough clinical examination is necessary to check for specific conditions eg, stroke, Parkinson's disease and to exclude the presence of delirium.
4. An accurate drug history (including alcohol) is essential.
5. Depression must always be considered a possibility and excluded. Consider using the CES-D major depression score,[28] or the short EBAS-DEP.[29] If in doubt, psychiatric referral is required. Table 2 lists useful differentiating features between delirium, dementia and depression.
6. Appropriate investigations (dementia screening tests) must be performed.
7. A home visit is often useful in early assessment.
8. Many patients will require a CT head scan, and in a very small number an MRI scan to exclude treatable conditions (subdural haematoma, meningioma) or to identify more specific types of dementia (eg, vascular dementia, white matter disease and Pick's disease). For further discussion see Appendix 7.[22]
9. If dementia is suspected, specialist referral (psychogeriatrician, geriatrician, neurologist) may be required. However if the criteria for the diagnosis of dementia are fulfilled and treatable conditions excluded, then referral is not necessary unless there are particular management problems such as those of psychiatric co-morbidity.
10. Referral for neuropsychologic testing may be useful in younger patients or where there is diagnostic uncertainty.
11. Regular review is important to confirm a progressive deterioration with time and to address other problems that may arise.
12. Patients, carers and families should be encouraged to keep regular contact with the general practitioner, particularly if changes occur. (See "Helpful suggestions for GPs and carers".)[30]
13. Once an accurate diagnosis has been made treatment can commence where indicated and a management plan can be implemented.

Algorithm 1: Algorithm for diagnosis and initial management of dementia



Please note: this draft image will be replaced with a final rendition later in June.

* Mental status questionnaire or mini mental state examination (refer Appendix 1) (refs 5,6 page 16)

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*** CT/MRI scanning (refer Appendix 7(2)).

Table 2: A comparison of the clinical features of acute confusion, dementia and depression

Feature	Acute confusion	Dementia	Depression
Onset	Acute/subacute depends on cause, often at twilight	Chronic, generally insidious, depends on cause	Coincides with life changes, often abrupt
Course	Short, ***diurnal*** fluctuations in symptoms; worse at night in the dark and on awakening	Long, no diurnal effects, symptoms progressive yet relatively stable over time	Diurnal effects, typically worse in the morning; situational fluctuations but less than acute confusion
Progression	Abrupt	Slow but even	Variable, rapid–slow but uneven
Duration	Hours to less than one month, seldom longer	Months to years	At least two weeks, but can be several months to years
Awareness	Reduced	Clear	Clear
Alertness	Fluctuates; lethargic or hypervigilant	Generally normal	Normal
Attention	Impaired, fluctuates	Generally normal	Minimal impairment but is distractible
Orientation	Fluctuates in severity, generally impaired	May be impaired	Selective disorientation
Memory	Recent and immediate impaired	Recent and remote impaired	Selective or patchy impairment, ‘islands’ of intact memory
Thinking	Disorganised, distorted, fragmented, slow or accelerated incoherent	Difficulty with abstraction, thoughts impoverished, make poor judgements, words difficult to find	Intact but with themes of hopelessness, helplessness or self-deprecation
Perception	Distorted; illusions, delusions and hallucinations, difficulty distinguishing between reality and misperceptions	Misperceptions often absent	Intact; delusions and hallucinations absent except in severe cases

Adapted from Foreman 1986

Genetic testing

During recent years an understanding of particular genetic associations with Alzheimer's type dementia has developed. Specific mutations on chromosomes 1, 14 and 21 have been identified in patients with a family history of Alzheimer's Disease. Patients with Alzheimer's Disease also have a higher frequency of apolipoprotein E4 alleles than those without the disease raising the possibility that apolipoprotein E genotyping could assist in the diagnosis.[32] The lifetime risk of developing Alzheimer's Disease has been calculated as 15% if the apolipoprotein E4 status of a person is unknown.[33] The same authors calculate that the risk of developing the disease is 29% in those with an apolipoprotein E4 allele and 9% in those without. The presence of the gene is best viewed as an increased risk for Alzheimer's Disease but is neither necessary nor sufficient for diagnosis. It is considered that apolipoprotein E testing will not be ready for clinical use as either a predictive or diagnostic test until better population based estimates of risk and appropriate genetic counselling are available.[34] This is an area where knowledge is rapidly expanding, however, and future clinical trials will probably require patients apolipoprotein E status to be known before assignment to treatment groups.

Cognition of enhancing drug treatments in dementia

Currently there are no known treatments which delay progression or reverse deterioration for people with the primary dementias. Dementias which are possibly reversible (eg, hypothyroidism, vitamin B_{12} deficiency, space occupying lesion and depression) have been mentioned elsewhere. A large number of compounds have been examined for possible cognition enhancing effects with mostly disappointing results.[35]

This contrasts with the known worsening effect on cognition of several agents (including sedatives, anti-cholinergics, anti-psychotics, some anti-hypertensives, alcohol and potentially 'any' drug).

Restorative treatments have mostly been examined for people with Alzheimer's Disease. Tacrine is a centrally acting, non-competitive, reversible acetyl cholinesterase inhibitor which enhances central cholinergic activity. This may be relevant as Alzheimer's Disease especially affects cholinergic neurones and cholinergic loss has been correlated with severity of cognitive deficits. It is the only agent so far to show any suggestion of any effect. It is currently available in the United States, Australia and some parts of Europe. It has been subject to criticism and some regard it as a controversial treatment, but a large recent US study has helped clarify the situation.[36] This study used high doses and showed a benefit equivalent to six months' progression in the 27% of people who are able to tolerate the highest dose (160 mg per day). In this group 42% of patients given treatment experienced some improvement in cognition compared with 18% of those given placebo. That is, approximately one-quarter of people tolerate the highest dose of whom one-quarter have an effect greater than placebo. This was found in fit people who are eligible for a clinical trial. In practice, the effect may be less than this. Tacrine is subject to side effects, including those related to its cholinergic effect (nausea, diarrhoea, dyspepsia, flatulence). It may also have a significant adverse effect on liver function.

Tacrine may have a place in the otherwise fit person in whom a small increase in cognition would result in a significant improvement in quality of life. It should be noted that cognition and quality of life are not always positively correlated and that in a minority of people an improvement in cognition may well worsen quality of life. It plays a small part in the overall management of a person with dementia and should be used only after detailed discussion with the patient and carer and by a doctor experienced in dealing with the drug and with people with dementia. Tacrine is currently not registered for use in New Zealand but can be made available on a named patient basis at approximately $3000 per year. For a fuller review of the treatment of dementia refer to Wood.[38]

It is likely that other anticholinesterase agents and other drugs with possible cognition enhancing effects will become available in the near future. Research into these agents should be encouraged, but their use can only be recommenced following evaluation in properly conducted clinical trials. Evaluation of new drugs must take account not only of effects on cognition, but also on any global effect on functioning.

For vascular dementia, there is some evidence that controlling risk factors may result in some improved cognitive function.[37] Such risk factors would include control of hypertension, control of glucose for people with diabetes and the use of anti-platelet treatment.

Management of dementia

Management after initial diagnosis

Risk management assessment

The first priority is to assess whether there is any evidence of danger to the person with dementia or to others. Accidents in the home (eg, stove, appliances, open fires), assaultive behaviour, impaired driving, malnutrition, suicide threats or apparent abuse or neglect may require urgent action. Emergency intervention using the Mental Health Act may be necessary – seek the advice of a Duly Authorised Officer (DAO) of the local Mental Health Service. Other actions that may be considered are: urgent referral to a specialised Dementia Team, use of the Protection of Personal and Property Rights Act or referral to the Land Transport Safety Authority.

Specific treatments

Sometimes medical or surgical treatment can be offered for potentially reversible causes of dementia (eg, hypothyroidism, vitamin deficiency, hypercalcemia, normal pressure hydrocephalus, subdural haematoma and brain tumours). Psychiatric illnesses such as major depression or schizophrenia may sometimes present with a dementia-like clinical picture which can be improved with appropriate treatment.

Cognition-enhancing medication

The option of drug treatment to improve cognition in early dementia is increasingly available (see Section 6.0). Tacrine is the only drug being widely marketed to date, but others are in the later stages of clinical trialling. Some larger centres have set up Memory Clinics to foster research and improve the treatment of early dementia.

Non-drug strategies for maintenance of functioning

It is important to focus on the remaining strengths, skills and resources of people with dementia, and work toward the maintenance of these. Regular review and care planning, with referral on to counselling support groups or other support agencies, is vital.

There is evidence that cognitive decline in dementia may be delayed by participation in stimulating intellectual activities (the “use it or lose it” theory). People with dementia should be encouraged, as far as is possible, to maintain their customary hobbies and activities.

Support groups for people with early dementia may improve insight and coping skills and assist in coming to terms with disability.[39] Such groups are available in some New Zealand centres. Day care centres can be a very useful management aid for people with dementia.

Medical treatment to minimise dementia-related disability

The patient's general medical problems and treatments should be reviewed regularly to rule out adverse effects on mental functioning. Medications which may produce central nervous system side-effects (Table 3, page 32) should be minimised. Polypharmacy should be avoided in light of the potential for additive drug toxicity or complex interactions. Supervision of medication-taking, especially in those living alone, may be vital.

The patient's consumption of alcohol and other potential drugs of abuse (especially minor tranquillisers) should be reviewed. Clear advice should be given about restriction of intake if necessary, bearing in mind that habitual doses (previously tolerated) may produce more obvious toxic effects once dementia ensues. Withdrawal syndromes may also adversely affect cognition. The medical management of vascular dementia is the same as for stroke disease.[40] There should be careful treatment of hypertension (whilst avoiding hypotensive episodes), hyperlipidemia, carotid atherosclerosis and atrial fibrillation. Some clinicians prescribe aspirin in the hope of delaying progression of vascular dementia, but there are no empirical data to support this.

Other medical conditions warranting preventive measures or optimal management in the dementing patient are: diabetes (particularly, avoidance of hypoglycemia), hypoxia, anaemia, postural hypotension, epilepsy, infective illness, pain and urinary or faecal retention. Even apparently trivial medical problems (eg, mild dehydration) can worsen dementia.

Genetic counselling

Over the past five years it has become increasingly apparent that Alzheimer's Disease is, in great part, a genetic condition.[41] As research progresses there will be a growing need to offer appropriate support to worried relatives, particularly family members of early-onset and/or familial cases.

Managing the person with dementia in hospital

Special considerations pertain (in addition to the above) to managing dementia in a secondary care setting. Dementia patients are commonly found in medical and surgical wards but are often poorly cared for. Problems may include: inadequate initial assessment (failure to seek ancillary history); acute confusion mistaken for dementia; failure to recognise the disorienting effect of hospital environment (undue haste, noise, bed shifting etc); failure to appreciate non-specific presentation of illness or the complexities of multiple interacting medical and psychiatric problems; resentment of failure to cope as a reason for admission; ward culture which fails to tolerate muddled/disturbed behaviour (especially at night).

The outcomes of such poor management may include: acute confusion and/or behavioural problems precipitated or exacerbated; iatrogenic problems from inappropriate use of sedatives or restraints; failure to provide adequate social assessment/intervention; admission unnecessarily prolonged (or premature discharge). These can often be prevented by thorough multi-disciplinary assessment/reviews and close liaison with geriatric medicine/psychiatry. As far as possible staff should strive to improve ward environments and routines to suit dementia patients and to promote ready access to family and friends.

