



Care of Patients with Dementia in General Practice

Guidelines



Royal Australian College
of General Practitioners

NSW HEALTH
Working as a Team

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The Mind's Decay

*Some of God's people have to go that way,
Who once were loving, witty, joyful, sage,
Showing the Spirit's gifts in rich array,
Now aged babes;
Like ships adrift from reason's anchorage,
No hand upon the rudder of the will,
Abandoned derelicts, yet floating still.*

ELIHU

Foreword

The project to develop these guidelines was funded by the NSW Department of Health under the *NSW Action Plan on Dementia 1996-2001*.

The purpose of the project was to provide general practitioners with a resource for the care of people with dementia that encourages early intervention, ongoing management throughout the course of the disease and partnership with carers and other service providers. The project was funded following advice from the General Practitioner Working Group on Dementia and aimed to address some of the issues raised in the Mid-Plan Report on the *National Action Plan for Dementia Care 1992-1996*.

The project aimed to bring together the Royal Australian College of General Practitioners (RACGP), representing practising doctors, and two university departments of general practice to address the important and so far somewhat neglected issue of quality care of patients with dementia in the community, including support for their families and carers. It did this by establishing these guidelines, and then testing them in general practice.

The objectives were:

1. To develop guidelines for the diagnosis and ongoing management of people with dementia in general practice in partnership with carers, families and relevant services.
2. To field test these guidelines in general practice.

An advisory committee of GPs and other relevant stakeholders such as geriatricians, psychogeriatricians, nurses, and carer consumer representatives was established to oversee the project, and met three times during the course of the project. A half-time project officer was employed to work under the guidance of the grant holders and the advisory committee.

The team conducted a review of the literature and current guidelines and liaised with practitioners in related disciplines. Draft guidelines specifically related to the usual working procedures of general practice were developed with input from the advisory committee and three focus groups of general practitioners. These were then field tested by 17 general practitioners who used them in their practices to audit their current management of 119 patients against the guidelines. They then provided feedback about the usefulness of the guidelines with these patients, and their comments were used in finalising the guidelines.

A further survey by the NSW Department of Health of eight GPs unconnected with the trial indicated satisfaction with the format of the guidelines.

Subsequently the guidelines have been updated from time to time when new information has come to hand.

The guidelines have been endorsed by the Royal Australian College of General Practitioners.

Advisory committee

An advisory committee was established to oversee and provide input to the project. As well as meeting formally three times during the course of the project members were able to provide input on an ad hoc basis throughout the project period.

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Using these guidelines

These guidelines are directed to the care of patients with dementia who are living at home or with family, rather than to those in facilities such as hostels or nursing homes, though they may apply to some of these.

The guidelines are arranged in 3 parts with increasingly detailed content in each part:

- Summary guidelines (Part 1)
- Full practical guidelines in a format suitable for general practice (Part 2)
- Background and supporting evidence (Part 3).

For convenient access, each part of these guidelines follows the same format, consisting of the following 3 sections:

- Patient presentation
- Assessment
- Management.

This means that the general practitioner can simply refer to the summary guidelines (**Part 1**) for **brief information** regarding assessment, for instance. If required, **more detailed information** can be found in the assessment section of the full guidelines (**Part 2**), and **background and supporting evidence** for this information can be found in the assessment section of **Part 3**.

It is recognised that in practice these aspects of care are not undertaken separately but rather, are part of an iterative process often taking place over a long period of time.

These are at present consensus guidelines, since the process of gathering formal evidence to support them is still to be done. They rely heavily upon previous guidelines issued in a number of countries, only one of which claims to be evidence based (*see references*).

The guidelines were updated in December 2002.

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The general practitioner may become aware of the possibility of dementia in three ways:

Presenting problems

Patient or family presents with symptoms possibly relating to dementia:

- decline in memory
- decline in thinking, planning and organising
- reduced emotional control and changed social behaviour to the extent of interference with everyday activities.

Early pointers

GPs should be aware of case-finding by seeking early pointers to dementia when treating other conditions in older patients, such as:

- forgetting appointments, medication
- decline in grooming, self-care
- social withdrawal.

Screening

Should older people without symptoms be screened for dementia?

No, there is no evidence of benefit but practitioners should have a high level of suspicion and assess the patient if there are any possible indications.

When the issue of possible dementia has been raised, assessment is needed to confirm dementia, consider differential diagnosis, determine severity and extent of disability, evaluate any co-morbidity and assess family and social support and environment.