The role of the specialist dementia assessment and intervention team

When to refer to specialist services

There are a number of instances where referral to a Psychiatric Service for the Elderly (where available) or the hospital department which takes responsibility for people with dementia is required.

These include:

- if the diagnosis is more complex
- when symptoms are causing acute distress or jeopardising safety
- difficult behavioural problems
- respite care.

Specialist services seek to stabilise the problem and restore the person to the community if possible.

Every New Zealand citizen should have access, when necessary, to expert specialist advice on dementia from a publicly funded service.

This may be from an Old Age Psychiatry service, from Geriatric Medicine or from General Psychiatry or General Medicine. Neurologists also provide diagnostic and management advice, especially for presenile or atypical dementias.

Comprehensive dementia assessment requires multidisciplinary input; medical assessment alone is seldom adequate. Other key personnel are: specialist nurses, social workers and occupational therapists. Depending on the particular case, there is often a role for clinical psychology, physiotherapy and speech-language therapy.

Dementia assessment should ideally begin in the patient's usual place of residence. This makes possible a more accurate, objective assessment of the patient's functioning and environment than in a clinic or hospital ward.[42] However, there should also be access to inpatient/residential assessment and treatment when necessary. Day Hospitals can be useful facilities, and ideally Memory Clinics for early dementia should also be available.

Criteria for referral

The threshold for referral to some extent should be dependent upon the expertise of individual general practitioners and the local availability of specialist dementia services. If possible, most cases should be referred, especially those that are atypical or complex. Referral is also indicated if there are serious safety issues or significant behavioural or psychiatric complications. Early referral for assessment and intervention is clinically advisable, as this allows care options to be planned in advance and may prevent social or psychiatric complications and minimise secondary disability. It is always preferable to intervene before rather than after a crisis point has been reached.

Ongoing community casework

In addition to assessment, specialist services will ideally offer ongoing monitoring and management advice for a proportion of referred cases (usually those living alone or otherwise at risk), in liaison with the primary care team. Generally one 'keyworker' will take on this co-ordination role.

Management of psychiatric symptoms/syndromes in dementia

Status of non-cognitive symptoms

The central importance of psychiatric and behavioural symptoms in the diagnosis of dementia has been re-emphasised in recent years.[43] It is important to enquire specifically about these issues, as they may not be volunteered.

Clinical features

Table 2, page 20. See references [44-47].

Distinguishing depression from dementia

Table 5, page 34. Depression can sometimes mimic dementia in old people, although many cases of so-called 'pseudodementia' later turn out to have an unequivocal dementing illness. A trial of antidepressant medication is often indicated when depression is suspected, as reliable clinical diagnosis is difficult.

Management

- **Psychosis** (ie, loss of touch with reality). Symptoms stemming from this include delusions (false beliefs), hallucinations (false sensory perceptions) and misidentifications (false recognition of people, things or places). These are often best dealt with by reassurance, re-orientation and other non-drug strategies. Low dose antipsychotic drugs may be considered if symptoms are persistent or distressing. Special care must be taken in Lewy-body dementia, however, because of marked sensitivity to standard antipsychotic drugs.

Depression

Social stimulation, appropriate activities, plus counselling when appropriate are first-line strategies for depressed mood. Antidepressant drugs are often worth trying for more pervasive or severe depressed states, even if the clinical picture is atypical. Many clinicians feel that the newer antidepressants such as selective serotonin re-uptake inhibitors (SSRIs) are preferable to tricyclics, due to a more benign side-effect profile (in particular, less anticholinergic action which can make confusion worse). However, agitation, sleep disturbance and low blood sodium levels can sometimes prove troublesome with SSRIs. Moclobemide also has proven efficacy[48] and is generally well tolerated.

Anxiety states

High anxiety levels are often situationally determined and may therefore be responsive to social or environmental manipulation. Sometimes patients may benefit from more formal anxiety management strategies, behaviour modification, or counselling. If these strategies have failed (or are unrealistic) anti-anxiety, anti-panic or anti-phobic drug treatment can be helpful.

Mania

This may respond to standard anti-manic treatment.

Managing behavioural concomitants of dementia

See Table 6. There is controversy about how to classify these symptoms, but the importance of assessment and intervention for behavioural problems is increasingly recognised, due to their impact on carers' burden and coping ability. Due to problems with definition there is lack of good data on prevalence of particular symptoms, but it is agreed that behavioural problems of some sort arise in the great majority of dementia cases.[49] Recent reports[50] have highlighted the occurrence of 'negative' symptoms (apathy, withdrawal and emotional blunting) in addition to positive behaviours.

Behavioural problems are commonly associated with psychiatric symptoms; for example, aggression may be attributable to psychosis.[51] It is particularly important to be aware that a depressive or anxiety state may underlie behavioural disturbance, in which case management should be focused accordingly.

Questions to ask in assessment

What exactly is the problem? Does it really matter? When does it occur? What are the precipitants? What are the consequences? What has been tried before to deal with it? What medical/social/psychological factors may underlie it?

Non-drug management strategies

See Table 7. Recent management practices in dementia care are moving away from a problem oriented focus, toward the assessment and fostering of an individual's 'personhood' and residual strengths.[53-56].

A patient, creative, trial-and-error approach to management, using multiple strategies, is often required; 'quick fixes' are rare. Handbooks are available which contain useful advice.[57] Careworkers in rest homes and hospitals should make an effort to familiarise themselves with the person with dementia's background, habits and personality. Without this knowledge they are unlikely to be able to understand or deal effectively with challenging behaviours.

Social work support and other counselling interventions (eg, validation therapy, music therapy, water therapy, doll therapy) have been advocated for people with dementia, but few have been scientifically validated. The availability of these approaches varies widely, depending on local interest and expertise. All of these may be beneficial. A regular activity programme for dementia patients in a nursing home has been evaluated. The activity programme appeared to reduce the presence of behaviour disorders in the treatment group as well as reducing the requirements for psychotropic drug use or restraints.[58] (See Appendix 7(3).)

The role of physical restraints (bedrails, chair-belts etc) for managing severe agitation or aggression is controversial. These should only be used as a last resort, in the interests of safety; the indications for, and amount of use should be accurately documented and regularly audited.

Guidelines for prescribing psychotropic drugs

General

Medication can be very helpful in treating some behavioural problems, but should not be regarded as first-line treatment (except in emergencies). Other strategies should be tried first and continue in parallel with drug treatment. Psychotropic medication will not solve disinhibition or wandering without producing over-sedation; nor will it help negative symptoms or incontinence. The specific goals of treatment should be clear at the outset.

The golden rule is to start with low doses and increase slowly, whilst carefully monitoring both beneficial and adverse effects. Dosage times should be tailored to the target problem – behaviour is often most difficult in the latter part of the day. The benefits and risks of treatment should be openly discussed with the patient (if possible) and carers. In this way unrealistic expectations and fears can be dispelled. Adverse effects are unfortunately very common. These include: sedation, confusion, decreased mobility, low blood pressure and Parkinsonism. It is also important to be alert to the possibility of paradoxical worsening of behaviour. Once instituted, drug treatment should be reviewed on an ongoing basis and attempts made to reduce or withdraw it. Many behavioural problems are relatively short-lived, so psychotropic drugs should not be prescribed indefinitely.

Drugs used

Major tranquillisers are the usual first-line drug treatment for agitation or aggression (especially if associated with psychosis) and have shown modest efficacy in controlled trials.[59] Haloperidol and thioridazine are the most commonly used. Other neuroleptics include pericyazine, loxapine, thiothixene and pimozide. A prospective study[60] has suggested that neuroleptic drugs may hasten cognitive decline in dementia. Whilst further studies are needed to confirm this, finding it emphasises the need for caution and judgement in the use of these drugs. The place of novel neuroleptics (clozapine, risperidone) is yet to be evaluated, but may prove particularly valuable in Lewy-body or Parkinsonian dementia.

If anxiety appears to be driving the behaviour problem, shorter-acting minor tranquillisers may be tried (eg, chlormethiazole, oxazepam or alprazolam). For sleep disturbance a course of a shorter-acting sleeping tablet (eg, temazepam or zopiclone) can be useful.

Other treatments which may be used by specialist dementia units[61] include: buspirone, clonazepam, carbamazepine, lithium, valproate, beta-blockers, phenergan, clonidine, trazodone (not available in New Zealand), other antidepressants, cyproterone and bright light therapy.

Management of stress and morbidity among carers of those with dementia

Epidemiology

At least 80% of people with dementia are cared for at home, with only 10–20% residing in institutions. Seventy-five per cent of dementia carers are female, many of whom are elderly. Within families there is an unspoken hierarchy of obligation to give care in Western society. Primary obligation falls to spouses, followed (in order) by unmarried daughters, married daughters, daughters-in-law, sons and other kin.

Strain and burden

Dementia carers have been shown to have poorer physical health status and impaired immune function, as well as higher levels of emotional distress, compared to equivalent samples of carers for other disabled groups.[62] A substantial minority suffer from psychiatric illness, especially depression. There is minimal data on strain among professional carers.

It should be noted that caring for a person with dementia, whilst often stressful, may also be a positive, life-enhancing experience.

Determinants of poor emotional health [62-63]

Factors related to dementing illness

Neither severity of cognitive impairment nor duration of dementia seem to be correlated with strain as strongly as behavioural problems of the person with dementia. Particularly stressful are: sleep disturbance, incontinence, immobility/falls, repetitive demanding behaviour and aggression. 'Negative' symptoms grind down the carer and produce a build-up of strain over time. These include loss of initiative, loss of good company/conversation and the need for constant supervision.

Relationship factors

Spouses are generally more stressed than other kin. The quality of the past relationship has a major bearing on strain, with ambivalent, conflictual or highly mutually dependent premorbid relationships predicting high levels.

Caregiving factors

A problem-focused approach, compared to an emotion-based approach to caregiving appears to protect against strain. Similarly, those carers adopting a managerial rather than 'hands-on' style of caregiving tend to be less strained and are likely to relinquish care at an earlier stage. Dysfunctional caregiving[63] is characterised by:

(i) inability to set limits when the cared-for person behaves unreasonably

(ii) inability to leave the cared-for person, even when adequate arrangements are made

(iii) difficulty engaging with outside agencies when help is offered

(iv) marked discrepancy in the cared-for person's level of functioning between home and other care settings.

Support

The relationship between support levels and strain is highly complex and variable. Informal (unpaid) support appears to be protective in some circumstances but scientifically sound evidence for any protective benefit of formal (paid) support services is lacking. There is, however, a great deal of descriptive and anecdotal data indicating support services are helpful in many ways to carers and people with dementia.

Gender

Studies have consistently shown that female carers experience, on average, much more strain and morbidity than their male counterparts.[63] This appears to be mainly related to attitudinal factors and differences in coping style.

What can be done to relieve carer strain and distress?

Training programmes for carers have been shown both to relieve strain and to delay institutional placement, and are therefore cost-effective.[65] Key elements in such programmes are: education about the dementing illness, together with its prognosis and possible complications; encouraging the carer to come to terms with losses involved, through expression of feelings; encouraging a more objective caregiving style; and coaching specific practical strategies.

Despite the dearth of solid empirical evidence for effectiveness of formal support services, demand for these services among carers (especially for respite care) tends to be high; once provided, they tend to be well accepted. Support groups and various other forms of counselling are helpful for some carers, although scientific evidence for this is also scarce.

There is good evidence that institutional placement of the person with dementia usually results in reduction of measured strain levels in the carer (although it may also produce a new set of adjustment difficulties).

Table 3: Drugs which can cause or exacerbate cognitive impairment

All psychotropic drugs	Others	
• Antidepressants • Lithium • Minor tranquillisers • Neuroleptics	• Alcohol and other recreational drugs • Analgesics (dextropropoxyphene, nefopam, opiates) • Anticholinergics • Anticonvulsants • Antidiabetics (if cause hypoglycemia) • Antihistamines • Beta-blockers • Corticosteroids	• Ciprofloxacin • Digoxin • Dopamine agonists (eg, levodopa, bromocryptine) • H2-antagonists • Non-steroidal anti-inflammatories • Quinine • Theophylline

Table 4: Psychiatric symptoms/syndromes in dementia

Delusions (false beliefs) (30% of cases*)	• Usually paranoid type: theft, infidelity, persecution, abandonment. • Often evanescent rather than fixed/systematised. • Usually occur in mid-stages; early onset predicts poor prognosis.
Misidentifications (30% of cases*)	• For example, failure to recognise own home, delusion of 'phantom boarder', misidentification of other people, accusations of others being imposters, mistaking TV for reality, mistaking mirror image.
Misperceptions (illusions) and hallucinations (25% of cases*)	• Visual more common than auditory (eg, deceased relatives). • More common in later stages; indicate poor prognosis.
Depressive states (20–40% of cases*)	• More common in earlier stages of dementia and in vascular dementia. • Correlates with degree of disruption to brain monoamine systems (and possibly to retained insight). • More common if previous history of depression. • Carers' observations important in making diagnosis. • Diagnosis difficult as many symptoms (eg, apathy, loss of interest, sleep/appetite disturbance, agitation/retardation) can be due to dementia alone.
Anxiety states (up to 40% of cases*)	• Mostly situational anxiety with unfamiliar situations or if left alone. • Catastrophic reactions, panic attacks, compulsive rituals and phobias can also occur, and may require specific intervention.
Mania (2–3%)	• Dementia may occasionally present with a syndrome which is indistinguishable from hypomania: overactivity, sleep disturbance, talkativeness, disinhibition, and cheerfulness or irritability.

Table 5: Features that may distinguish depression from dementia

Feature	Primary depression	Primary dementia
General features	Family aware of illness; onset more acute and can be dated; symptoms of short duration; rapid progression; family history of affective disorder	Family often unaware of illness; insidious onset, only vaguely dated; symptoms of long duration; slow progression; possible family history of dementia
Patient's history	Past history of depression; seeks help with complaints of memory loss; complaints given in great detail; cognitive deficits emphasised; failings highlighted by patient	No history of depression; few complaints of memory loss; vague, non-specific complaints; cognitive deficits concealed; accomplishments highlighted by patient
Mental state observations	History consistent and sequential; patient makes little effort with tasks and readily gives up; subjective distress common; affective symptoms pervasive; complaints greater than observed dysfunction	Inconsistent history with poor temporal sequencing; patient struggles with tasks; efforts sustained and may use cues or evasions; unconcerned attitude common; affect may be shallow or labile; observed dysfunction greater than complaints
Cognitive testing	"Don't know" answers common; recent and remote memory loss more equal; poor memory for specific periods common; concentration worse than general knowledge or memory; test performance may be highly variable; no typical WAIS pattern	Frequent 'near miss' answers; orientation tests poor; recent memory worse than concentration; consistently poor test performance; WAIS performance scores worse than verbal scores
Neurological	No primitive frontal release reflexes; no dyspraxias or agnosias; no language difficulties, corrects paraphasic errors; CT head scan more commonly normal	Frontal reflexes may be present; dyspraxias and agnosias common; word finding problems and paraphasia common; CT head scan usually abnormal, with cerebral atrophy

Adapted from [65-66].

Table 6: Problem behaviours in dementia

Inappropriate aggression	• Angry shouting, swearing, threats. • Resistiveness with personal cares. • Assaultive behaviour.
Catastrophic reactions	• Anxiety, tears, anger.
Excess motor behaviour	• Restless pottering/fiddling. • Repetitive pseudo-purposeful behaviour. • Agitation (increased motor behaviour, with dysphoria): eg, distressed pacing, inability to stay seated, 'sundowning'.
Wandering (inappropriate locomotor behaviour)	• 'Trailing'. • Getting lost. • Absconding.
Disinhibition/personality change	• Inappropriate toileting. • Undressing in public. • Repetitive questioning. • Repetitive calling out/screaming. • Sexual disinhibition. • Egocentricity. • Stubbornness. • Demandingness. • Querulousness.
Sleep disturbance	• Insomnia (various types). • Hypersomnia.
Incontinence	• Urinary or faecal.
Negative symptoms	• Affective blunting. • Avolition/apathy. • Social/conversational withdrawal.

Table 7: Non-pharmacologic prevention/management strategies for behavioural problems in dementia

Some general practical strategies	• Tolerate the behaviour (avoid arguing or scolding). • Ignore unwanted behaviour or walk away; positive reinforcement of adaptive behaviour. • Distraction: try to focus attention away from what is upsetting the person with dementia. • Use empathy and humour to defuse tension. • Maintain respect, avoid infantilisation. • Slow pace, avoid rush. • Repeated explanation and reassurance. • Don't say to the person "I just told you that ...". • Clear, direct, short and simple communication; importance of eye contact, gestures and appropriate touch. • Break tasks down into small steps. • If resistance encountered with task, try again later. • Establish a routine that suits the person with dementia. • Establish a physical environment that suits the person with dementia (safe, comfortable, familiar, interesting).
Specific activities or therapies	• Reality orientation. • Reminiscence. • Validation therapy. • Behaviour modification. • Cued recall. • Music therapy and dance. • Motivational therapy. • Doll therapy. • Water therapy.

Dementia and driving

Under Section 45A of the Vehicle and Driver Registration and Licensing Act 1976, doctors and optometrists have a legal obligation to notify the Secretary of Transport if a person is not physically or mentally fit to drive. The practitioner, in making the notification, must be satisfied not only about the person's medical unfitness to drive, but also that the licence holder will probably continue to drive despite medical advice.

Information should also be sought from the caregiver about the person's continuing ability to drive safely. Many small incidents can illustrate deteriorating ability long before a serious or life endangering accident occurs. The role of the medical practitioner in encouraging the person to give up driving cannot be understated. This task must not be left to caregivers or families. Medical practitioners may find this difficult involving as it does a loss of independence for someone who may have been a patient for many years. The discussion may provoke anger on the part of the patient. Some may feel that there is an ethical dilemma at stake. This should be seen, however, as a situation where the safety of others outweighs the rights of the individual.

Some people will acknowledge the problems of slowed reaction time and judgement. Others may recognise potential problems with Insurance cover.

Options for alternatives should be discussed including:

- the offer of a second opinion
- the suggestion of a formal driving assessment or a simulated test available in occupational therapy departments in some hospitals
- the use of mobility vouchers to reduce taxi costs.

There is no nationwide standardisation of driving tests for the cognitively impaired and this is regarded as an anomaly that should be corrected.

Legal matters

People with dementia often become unable to manage their business, financial or personal affairs. They may be unaware that a problem exists. This makes them at risk from the unscrupulous. Forward planning of legal and business administration together with discussion of treatment decisions are best addressed as soon as diagnosis is confirmed when the person with dementia may still be able to express their views. This may be difficult, however, if the person has impaired insight. Testamentary capacity and enduring Power of Attorney should be considered.

A person with early dementia who has retained insight may wish to record their options for management of intercurrent illnesses in the form of an 'Advanced Directive'.

Impaired driving ability is frequent. Notification of a person who is considered to be physically or mentally unfit to drive is a legal requirement under Section 45A of the Vehicle and Driver Registration Licensing Act 1976.

The Protection of Personal and Property Rights Act 1988 allows for a variety of orders to be made from operating one bank account through to full scale management of all business affairs. Information about the Act is available from lawyers, the Public Trust, a Family Court Office, one of the Trustee corporations or the Citizen's Advice Bureau. A social worker should be able to assist with advocacy, information giving and coordination of resources.

It has been suggested that some health professionals are not as familiar with the Act as they should be. **It is recommended that a refresher information package about the Act should be distributed to relevant health professionals.** The need for careful documentation in clinical reports prepared under the Act is particularly important.

Ethical issues

Ethical issues arise frequently in dementia care. By their very nature the dementias cause progressive loss of memory and later judgement and insight. This can lead to risks to personal autonomy and decision making. A time may occur when the patient's memory and judgement are so impaired that it is appropriate for others to either assist with decision making or to take responsibility on their behalf. A problem that often arises is that the person with dementia may have such impaired insight that they fail to recognise that they need help.

Dementia does not always affect cognition globally. A person can retain insight in decision making ability in some aspects of their life while otherwise being quite disabled.

Resolving some of these problematic issues can be difficult in people with dementia and their carers need support from general practitioners and specialists in their resolution.

The spirit and practice of modern old age psychiatry aims to encourage general practitioners, patients and families, to contact services at an early stage, seeing them throughout as being flexible and informal.[67] This can cause conflicts if contact with the services results in losses for the person with dementia such as inability to drive or the suggestion that a move to continuing care is necessary. However, ethical issues, although difficult, are best addressed when early diagnosis has occurred and forward planning can happen at a time when the person is still able to indicate their preferences.

Particular areas of ethical difficulty include:

1. implications for the patient (eg, driving, management of finances, decisions about further treatment and care options)
2. implications for the family, in particular at what stage the person's autonomy is impaired by loss of memory and judgement to a point where others have to act as proxy
3. implications for the community (eg, risks and dangers of a person with dementia living alone, the costs of vigorous intervention and the costs of community and institutional care)
4. consideration of the ethical implications of technological advances
5. dilemmas associated with treatment which include legal and moral dilemmas and maintaining 'quality of life'.

Health professionals and community groups such as Age Concern and the Alzheimers Society must be prepared to assist in the resolution of the tricky ethical problems that can arise.

Educational interventions must emphasise the need to plan ahead and to address 'end of life' decisions.

Abuse

People with dementia are at increased risk of abuse. This can be physical, psychological, financial or sexual. The stresses associated with caring for someone with dementia can tax the resources of even the most patient and this can lead to physical or psychological abuse. This can occur more readily if the carer is unaware of supports.

It should also be recognised that the person with dementia can sometimes be the abuser. Recognition of situations where abuse is occurring may be difficult and requires awareness of the possibility by health professionals and tactful enquiring about the stresses of caring.

- Those working with older people, particularly caregivers in rest homes and long stay hospitals, should be aware of the issues of elder abuse.
- It is recommended that undergraduate programmes of health professionals should include teaching about the issues of elder abuse.
- Education programmes for older adults, including retirement programmes, should stress the need for older people to be aware of their rights.
- Elder abuse resource services are not developed uniformly throughout New Zealand. In a number of places they consist of an interdisciplinary team co-ordinated by the local branch of Age Concern. This arrangement works well.

It is recommended that there should be uniformity for these services and that each region of the country should have a publicly funded elder abuse resource team.