In many cases for patients over the age of 75 or indigenous people over 55 the Enhanced Primary Care health assessment item in the Medical Benefits Schedule can be used.

What to include

History and functional assessment

This should include:

- full clinical history
- interviews with patient and family, conducted together and separately
- ability to undertake daily activities (dressing, washing, managing finances, telephone).

Physical examination

A complete and thorough examination directed towards known and possible co-morbidity.

Investigations

Tests to exclude reversible causes.

Cognitive assessment

Use of one of the simple tests of cognitive ability such as MMSE and/or the clock drawing test.

Home visit

This is necessary to get the best history and assess the safety and quality of the environment.

What to determine

Differential diagnosis

Dementia must be distinguished from other conditions, particularly:

- normal ageing
- delirium
- depression
- drug effects.

Sub-types of dementia should be considered.

Ability/disability

Functional status must be assessed in terms of:

- activities of daily living (ADL)
- instrumental activities of daily living (IADL)
- personal safety
- communication ability
- nutrition, hygiene and medications
- driving
- legal capacity for decision making.

Co-morbidity

Exclude or manage optimally, conditions which may aggravate dementia, such as cardiac or renal failure, nutritional deficiencies and visual and hearing impairments.

Family/social support and environment

Assess carer and family stress and support, and any improvements needed to the home environment.

Decisions to be made

Plan of action

Assessment and management need at least several consultations over weeks or months, and probably a plan for some years, arranged with patient and family. The Enhanced Primary Care health assessment or care planning items in the Medical Benefits Schedule can be used.

What, when and how to tell patient and family

Patient, carer and family need to know what to expect, and the distress of the diagnosis needs to be handled sensitively.

Referral

Referral may be necessary if the diagnosis is uncertain or the problems cannot be handled in the general practice.

When dementia has been diagnosed, severity determined, abilities and disabilities clarified and family/social support and environment assessed, management can continue.

Areas for management

Dementia and disability

Management of the dementia may require:

- behavioural strategies
- environmental change
- drugs, which may delay cognitive decline but do not influence underlying pathology.

Co-morbidity – acute – chronic

Regular review to ensure optimal control of co-morbidity should include:

- medication and compliance review
- consideration of extent of depression and anxiety
- nutrition and hydration
- prevention of constipation
- exclusion of silent infection, particularly urinary
- early detection of any physical illness and need for pain relief.

Health promotion

- diet – Meals-on-Wheels?
- exercise
- medications – need for domiciliary review? Webster pack?

Prevention

- immunisations – pneumococcal vaccine, flu vaccine
- falls prevention.

Patient / family / social support

- housing
- legal and financial matters
- driving and other risk activities
- regular checking of carer's health
- full reassessment of the patient at least annually.

Aspects of management

A management plan should be drawn up with the patient and family, taking into consideration the following issues:

- Initial stage
- Long-term plan
- Follow-up.

This should include regular consultations as well as allowing for extra consultations when necessary.

- Referral?

Audit of care for persons with dementia

1.4

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

Circle yes or no to each item:

	YES	NO
Does this person have a definite diagnosis?	Y	N
Have reversible causes of confusion been excluded?	Y	N
Is co-morbidity managed optimally?	Y	N
Have the person and their family been:		
1. Consulted throughout the process?	Y	N
2. Told about available services?	Y	N
3. Told about sources of education?	Y	N
4. Given the contact phone number of their State branch of Alzheimer's Australia?	Y	N
Have medications been reviewed:		
1. At the time of diagnosis?	Y	N
2. Three-monthly?	Y	N
3. Six-monthly?	Y	N
Has psychiatric co-morbidity been assessed?	Y	N
Have measures such as driving, enduring power of attorney, enduring guardianship and will been discussed?	Y	N
Have arrangements been made for a three-monthly review of support needs of carers?	Y	N

(Adapted from NZ Guidelines, 6:41)

Patient presentation

The general practitioner may become aware of the possibility of dementia in three ways:

- presenting problems
- noting early pointers when treating other conditions, or screening.

Presenting problems

Patient or family presents with problems possible relating to dementia.