Community care

Practical treatment and support for people with dementia and their families

Once the presence of dementia is established, information and support become crucial to the management of the condition for the medical practitioner, the person with dementia, and the family. Access to support and counselling often minimises carer stress and burden, and assists in the maintenance of social and functional skills of the person with dementia.

Carers need to be able to access information in small, manageable 'bites'. They need information on:

- what the diagnosis is, and its prognosis
- how dementia affects the brain
- how this may affect the person's personality, behaviour and functioning
- when and how to ask for help
- what services are available and how to access them
- legal and financial matters (eg, enduring power of attorney, operation of bank accounts)
- emotional support systems available including:
  - support groups
  - counselling
  - social work services
- respite care available:
  - day care
  - short-term respite
  - in-home respite (eg, sitter service)
  - intermittent/rotational care
  - night care

- financial assistance available
- how to deal with challenging behaviours and difficult issues such as giving up driving
- residential care options and how to access and evaluate these.

Alzheimers/ADARDS groups have comprehensive written information specifically for carers. All have support groups, and many have education programmes for carers. These may also be available through other agencies providing dementia support services in your area.

Not all people with dementia will have a carer available, and some will have family members who do not wish to take on the caregiving role. Adequate support systems must be set up to enable these people to remain at home for as long as desired and practicable.

It is recognised that people with dementia living alone will usually need to access residential care sooner than those living with a carer. There are complex ethical and legal issues involved in ensuring that a person's wish to continue living alone are balanced with those of their safety and that of others.

Recognising carer burden or stress

The stress associated with caring for a person with dementia should never be underestimated. It places an extraordinary burden on those who undertake the caring role.

Some people find themselves unwittingly and unwillingly in the role of carer. Other family members may look to one member of the family to take on this role without considering whether this person has the desire, ability or emotional capacity and physical health to cope. For some families, geographical location may place responsibility for care on one member only.

Several factors should be considered when evaluating the strengths of a caregiving relationship and the degree of burden likely to be experienced (see Diagram 1).

The ability to cope with caring depends on:

- the symptoms exhibited by the person with dementia
- the type, frequency and disruptive effects of aberrant behaviour
- the duration and severity of the dementia symptoms
- the carer's response to these symptoms and tolerance of aberrant behaviour
- the formal and informal support services available to assist
- the carer's emotional and physical health
- the carer's perception of whether they have sufficient emotional support
- the quality of the carer relationship with the person with dementia prior to the onset of dementia
- the carer's ability to make lifestyle adjustments
- the carer's ability to take over responsibilities and decision making within the home
- the carer's other commitments.

Difficulties experienced with any one of the above areas can be enough to produce sufficient stress to place either the person with dementia or the carer at risk, or jeopardise the success of community care. It needs to be recognised that carers often become physically and mentally exhausted over time. This can have a profound effect on their decision-making ability. It is important to be aware that carer stress can lead to abuse and neglect of the person with dementia.

Stress may also be caused by the need for carers to take on the roles and functions formerly performed by the person with dementia. A son or daughter may find themselves in the role of parent to their own parent. The person with dementia may resist and oppose this carer's good intentions.

Grief is a constant feature of dementia. Initially this sense of loss and bereavement may be shared by both the person with dementia and those who are close to him or her, but later these feelings are experienced by the carer, often in isolation. Carers have described the journey through dementia as "the funeral that never ends". As losses continue throughout the progress of the dementia, so the grief process is ongoing. There is potential for carers to become depressed.

Identifying sources of stress

- Dementia symptoms increasing.
- Increased dependence of the person with dementia.
- Challenging or difficult behaviours.
- Change in informal or social support systems.
- Change in carer's health status.
- Deteriorating relationship between person with dementia and carer.
- Financial strain.
- Uncertainty about the future.
- Inability to accept the diagnosis.
- Other concurrent life crises.
- Lack of support from family.

Identifying signs of stress

- Self-reported stress.
- Increased dependency on alcohol or other drugs.
- Reported weight loss or gain.
- Sleep disturbance.

Assessing stress levels

Ask the carer "How is this affecting you? What has changed for you?". Ask about the carer's mood level. Note any changes in the carer's health which could be stress related.

Modifying stress levels

- Provide information about the effects of dementia.
- Encourage use of new services.
- Facilitate respite care.
- Refer for counselling or to support groups.
- Assess carer's health needs.
- Assist the carer to access all available financial assistance.
- Refer to carer education courses if available.

Reviewing stress levels

- Review carer stress levels at least six-monthly; three-monthly would be ideal.
- Monitor the efficacy of increased support.

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Services for people with dementia and their carers

Currently, quality services for people with dementia are scarce, and sporadic. There is wide variation from region to region and respite care and home support services are severely restricted. Standards for home-based support services and residential care are in place but monitoring/auditing procedures are questionable and vary greatly even within Regional Health Authorities. No national standards exist for daycare services for older people.

Information, education, and support of families are still largely unrecognised as key services, yet their worth has been proven[68] in reducing the impact on higher cost services, such as residential care, access to which may be delayed considerably when families are given the skills to care for the person with dementia at home. Psychological stress in carers is also reduced.[69]

The GP is frequently the gatekeeper for service delivery. Referral or authorisation is needed for many services (eg, Support Needs Assessment Form (SNAF) to access Carer Support Subsidy), or provision of medical certificate proving eligibility for Disability Allowance. GPs may need to suggest services which may benefit the person with dementia and the carer, and any financial assistance available for these. The practice nurse could hold this information and ensure it is kept up to date.

Management of dementia is long term. In planning or reviewing community care, the following should be taken into account:

- the dynamics of the relationship between the person with dementia and the carer
- the strength and the resources of the primary carer
- other demands on the primary carer
- availability of support, both formal (eg, home support, day care) and informal (eg, family, friends, church).

People with dementia, their carers and families need sufficient information about services to enable them to make realistic choices. Carers should be forewarned that the person they care for may eventually require residential care. By being forewarned they will have time to anticipate and prepare for residential care. Counselling at this point may be useful in assisting the carer's transition from carer to care-guardian.[70] (Care-guardian refers to the important protective function which carers assume once their relative enters a residential facility.)

The issues of care should be sensitively discussed, and health professionals should ensure that their own values do not intrude.

Domiciliary management by initiating and supporting caring networks have been shown to reduce crisis calls and hospital admissions.[71]

Community services

- Information on the available community services can be obtained from the Alzheimers Society, Age Concern or local assessment, treatment and rehabilitation (AT&R) Unit.
- Information, education and support – Alzheimers Society/ADARDS.
- Social work support.
- Counselling.
- Day care.
- Respite: sitters, short-term care.
- Home support: personal care including showering/bathing, administering and monitoring medication domestic assistance, including cleaning, cooking, assistance with shopping.
- District nursing.
- Meal services.
- Laundry service.
- Gardening and lawns.
- Volunteers.
- Total Mobility.
- Incontinence aids and advice.
- Occupational therapy.
- Physiotherapy.

- Diversional therapists.
- Domiciliary dentists, hairdressers, podiatrists.
- Financial advice (eg, Income Support Services).
- Personal alarms (may have limited use for a person with dementia).

Barriers to accessing services

- No diagnosis/assessment, therefore no knowledge of where to turn to for help.
- No information about dementia, therefore no idea of what is ahead, no understanding of the nature and probable course of the illness, and no chance to prepare for the future.
- Denial of need, by the person with dementia, the carer, or both, resulting in refusal to accept help, and cancellation of arranged services.
- Values and vows (eg, independence); belief it is better to give than receive; marriage vows; values of privacy.
- Lack of ability/experience in finding out about services, negotiating for them etc – give up easily.
- Guilt and/or embarrassment:
  - about the behaviour of the person with dementia
  - about the home circumstances
  - about not wanting to be involved in the caring role
  - about being somehow responsible, or to blame for the illness and therefore not worthy of help.
- Stigma:
  - correlation with mental illness
  - not wanting others to know: “best kept in the family”.
- Cost:
  - actual cost of services or concern about what help might cost
  - lack of knowledge of available financial assistance.

Day care

Day care is a valuable support for many people with dementia and their carers and may delay the need for rest home care.

Attendance at day care can help meet the emotional, physical and intellectual needs of the person with dementia, by providing stimulation, companionship and social interaction.

It also gives the carer a break.

A day care service is able to monitor, report, and assist with the management of dementia.

Attendance at day care can also provide transition to residential care.

Residential care: when, why and how

Residential care can have benefits for both the person with dementia and the carer. Counselling for the carer at the time of placement can ease the transition and allow feelings to be dealt with. Many carers experience difficulty in deciding on the appropriate time for residential care. They often look to medical practitioners for direction and then for reassurance that the correct decision has been made. The change in role for the carer can be quite traumatic, as often carers feel they have no further place in the person with dementia’s life, except as a visitor. The GP has a continuing role in supporting the carer through this stage in the caring journey.

Information must be given to families to assist them to understand the process of making the transition to residential care. They also need to know the range of residential care options available, and how to assess these, in order to choose appropriate care for the person with dementia.

When?

- When the emotional and attentional demands of the person with dementia become too much for the primary carer.
- When the carer's health begins to show the effects of stress from the caring role.
- When the person's skills deteriorate making it very difficult for care to be provided at home.
- When the person with dementia lives alone, and is now in danger – when there are intergenerational stresses.
- When there are inadequate support services available.
- When the cost of community care outweighs the benefits.

Why?

- May improve quality of life for the person with dementia and the carer.
- To reduce the possibility of abuse.
- To optimise the carer's health.
- To enable the person with dementia to settle into a new environment before his/her dementia is too far advanced. (This needs to be balanced against the willingness of the person with dementia to accept residential care and the confusional effects of leaving a familiar home environment.)

How?

- Provide as much information as possible to the carer and family on the process.
- Visits to the facility by the person with dementia and their carer.
- Where possible use day care or intermittent care to ease the transition.
- Ensure appropriate assessment has been carried out.

Public awareness, education and training

Whilst public awareness of Alzheimer's and related dementias has improved markedly over the past 10 years greater understanding is still needed.

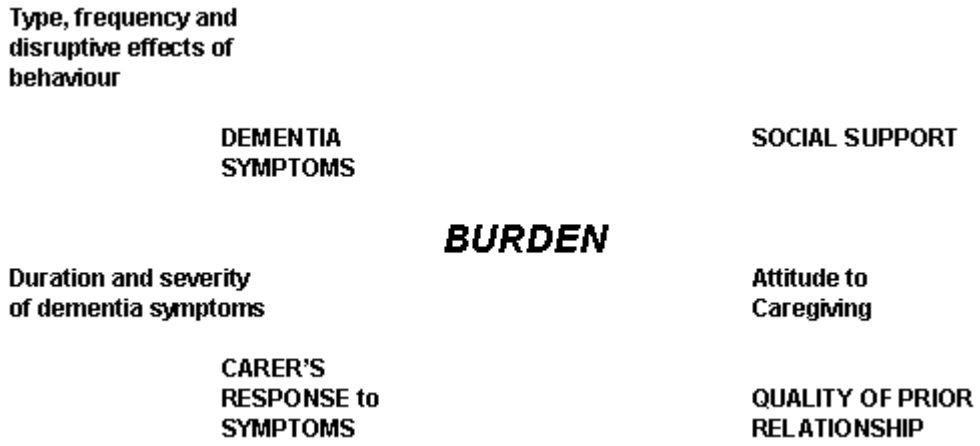
Awareness is the key to early diagnosis, support and better management of dementia. As drug treatments become more readily available early detection of dementia will be vital for these to have maximum benefit.

The Alzheimers Society/ADARDS has developed a comprehensive range of written material which is available throughout the country. It has arguably been the most effective agency in raising awareness of dementia, and its partnership with key health professionals has resulted in real progress in the area of education and training of families and health professionals.

However, there is a wide variation in training standards throughout the country and even within regions. The following actions are recommended:

1. Implementation of standardised, mandatory training in dementia for all medical students in both the pre-clinical and clinical years.
2. Implementation of standardised, mandatory training in dementia for all nursing staff and allied health professionals at undergraduate level. Training of ancillary staff should also reflect this standard.
3. National standards for dementia – specific training included in service contracts with residential care facilities, in particular those providing specialised dementia care.
4. Training programmes for family carers available throughout the country, resourced by RHAs.
5. Appropriate funding for the Alzheimers Society's administration of its national awareness and information programmes. Government policy and funding which recognises the importance of trained careworkers, and requires and resources the RHAs to ensure funding for training and adequate payment of trained staff is built into service contracts.

Diagram 1: Determinants of carer's burden



Note: This is a draft copy only. The finished diagram will be placed in soon.
Adapted from Zarit (1985).

Algorithm 3
This algorithm is not available yet.

Cultural issues

Among people with traditional Maori values, there is a high level of tolerance for changes in the behaviour of their older people or kaumatua. A person who is dementing will maintain their mana (status) if they can still perform well-learned functions of tikanga Maori. In such situations behaviour changes and difficulties with short-term memory or adapting to new or unusual situations, may be seen as less problematic, and whanau may delay seeking help for their older person.

A useful framework for understanding traditional Maori health perspectives is Te Whare Tapa Wha, which incorporates four inter-related components: taha hinengaro (emotions and mind), taha wairua (spirit), taha tinana (body) and taha whanau (extended family). Disruption in any one component can interfere with the well-being of other components. An holistic approach to health service delivery is essential. The role of whanau in the care of a person with a disability is especially important.

Culturally appropriate service provision

Dementia services should be provided in a way that respects cultural values and beliefs. Many disability services, however, are based on essentially monocultural models of habilitation. *He Anga Whakamana, A framework for the delivery of disability support services for Maori* provides advice on what Maori consider to be accessible and appropriate disability support services (see Appendix). While *He Anga Whakamana* does not specifically address the issue of dementia, many of the recommendations will have relevance to working both with Maori with dementia and their families. Applying the following principles from *He Anga Whakamana* to service delivery will help ensure services are appropriate to Maori:

- Whakapiki: enablement of client decision-making on service options.
- Whai wahi: participation of clients, whanau and Maori institutions.
- Whakaruruhau: safety including both physical and non-physical safety.
- Totika: effectiveness with a focus on health status issues and health gains.
- Putanga: accessibility, which requires good information, service availability.
- Whakawhanaungatanga: integration by making links with other appropriate services.

The report itself provides greater detail of appropriate and accessible health service delivery of DSS services to Maori. Copies of the report are available from the National Health Committee.

Assessment of Maori with suspected dementia

Any assessment of suspected dementia should take into account the social, economic and cultural background of the person concerned. It may help to compare current versus former performance in these areas. This is especially important when assessing Maori with suspected dementia, as there is some uncertainty about the relevance of neuropsychological tests (and psychological tests *per se*) in the absence of normed data for Maori.

The assessment process should recognise the sensitivities in the relationship between the health service provider and the Maori person being treated. Appropriate communication is essential if the health service provider is to elicit the information required to identify both dementia and develop the rapport necessary to initiate a management plan. Health professionals should consider the following:

- The person may prefer that family members also attend the interview, so inform them that it is okay to have whanau present. Make sure the physical setting can comfortably accommodate a group.
- Make early efforts to establish rapport with them and/or their whanau. It is generally inappropriate to ask patients immediately for personal information.
- Direct eye-to-eye contact may make the person uncomfortable and uncommunicative.
- A whanau member who answers questions on behalf of a person is not necessarily being dominant. Often it will be appropriate and helpful to all parties involved. In effect they may act as an advocate for the person concerned.
- People may be reluctant to ask questions about things such as diagnosis, treatments and medications. Whanau members may be able to help. Give as much information as possible including any information handouts for people to take away. Inform them that it is okay to ring to discuss any questions or concerns.

Sightings or hearing voices of the deceased ancestors (especially recently deceased), or preoccupation with cultural injustice, are not necessary indications of confusion or perception disorders. If the person describes symptoms such as these, give serious consideration to involving Maori health workers, tohunga (Maori traditional healers) or kaumatua (Maori elders) experienced in mental health and spiritual issues.

Ongoing support and management of Maori with dementia

Serious consideration must be given to involving Maori health workers in the ongoing support of both Maori with dementia and their whanau.

Roles and responsibilities for different aspects of the person's ongoing care need to be developed between the person concerned, whanau, other health service providers involved. A team approach incorporating Maori health expertise will help to overcome problems that may arise through a lack of understanding of cultural perception and needs of Maori clients.

The role of the extended family, including hapu and iwi, in the long-term care of their kaumatua is of cultural importance, but should not be taken for granted. Maori families have pressures similar to those of Pakeha families, for example, increasing numbers of women in the workforce and smaller families with fewer members available to give care (Ratima et al 1995). When Maori people with dementia are placed in residential care, it should be seen as a response to the stresses of caring.

Where a referral is made health service providers should continue to be available to and supportive of the person and their whanau as appropriate.

Assistance or direction on obtaining cultural support may be found by contacting local iwi authority offices or regional offices of Te Puni Kokiri (TPK also have iwi authority contact details).

Research priorities

The ageing population means that dementia is going to continue to be a major challenge for health and social services.

It should therefore be considered an area of research priority. Projects which assess service innovation and ways to deliver services cost effectively should be encouraged. Dementia research includes high technology biomedical research. Projects about service provision and stress levels in carers should be regarded with equal importance to those in other areas of medicine that have a higher public profile.

1. Further studies into the prevalence of dementia in New Zealand with particular emphasis on rates in Maori.

2. Clarification of risk factors for Alzheimer's Disease and vascular dementia and strategies for primary prevention.
3. Pathogenesis of Alzheimer's Disease:
   – neurochemistry
   – neuropathology
   – genetics.
4. Development and evaluation of cognition enhancing medications.
5. Evaluation of non-drug and drug treatments for behavioural disturbances.
6. Evaluation of design and environment on behaviour and management of dementia.
7. Evaluation of different drug treatments for depression and dementia.
8. Clarifying the incidence, prevalence and clinical features of Lewy body dementia.
9. Assessing the efficacy and cost effectiveness of formal support services.
10. Assessing the use of formal and informal supports among non-Europeans.
11. Evaluation and cost effectiveness of education/training for carers.
12. Evaluation of the effects of caregiving in people with dementia.
13. Exploration of non-medical models of care delivery.

Audit of care for persons with dementia

These questions are suggested as an audit check list for the management of a person with dementia in general practice.

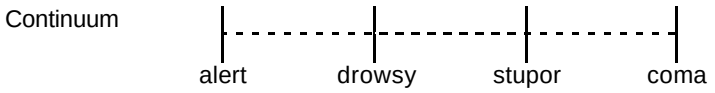
	Yes	No
Does this person have a diagnosis?		
Have reversible causes of confusion been excluded?		
Have the person and their family been: 1. Consulted throughout the process? 2. Told about available services? 3. Told about sources of education? 4. Given the phone number of their local Alzheimers Society?		
Have medications been reviewed: 1. At the time of diagnosis? 2. Six monthly?		
Has psychiatry co-morbidity been assessed?		
Have measures such as driving, Enduring Power of Attorney and Will been discussed?		
Have arrangements been made for a three-monthly review of support needs for carers?		

Have arrangements been made for a six-monthly assessment of safety, including driving?		

Appendix 2: Mini mental state examination

	Maximum score	Patient score
Orientation What is the (year), (season), (date), (day), (month)? Where are (country), (province), (city), (hospital), (ward)?	 (5) (5)	
Registration Name three objects, one second to say each. Ask the patient to repeat all three after you have said them. One point for each correct answer. Repeat until the answer is correct. Count all trials and record. Trials	(3)	
Attention and calculation Serials 7s. One point for each correct. Stop after five answers. Alternatively spell 'world' backwards.	(5)	
Recall Ask the patient to name three objects repeated above. One point for each answer.	(3)	
Language Ask patient to name pencil and watch. One point for each correct. Repeat the following "no ifs, ands or buts". One point. Follow a three-stage command – "Take paper in your right hand, fold it in half, and put it on the floor". Three points. Read and obey the following: • "Close your eyes." One point. • "Write a sentence." One point. • "Copy a design." One point.	(9)	
Total score	**(30)**	

Assess level of consciousness



Clock drawing test

"From memory, draw the face of a clock with the numbers and mark the hands to say 8.45."

* From Folstein MF, Folstein SE and McHugh PR. 1975. "Mini-Mental State: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research* 12: 189–93. Copyright 1975, Pergamon Press Ltd.

Appendix 5: Dementia screen tests

Hb, WBC, ESR
Renal function/electrolytes
Liver function
Thyroid function
Blood sugar
Serum calcium
Serum B12, folate levels
Urine – WBC, protein, sugar

CXR
Syphilis serology

Appendix 7: Systematic review of the literature

We were asked to review the literature to assess the strength of the evidence for several aspects of the support and management of people with dementia. In particular we were asked, where possible, to develop evidence tables and balance sheets. The development of balance sheets was not possible on the basis of current literature.

A number of overseas studies have attempted to determine the financial costs of caring for those with dementia but most have been beset with methodological problems. There is universal agreement, however, that:

1. the costs are considerable
2. the costs of informal caregiving are usually under-estimated
3. the costs of dementia care are going to increase markedly with the ageing of the population.

There is an urgent need for New Zealand data on the economic impact of the dementias, and for studies of care innovations which might contain the costs of dementia care. Care innovations must, however, seek ways to enhance the quality of life for both patient and carer rather than be concerned with cost containment.

The three areas that we examined in detail were:

- Appendix: The economic costs of caring for those with dementia
- Appendix: Diagnostic work-up with particular reference to CT head scanning
- Appendix: The extent to which training and activity programmes might benefit both carers and those with dementia causing illnesses.

Basic evidence grading strategy

Grade of evidence	Description	Comments
Grade 1	Randomised controlled trials	RCTs can control for selection bias.
Grade 2	Non-randomised controlled studies	These studies compare contemporary patients who did and did not receive the intervention. Selection bias may result from unrecognised or recognised differences between the study and comparison group. Only through randomisation can unknown selection bias be controlled.
Grade 3	Non-randomised historical cohort studies Other studies with non-experimental designs (eg, population-based studies, case control studies)	Comparisons between current patients who did receive the intervention and former patients who did not receive the intervention. Selection bias, confounding caused by non-randomisation and biases resulting from inappropriate comparisons over time are possible.
Grade 4	Case series	The reader is simply informed of the fate of a group of patients. Series may provide useful information about clinical course and prognosis but can only hint at efficacy.
Grade 5	Expert opinion	Expert opinion is not evidence but is included to assure that when it is considered we place more emphasis on evidence than opinion in determining appropriateness of care.

Appendix 7.1: Economic costs of dementia

Authors: **Title:** **Journal details:**	Stommel M, Collins CE, Given BA. The costs of family contributions to the care of persons with dementia. *The Gerontologist* (1994) 34(2): 199–205
Study aim:	• To give an account of the costs of family care for dementia patients residing in the community that includes the tangible, yet mostly unpaid contribution of family member. • To distinguish care components that are paid for by the family from the costs of families unpaid contributions. • To explore factors which predict total costs of family contributions and factors which predict the relative reliance on paid vs unpaid care among families engaged in dementia care.
Study population	Michigan, United States of America
Eligible population	182 Alzheimers patients and their primary caregiver
Population agreeing to be randomised	Not a randomised trial
Gender distribution	**Patients** Men – 43 Women – 139
Age distribution	Mean age 73.3 8.4
Degree of cognitive impairment	Moderately severe
Residential setting	Caregiver and patient in some household – 162 Caregiver and patient in different household – 20
Inclusion criteria	Patient age over 54 Caregiver report of Alzheimers disease or dementia At least one ADL dependency Existence of a primary family caregiver
Exclusion criteria	Determined by inclusion criteria
Extent to which study population can be extrapolated	There will be differences in the costs of services between states and countries; however, the principles of determining costs can be extrapolated
Study design/type:	Not a randomised trial but one that seeks to determine caregiver costs
Baseline measures	Patient household income Caregiver age Patient age Months since diagnosis Household size Patient's functional status Patient's cognitive status Living arrangement Caregiver relation to patient
Comparison of baseline measures between groups	Not a comparative study
Intervention Type/description	No intervention Assessment of costs of care
Duration of intervention	Three-monthly

<table>
<tr><td>Outcome:
Cost and outcome measures</td><td>Out-of-pocket expenditures for supplies and out of the home services
Caregiver labour cost
Family labour cost
Other labour cost
Total cash expenditures
Patient physical functioning
Patient cognitive impairment
Patient household income</td></tr>
<tr><td>Measurement of outcomes</td><td></td></tr>
<tr><td>Total costs</td><td>Cost of care to families during three-month period prior to interview
<table>
<tr><th></th><th>Adjusted mean</th><th>Range</th><th>% of cost</th></tr>
<tr><td>Out-of-pocket expenditures for supplier and out of the home services</td><td>$522</td><td>$100–$7600</td><td>14</td></tr>
<tr><td>Caregiver labour cost</td><td>$2890</td><td>$704–$8446</td><td>59</td></tr>
<tr><td>Family labour cost</td><td>$1106</td><td>$8–$5425</td><td>12</td></tr>
<tr><td>Other labour cost</td><td>$2172</td><td>$8–$11,800</td><td>15</td></tr>
<tr><td>Total costs to family</td><td>$3475</td><td>$100–$19,565</td><td>100</td></tr>
</table>
Predictors of total costs to families:
Functional disability scores, caregiver income, additional $10,000 of household income. Separate living arrangements.</td></tr>
<tr><td>Analysis bias</td><td>Use of a state-wide average wage rate disregards local variations and thus lowers the reliability of the cost variable. An average cost based on caregiver hourly wage rates was used to estimate the value of services rendered by family members – this may well under-estimate opportunity costs.</td></tr>
<tr><td>Summary assessment:
Level of evidence</td><td>Moderate</td></tr>
<tr><td>Recommendations:</td><td>Further data, particularly local New Zealand data, is urgently required about the costs to families in caring for those with dementias</td></tr>
<tr><td>Comments:</td><td>Family costs are substantial and should be included in calculations of the total economic costs of senile dementia. Families tend to substitute services paid for in cash for their own labour contributions. Economic status seems to raise the opportunity costs of unpaid family care, separate living arrangements may necessitate greater investment in paid care.</td></tr>
</table>

<table>
<tr><td>Authors:
Title:
Journal details:</td><td>Rice DP, Fox PJ, Max W, et al.
The Economic Burden of Alzheimer’s Disease Care.
Health Affairs (Summer 1993): 164–76.</td></tr>
<tr><td>Study aim:</td><td>To determine the total formal and informal costs attributable to Alzheimer’s disease for persons living in the community and in institutions.</td></tr>
<tr><td>Study group</td><td>A sample drawn from five counties in Northern California – 93 non-institutionalised patients and 94 institutionalised patients together with caregivers and staff. The groups were not comparable as those in institutions were older (39% vs 14% 85 and over), female (77% vs 59%), widowed (59% vs 36%) and with low incomes (38% vs 25%), incomes less than $US10,000 pa.</td></tr>
<tr><td>Degree of cognitive impairment</td><td>Community dwellers – 55% severe dementia
Institution dwellers – 94% severe dementia</td></tr>
<tr><td>Extent to which study population can be extrapolated</td><td>Small geographic study area means that cost findings are not easily generalised as costs may well vary from state to state and country to country.</td></tr>
<tr><td>Study design/type:
Level of randomisation</td><td>No randomisation</td></tr>
</table>

Cost measures	When formal and informal costs are combined, annual costs of caring for a person with Alzheimer's disease in the two settings are not significantly different – $US47,083 for those in the community and $US47,591 for those in institutions. However for those in institutions, informal services comprise 12% of the total costs of care compared with 73% for patients residing in the community. However for the severely demented in the community the total cost of care was $US52,667 9% higher than in institutions.
Study strengths	A reasonably large sample Costs estimated over an extended period Attempts made to calculate costs associated with medical care, lost productivity and informal care
Study weaknesses	Sample was not random Limited geographical area Characteristics of the two groups were dissimilar – probably reflecting factors that determine a move to institutional care In Northern California, patients may be diagnosed earlier because of the availability of state-funded Alzheimer's Disease diagnostic and treatment centres
Summary assessment: Effectiveness (potential benefit)	For patients with Alzheimer's disease living in Northern California the total annual cost of care is approximately $US47,000 whether the patient is at home or in a nursing home. For community resident patients, three-quarters of the total cost represents an imputed value for unpaid informal care compared with 12% for those in institutions. Over 60% of the services provided to patients in either care setting were paid out of pocket. With the projected increases in the number of persons at risk of developing Alzheimer's Disease, the economic impact of the disease will be significant.
Level of evidence	Grade 4 evidence
Recommendations:	This study carefully assesses the costs of care for Alzheimer's patients in the community and institutions and considers factors such as out of pocket expenses and lost income.
Comments:	There is an urgent need for New Zealand based studies on the costs of care in dementia and of evaluating interventions that might reduce care costs without prejudicing the quality of care.

Appendix 7.2: Evidence for use of CT brain scans and diagnostic work-up for people with dementia

There are no controlled trials evaluating the utility of routine CT brain scans in the diagnostic work-up of people with dementia.

There have been a number of case series, some of which are highly selected, evaluating the diagnostic yield of routine CT scans. These have shown reversible lesions in 2–10%.[1,2,3] This may fall to as low as 0.5% if there are no supporting clinical features.[4]

Evaluation of benefit is subject to a number of assumptions and inaccuracies: the prevalence of potentially reversible lesions, the consequences of intervening in a potentially reversible lesion (costs, complications and clinical improvement), the costs of diagnostic procedures, the costs incurred by false positive results, the costs of caring for people in whom a reversible lesion is missed. In addition the chance of Alzheimer's Disease being the cause of dementia increases with age.[7] This means the chance of detecting a reversible lesion decreases with age.

For people with focal neurological signs, abnormalities of gait or history of trauma, seizures or fever, there is Grade 3 evidence supporting the use of routine CT brain scans. [2,3,4,5 and 7]

This evidence also suggests considerable cost savings in these settings.

The cost benefit of performing routine CT brain scans in all people with dementia is less clear. The best analysis is found in Simon's work[4] which has used US costs from the 1980s. This has included the cost of a CT brain scan as being US$300 and the cost of caring for a person in institutional care as US$20,000 per year. Treatment costs were based on US Medicare reimbursement schedules. Prevalence figures, chances of actual reversibility in detected lesions and assumptions on life expectancy could be applied to the New Zealand situation.

Using this model, routine CT could be expected to detect between 1425 and 14,930 additional surgically correctable cases at an extra cost of between US$0 and US$49 million per 100,000 persons scanned. This equates to a cost of US$3,281 to US$34,385 to result in benefit for one person. These figures need to be calculated using realistic contemporary New Zealand data as it is likely that CT brain scan costs have shown a relative decline over time while institutional care costs have shown a relative increase. This would result in lower costs per person benefited. Thus while the costs of routine scanning are likely to be greater than the savings, the cost per person needs to be weighed against the cost of other health interventions in New Zealand. The yield of routine CT brain scan will be lower in people without focal neurological signs, an insidious onset over years of the dementia, who are aged over 80 years.

There is Grade 3 evidence to support routine CT brain scans in all people with dementia. This approach would probably result in a net cost in health expenditure but the actual financial costs need to be calculated in New Zealand terms.

There is Grade 3 evidence supporting CT scanning as being of no lesser benefit than MR scanning in detecting surgically correctable lesions. [6]

Evidence for use of other investigations in the diagnostic work-up of people with dementia

This has not been as well studied as CT brain scans. Much of the evidence is based on consensus views with experts[5] or case series.[2]

There is Grade 4 evidence to support the routine use of the following tests: complete blood count, plasma sodium, calcium, glucose, creatinine or urea, vitamin B12, liver function tests, thyroid function tests and syphilis serology.

There is Grade 5 evidence to support the use in selected cases of the following tests: ESR, red cell folate, HIV testing, chest x-ray, heavy metal screening, CSF analysis, EEG, MRI brain.

It should be emphasised that most reversible causes of dementia are due to medications, depression or metabolic abnormalities. [2,8]

References

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8. Barry PP, Moskowitz MA. 1988. The diagnosis of reversible dementia in the elderly – a critical review. *Arch Intern Med* 148: 1914–18.

Appendix 7.3: Evaluation of training and activity programmes

Authors: **Title:** **Journal details:**	Brodaty H, Gresham M. Effect of a training programme to reduce stress in carers of patients with dementia *British Medical Journal* (1989) 299: 1375–9
Study aim:	To reduce the psychological stress and improve skills in coping of people who care for relatives with dementia
Study population	A Sydney teaching hospital, Australia
Eligible population	People less than 80 years old, mild to moderate dementia, living at home with carer
Population agreeing to be randomised	101 patients and carers
Gender distribution	**Carers** 44 men 52 women **Patients** 50 men 46 women
Age distribution	**Patients** 49–79 years [70.2 (6.5)]
Degree of cognitive impairment	Clinical dementia rating scale 1.1 (0.5) MMSE 17.1 (6.5)
Residential setting	Living at home with carer
Inclusion criteria	Under 80 Living at home with carer
Exclusion criteria	Over 80 years No carer In institutional care
Extent to which study population can be extrapolated	Could be extrapolated to New Zealand subjects
Study design/type: Level of randomisation	Assignment in fours to one of three groups
Method of randomisation	Sequential allocation according to date of postal application
Numbers of groups	3
Numbers allocated into each group	33 carers programme, 31 memory training, 32 wait list
Blinding	
Baseline measures	**Patients** Orientation information memory concentration scale Dementia rating scale (blessed) Mini mental state examination (MMSE) Activities of daily living/ADL Hamilton scale for depression Geriatric depression scale Clinical rating scale for dementia **Carers** General health questionnaire Zung depression scale Hamilton scale Health diary
Comparison of baseline measures between groups	Groups were comparable

Intervention Type/description	**Group 1** Carers received training in coping with people with dementia and patients had memory retraining **Group 2** Patients admitted for 10 days carer respite and had memory retraining **Group 3** Carers waited six months before receiving training
Duration of intervention	12 months
Dates of intervention	
Compliance	96 of 101 entrants completed the trial
Co-intervention or contamination	Nil
Outcome: Outcome measures	GHQ scores at 12 months Entrance into institutional care Measures of clinical deterioration in patients
Cost measures	Not assessed
Measurement of outcomes	At 12 months and at 30 months
Numbers lost to follow-up	5
Evidence of intervention effects • size of effect • precision of effect	Carers' programme resulted in significantly lower psychological stress than memory retraining, 12 months 4.69 (5.58) and 7.4 (9.39); $p<0.05$. At 30 months, 65% of patients were still living at home compared with 26% in memory retraining group.
Total costs	Not assessed
Adverse effects	Nil
Analyses: Intention to treat analyses undertaken	Yes
Appropriate analyses undertaken	Yes
Random error: Sufficient power to detect an effect	Yes
Sufficient length of follow-up to identify an effect	Yes
Systematic error: Confounding bias	None apparent
Bias due to misclassification and missing subjects	Nil
Analysis bias	Nil
Summary assessment: Effectiveness (potential benefit)	The intensive intervention programme described for carers of patients with dementia can reduce the psychological morbidity of the carer and delay placement in an institution without increasing the use of health services by patient or carer
Level of evidence	Reasonably strong
Cost effectiveness	Not assessed
Recommendations:	Evidence in favour of the effectiveness of intensive intervention programme for carers in improving their well-being and delaying placement of persons with dementia in continuing care.
Comments:	

Authors: **Title:** **Journal details:**	Rovner BW, Steele CD, Shmuely Y, Folstein MF. A Randomised Trial of Dementia Care in Nursing Homes. *Journal of the American Geriatrics Society* (1996) 44: 7–13.
Study aim:	To evaluate the efficacy of a dementia care programme to reduce behaviour disorders in nursing home patients with dementia
Study population	Community nursing home, Maryland, USA
Eligible population	118
Population agreeing to be randomised	89 81 (91%) completed the trial
Gender distribution	Intervention group N = 42 Control N = 39 % female 86% 67% (p<0.05)
Age distribution	Intervention group control group Mean age 82.0 (8.0) 81.2 (7.2)
Degree of cognitive impairment	Moderate – severe MMSE 9.1 (7.4) intervention 8.9 (6.1) controls
Residential setting	A community nursing home
Inclusion criteria	Presence of a behaviour disorder determined by research nurse or research psychiatrist and psychogeriatric dependency rating scale
Exclusion criteria	Nil
Extent to which study population can be extrapolated	Extent to which these patients with dementia are similar to populations within New Zealand
Study design/type: Level of randomisation	Randomised controlled clinical trial
Method of randomisation	Uniform randomisation by computer algorithm
Numbers of groups	2
Numbers allocated into each group	Intervention group – 42 Control group – 39
Blinding	Psychiatrist – blinded Nurses – unblinded
Baseline measures	Behaviour rating scales Psychogeriatric Dependency Rating Scale (PGDRS) MMSE
Comparison of baseline measures between groups	All characteristics similar except for greater numbers of females in intervention group
Intervention: Type/description	Regular activity programme Psychotropic prescribing carried out by psychiatrists according to a protocol Education of staff by study psychiatrist
Duration of intervention	6 months
Dates of intervention	1989–1991
Compliance	Full compliance
Co-intervention or contamination	Nil

Outcome: Outcome measures	**Primary** Composite behaviour disorder 'present' or 'absent' at six months **Secondary** Patients requiring antipsychotic medication Restraint use Participation in activities Patient care reimbursement costs
Cost measures	Monthly billing records at baseline and six months
Measurement of outcomes	2, 3, 5 and 6 months after baseline
Numbers lost to follow-up	One control and one intervention patient died during the trial (three-month data used)
Evidence of intervention effects • size of effect • precision of effect	At six months 12/42 (28.6%) intervention patients exhibited behaviour disorders cf 20/39 (57.3% controls) OR = 0.38; 95% CI (0.15–0.95) p = 0.037. Controls more likely to be restrained during activities OR = 2.98; 95% CI (1.1–8.04) p<0.03 or on nursing units OR = 2.14; 95% CI (0.9–5.3) p<0.1 Controls were more than twice as likely to receive antipsychotics OR = 2.55, 95% CI (0.96–6.76) p<0.06 Intervention patients activity participation OR = 13.71; 95% CI (4.51–41.73) p = 0.001
Total costs	No significant differences between treatment and controls Treatment $US2290.6/month Controls $US2336.6/month
Adverse effects	Nil
Analyses: Intention to treat analyses undertaken	Yes – also active treatment
Appropriate analyses undertaken	Yes
Random error: Sufficient power to detect an effect	Yes
Sufficient length of follow-up to identify an effect	Yes
Systematic error: Confounding bias	Although the assessing psychiatrist was blinded s/he would need to talk to unblinded nursing staff in order to assess behavioural problems
Bias due to misclassification and missing subjects	Nil
Analysis bias	Nil
Summary assessment: Effectiveness (potential benefit)	An activity programme, structured prescribing and staff education appear to improve behaviour in patients with dementia and results in lessened use of psychotropic drugs and restraints
Level of evidence	Reasonably strong
Cost effectiveness	Not shown (neutral)
Recommendations:	Further studies to determine whether these findings can be replicated and longer duration studies should be undertaken
Comments:	

Authors: **Title:** **Journal details:**	Mittelman MS, Ferris SH, Shulman E, et al. A family intervention to delay nursing home placement of patients with Alzheimer's disease: a randomised controlled trial. *JAMA* (1996) 276: 1725–31.
Study aim:	To determine the long term effectiveness of comprehensive support and counselling for spouse caregivers and families in postponing or preventing nursing home placement of patients with Alzheimer's disease.
Study population: Country	New York City Metropolitan Area, United States of America
Eligible population	Volunteer sample of 206 spouse caregivers
Population agreeing to be randomised	206 of an eligible 208
Gender distribution	Caregivers no (% female) treatment 52 (50.5), control 68 (66)
Age distribution	Age of female caregivers % < 60y/60–69/70–79/80–89 (15/30/42.5/12.5) Age of male caregivers % <60y/60–69/70–79/80–89 (10.5/25.6/45.3/18.6) No differences between treatment and control groups
Degree of cognitive impairment	With female caregiver % mild/moderate/severe (32.5/40.8/26.7) With male caregiver % mild/moderate/severe (30.2/39.5/30.2)
Residential setting	Patients with Alzheimer's dementia living with spouse in community
Inclusion criteria	Living with spouse caregiver and one other relative living in the area
Exclusion criteria	Those without spouse caregivers
Extent to which study population can be extrapolated	Those persons with dementia with spouse caregivers Domiciliary supports available would differ in other societies
Study design/type: Level of randomisation	Randomised controlled trial
Method of randomisation	By lottery to treatment or control group
Numbers of groups	Two
Numbers allocated into each group	Treatment 103 / Control 103
Blinding	No
Baseline measures	Global Deterioration Scale (GDS) for subjects Caregiver assessment of own and patient's physical health Caregiver satisfaction scale of support.
Comparison of baseline measures between groups	Comparable in all respects except that despite randomisation 50.5% of the caregivers in the treatment group were female compared to 66% in control group (P<0.02). Sex of caregiver was therefore used as a covariant in all subsequent statistical analyses.
Intervention: Type/description	Two individual and four family counselling sessions in four months. Treatment group spouses were required to join support groups that met weekly. Thereafter counsellors were continuously available to the treatment group. Control group had normally available services.
Duration of intervention	Four months for counselling, then ongoing
Dates of intervention	Enrolment over a 3½ year period
Compliance	High – outcome of only one case unknown

Co-intervention or contamination	Control group were given counselling and advice on request. It is possible that the control group received more support than usual thus reducing the intervention effect.
Outcome: Outcome measures	Median time from baseline to nursing home placement in days Geriatric depression scale in carers Caregiver satisfaction scale Proportional hazards regression to test risk factors associated with nursing home placement
Cost measures	Not determined
Measurement of outcomes	Every 4 months during first year and every 6 months thereafter up to 8 years
Numbers lost to follow-up	One
Evidence of intervention effects: • size of effect • precision of effect	Median time to placement in nursing home was 329 days longer in the treatment than in control group p=0.02 Intervention effective in delaying nursing home placement in early/middle stages of dementia (RR, 0.67; 95% CI 0.47–0.96) p=0.02 Mild dementia (RR 0.38; 95% CI 0.17–0.82) Moderate dementia (RR 0.38; 95% CI 0.17–0.82).
Total costs	Not assessed
Adverse effects	Nil
Analyses: Intention to treat analyses undertaken	Yes
Appropriate analyses undertaken	Yes
Random error: Sufficient power to detect an effect	Yes
Sufficient length of follow-up to identify an effect	Yes
Systematic error: Confounding bias	No assessment of co-morbidity which is an important factor in determining a move to care
Bias due to misclassification and missing subjects	Nil
Analysis bias	
Summary assessment: Effectiveness (potential benefit)	A programme of counselling and support can substantially increase the time spouse caregivers are able to care for Alzheimer's disease patients at home, particularly during the middle stages of dementia when nursing home placement is generally least appropriate
Level of evidence	Grade 1
Cost effectiveness	Not available
Recommendations:	Strong evidence for benefits of the intervention in delaying nursing home placement for those with moderate dementia
Comments:	

Authors: **Title:** **Journal details:**	Weinberger M, Gold DT, Divine GW, et al. Expenditures in caring for patients with dementia who live at home. *American Journal of Public Health* (1993) 83(3): 338–41.
Study aim:	To estimate the estimated expenditures incurred in caring for dementia patients who live at home
Study population: Country	Subjects attending a university-based memory disorders clinic, USA
Eligible population	Primary caregivers of 264 patients with dementia
Gender distribution	67.4% female 32.6% male
Age distribution	Mean age 59.3 11.9 years
Degree of cognitive impairment	Moderate to severe
Residential setting	Living at home with carers
Extent to which study population can be extrapolated	Probably limited extrapolation to other societies
Numbers of groups	One
Numbers allocated into each group	141
Baseline measures	Primary caregivers were asked to produce service diaries in an attempt to identify costs of formal and informal services in home dementia care
Duration of intervention	Six months
Outcome: Outcome measures	Costs of formal and informal services for people with dementia in the community
Cost measures	Expenditures incurred over six months
Numbers lost to follow-up	264 primary caregivers – 141 returned diaries and these are analysed
Total costs	Expenditures for formal services $US6,986 for six months Expenditures for informal services $US786 for six months
Analysis bias	The costs in this study are based on conservative estimates. The subjects were those attending a university-based neurology clinic
Level of evidence	Grade 4
Comments:	The expense of caring for people with progressive dementia living at home may be higher than previously estimated and frequently involves expenses paid directly by patients and their families

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Appendix 1: Mental status examination (MSQ)

Name:..... Age:.....

Date of admission:..... Date of birth:.....

Mental test score:..... Date of testing: .....

1.	Age			
2.	Time (to nearest hour – allow consultation with clock or watch)			
3.	Address for recall at end of test – this should be repeated by the patient to ensure it has been heard correctly:- 201 Queen Street			
4.	Year (allow previous year)			
5.	Name of hospital or home address			
6.	Recognition of two persons (doctor, nurse, etc)			
7.	Date of birth (date and month only necessary)			
8.	Year of First World War			
9.	Name of present Prime Minister			
10.	Count backwards 20–1 (no errors)			
	(No half scores allowed)			

Reference

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Comments:

Appendix 3: CES-D major depressive disorder scale

Circle the score (0, 1, 2 or 3 for each statement that best describes how often you felt this way during the past week		*Rarely or none of the time (< 1 day)*	*Some of a little of the time (1–2 days)*	*Occasionally or a moderate amount of time (3–4 days)*	*Most or all of the time (5–7 days)*
1.	I was bothered by things that usually don't bother me	0	1	2	3
2.	I did not feel like eating; my appetite was poor	0	1	2	3
3.	I felt that I could not shake off the blues even with help from my family and friends	0	1	2	3
4.	I felt that I was just as good as other people	3	2	1	0

5.	I had trouble keeping my mind on what I was doing	0	1	2	3
6.	I felt depressed	0	1	2	3
7.	I felt like everything I did was an effort	0	1	2	3
8.	I felt hopeful about the future	3	2	1	0
9.	I thought my life had been a failure	0	1	2	3
10.	I felt fearful	0	1	2	3
11.	My sleep was restless	0	1	2	3
12.	I was happy	3	2	1	0
13.	I talked less than usual	0	1	2	3
14.	I felt lonely	0	1	2	3
15.	People were unfriendly	0	1	2	3
16.	I enjoyed life	3	2	1	0
17.	I had crying spells	0	1	2	3
18.	I felt sad	0	1	2	3
19.	I felt that people disliked me	0	1	2	3
20.	I could not 'get going'	0	1	2	3

* Developed by Radloff LS. 1977. The CES-D scale: a self report major depressive disorder scale for research in the general population. *Applied Psychological Measurement* 1: 385–401.

Appendix 4: Even briefer assessment scale for depression

The eight items of this schedule require raters to make a judgement as to whether the proposition in the middle column is satisfied or not. If a proposition is satisfied then a depressive symptom is present and raters should ring '1' in the right-hand column, otherwise '0' should be ringed. Each question in the left-hand column must be asked exactly as printed but follow-up or subsidiary questions may be used to clarify the initial answer until the rater can make a clear judgement as to whether the proposition is satisfied or not. For items which enquire about symptoms over the past month, note that the symptom need not have been present for the entire month nor at the moment of interview, but it should have been a problem for the patient or troubled him/her for some of the past month.

Question		Assessment	Rating	
1.	Do you worry? In the past month?	Admits to worrying in past month	1	0
2.	Have you been sad or depressed in the past month?	Has had sad or depressed mood during the past month	1	0
3.	During the past month have you *ever* felt that life was not worth living?	Has felt that life was not worth living at some time during the past month	1	0
4.	How do you feel about your future? What are your hopes for the future?	Pessimistic about the future or has empty expectations (ie, nothing to look forward to)	1	0
5.	During the past month have you at any time felt you would rather be dead?	Has wished to be dead at any time during past month	1	0
6.	Do you enjoy things as much as you used to – say like you did a year ago?	Less enjoyment in activities than a year previously	1	0

If Question 6 rated 0, then rate 0 for Question 7 and skip to Question 8. If Question 6 rated 1, ask Question 7.

7.	Is it because you are depressed or nervous that you don't enjoy things as much?	Loss of enjoyment because of depression/nervousness	1	0
8.	Are you – very happy-fairly happy-not very happy *or* – not happy at all?	Not very happy or not happy at all	1	0
		Total score	8	

A score of 3 or greater indicates the probable presence of a depressive disorder which may need treatment and the patient should be assessed in more detail or referred for psychiatric evaluation.

Appendix 6: He Anga Whakamana: A framework for the delivery of disability support services to Maori

Principles	Service implications	Indicators
Whakapiki Enablement	Client input and choice at all levels of decis ion making. Observation of Maori cultural requirements. Provision of Maori-focused services by Maori. Least intrusive service options.	Quality information collection Client participation
Whai wahi Participation	Active client participation Active whanau involvement Links forages with Maori institutions	Caregiver/case manager participation Whanau participation
Whakaruruhau Safety	Cultural safety, including cultural enhancement of mainstream services Professionally qualified services with representative staff Raised community awareness of disability	An appropriate use of Maori language
Totika Effectiveness	Improved health status and health gains for Maori Representative workforce Community contribution	Links with Maori institutions Consistency
Putanga Accessibility	Quality information Timeliness Availability of culturally and professionally safe services	Workforce composition and sensitivity
Whakawhanaungatanga Integration	Links with Maori institutions Links with other service providers Networking with Maori	Assessment procedures Consultation Maori-specific factors

Source: Ratima et al 1995, 43.

Evaluation of Dementia Guideline
Posted by Dr Stuart Foote on 31 July 1997 at 14:14:48

This review is made on behalf of the RNZCGP by its Guidelines Committee. The intention of this detailed review is partly to provide feedback to the developers and partly as a learning exercise for those of us on the Guidelines Committee as we all come to grips with the complexities of guidelines of best practice. Thus it is not our intention to be critical of the document but to use it as an exercise in evaluating the design and processes involved in developing such a guideline.

Summary

The Guidelines Committee felt that the document is a valuable resource for those caring for people with dementia. Its evaluation as a guideline, however, was made difficult by the mix of policy advice for funders, purchasers and health care planners with practical advice for carers (professional and others). For the purpose of this evaluation, we focus particularly on the 'guideline' aspects of the document and put it up to the standards suggested by the Guidelines for Guidelines document developed last year.

Finally, some recommendations are made for changes that could make the document of more practical use to general practitioners and others caring for patients with dementia.

Guidelines for guidelines principles

Principle 1: Guidelines should address a specific health care need

Intuitively, we all know that dementia is already a major health care problem in New Zealand and is becoming progressively more important. The information on prevalence and incidence was valuable in putting dementia into a New Zealand perspective and the almost total lack of economic information about dementia was acknowledged. Without knowledge of current practice to compare with optimal practice, it is difficult to judge whether or not a guideline is needed to 'bridge the gap'. Therefore, more work is needed to establish whether it is a guideline that is required or an educational programme to increase awareness or understanding of the issues.

In short, did the request for the work that led to this document arise from a need to guide clinical practice or formulation of health care policy? Different documents may have arisen from either option. We feel that this document arose from the latter but has been entitled from the former.

Principle 2: The aims and objectives of the guidelines must be clearly stated and achievable.

The aims and objectives were clearly stated – to provide assistance and improvement in dementia management in primary care. The request from the commissioning agent (P8) set the scene for the mix of clinical and policy issues. Although it is appropriate to consider these together, presentation in separate formats would result in more useful documents than the current combined one.

It was also felt that more specificity about expected outcomes, rather than 'improvement of primary care' would have been helpful.

Principle 3: Guidelines should be based on the scientific evidence and should clearly state the strength and source of that evidence.

Although it was clear, through frequent references to the literature, that evidence formed the basis of many statements, there was no evidence in the document of a systematic review of the literature. While it may be accepted that in many areas under review there is little firm experimental evidence, it was not always clear in the document what was evidence, what was expert opinion and what was a description of current practice as a rational or reasonable basis for management. The difficulties in providing a systematic review may relate to the very broad focus of the topic. A systematic review is more easily undertaken when the question being asked is clearly defined.

There is no explanation of any evidence not considered or excluded. General practitioners are already being asked by their patients for information on such therapies as melatonin, heralded in some newspapers recently as a 'breakthrough' in Alzheimer's Disease. Reports from UK indicate that the drug Donepezil has already been marketed there on very weak evidence of efficacy. The section in the document on Tacrine was very helpful but an extension to some other areas of speculation and current research in dementia treatment would be helpful for GPs in order to respond to patient enquiries.

A clearer explanation about how the panel reached consensus on interpreting the evidence or on expert opinion would also add value.

The inclusion of some critically appraised studies in the appendices was helpful but fragmented the text somewhat and did not assist ease of use from a guideline point of view.

Principle 4: Guidelines should be developed by a multi-disciplinary panel that includes representatives from all key groups.

Although a general practitioner was included in the panel, there was no record of how he was selected and it was noted that he is a GP with a special interest in geriatric medicine. Given that the guideline was aimed at primary care, additional representation by a GP without such a depth of geriatric care experience as the GP on the panel may have added some additional insights into needs of primary care doctors. As the number of GPs with training in guideline development increases, additional GP representation could be drawn from these people.

The absence of a nurse was thought to be an important omission as nurses clearly play a major role in caring for patients with dementia. It was noted that purchasers, funders and health care policy planners were not represented but that may not have had a significant impact on the guideline.

Principle 5: Guidelines should be flexible and adaptable to local conditions.

The guideline made recommendations that would frequently depend on local availability of services and expertise. Although the policy statements called for uniform availability of services throughout the country, the current reality is less than that. However, we felt that the resource presented by the document as a whole would be of valuable assistance to those without a full range of services immediately available.

Principle 6: Resource implications should be considered in the development and use of guidelines.

Although there was no information about the cost of developing and implementing these guidelines, nor of the likely impact of their implementation on health care resources, the document did recognise the lack of vital data in this area and called for this position to be remedied.

Principle 7: The means of ensuring that guidelines reach their target audience should be outlined.
and
Principle 8: Strategies for implementing the guidelines should be specified.
and
Principle 12: Guidelines should be written in clear, concise language and be presented in an easy-to-use format.

These issues were not dealt with by this guideline. The presentation at this time will make the guideline difficult to implement at GP level and considerable work is required to tease out the guideline from policy and to present the guideline in an easier format. The presentation should include the full document, a short summary of the principle points for professionals and a different short summary for patients and their carers. Discussions need to be held with IPAs and RNZCGP about the need for and most appropriate ways of disseminating and implementing the guideline.

Principle 9: The process behind the development, dissemination, implementation and evaluation of guidelines should be fully documented.

There are no details given of the processes involved in the development of this guideline or any statement of who initiated and funded the project. This should be accompanied by a statement about the motivation behind the project, whether it was driven by a perceived clinical need, a need to change utilisation or cost or any other motive.

Principle 10: The effect of guidelines should be evaluated to determine if the aims and objectives have been achieved.

Although this has not been proposed, the guideline did point out the need for better information systems to be put in place to collect, collate and analyse health care data. In the absence of consistent clinical markers or measures and the scope of the subject of dementia, evaluation of the effect of the guideline could only happen in the context of general health care information.

Principle 11: Guidelines should be regularly reviewed and revised.

Publication dates for the supporting evidence are given but there is no discussion of the need for, timing or responsibility for review of this guideline.

In summary, the document will be a valuable addition to the resources available to general practitioners. In its current format, however, it is likely to be picked up only by those who have a particular interest in geriatric care or dementia. By separating policy from guideline, presenting the guideline in a more concise manner and working with organisations capable of disseminating and implementing it, the effect of the guideline on care of people with dementia will be greatly magnified.