The common clinical symptoms contributing to diagnosis include:

- a decline in memory to an extent that it interferes with everyday activities
- a decline in thinking, planning and organising day to day things, to an extent that it interferes with everyday activities
- communication problems eg always repeating, asking same questions, not finishing sentences, always saying strange things
- decline in finding words or other aspects of language
- a decline in emotional control or motivation, or a change in social behaviour, as manifested by symptoms such as emotional lability, irritability, apathy and coarsening of social behaviour (eg in eating, dressing and interacting with others) (*see pp29-30 for a typical presentation*).

There may also be other presenting symptoms for less common forms of dementia.

Early pointers

Case-finding and warning signs

Mrs A, aged 78, attending regularly for management of hypertension and arthritis was only recognised as having dementia when police and NRMA contacted relatives when she reported having lost her car keys 16 times. She explained that thieves were taking them, and also stealing her Weet-Bix.

It is important to be alert to cognitive impairment in elderly patients. GPs may note early pointers to dementia when treating other conditions (*see p31*).

Early pointers that general practitioners should look out for or may note when treating other conditions:

- giving up activities/stopping going out (asking for home visit rather than attending surgery if not acutely unwell)
- presenting with mid-life crisis type symptoms, not coping at work, wanting demotion
- recent instability of previously well controlled chronic condition eg hypertension, diabetes
- recent increase in presentations to surgery with vague complaints
- recent presentation with apparently classic complaint which fails to respond to usual therapy eg angina which does not respond to anti-anginal therapy, fracture with pain persisting unusually long after healing apparent on X-ray
- failure to attend for repeat prescriptions on time or turning up too frequently for repeats
- failure to attend a specialist referral (especially if recurrent)
- asking to go into care (or hospital) without apparent physical problems
- recurrent attendances to local hospital Emergency Department for vague or non-acute reasons.

Early diagnosis is important because much can be done for the patient at this stage to improve lifestyle and reduce risks, and for carer and family by providing information and support. However this must be done sensitively to avoid distress, because dementia is frequently seen as a hopeless condition, referred to by one spouse as a ‘funeral that never ends’, or as stigmatising. (See p29 for benefits of early diagnosis).

If a problem is suspected by the doctor, a simple way of opening discussion is to ask the patient ‘how is your memory?’. However, many patients with mild dementing illness will be either unaware or unwilling to admit to cognitive problems. Patients who do complain of memory loss are more likely to have depression than dementia; dementia is more likely to be the cause if others complain about the patient’s memory. However, people who complain of memory problems are at greater risk of later developing dementia. It may be helpful to try to ask about the patient’s memory at regular intervals of time in order to assess the possibility of dementia (Schofield 1997).

Screening?

Screening is different from case-finding as it refers to action to determine the presence of likely or possible disease in a person without problems or symptoms pointing to the possibility of dementia.

Should patients be screened for dementia?
The short answer is no! (See p31).

When the issue of possible dementia has been raised, assessment is needed to confirm dementia, consider differential diagnosis, determine severity and extent of disability, evaluate any co-morbidity and assess family and social support and environment.

Full assessment may need several consultations over a period of time.

The most common cause of dementia is Alzheimer's disease, which accounts for about 40% of the cases seen. Other dementias include vascular dementia (20%), Lewy-body dementia (20%), with the remaining 20% made up of many others including:

- frontal lobe dementia
- parkinson's disease with dementia
- normal pressure hydrocephalus
- post traumatic
- toxic (particularly alcohol) or anoxic encephalopathy
- prion diseases eg creutzfeldt jakob disease
- down's syndrome
- AIDS.

Enhanced Primary Care medical benefit items

The Enhanced Primary Care (EPC) Package introduced by the Federal Government in 1999 includes several elements providing benefits for the assessment and management of patients with early dementia:

- health assessments of people aged over 75 (55 for ATSI people)
- care planning for people with chronic conditions and multidisciplinary care needs
- case conferencing for people with chronic conditions and multidisciplinary care needs.

Health assessment includes activities of daily living, mood and cognition, social function, home situation, and carer health needs. Patient consent is essential. If there are difficulties with patient consent, the carer and the patient's immediate family should be consulted.

Details are available in the Royal Australian College of General Practitioners (RACGP) document *Standards and Guidelines for the Enhanced Primary Care Medicare Benefit Schedule Items* available on the RACGP website www.racgp.org.au

Particularly useful may be the following appendices:

- Patient Information sheets
- Home Safety Checklist
- Health Assessment Proforma – practice record and patient summary.

For further information, see the Commonwealth Department of Health and Ageing's website www.health.gov.au/epc

History and functional assessment

Mr B, aged 72, lives with his wife. He attends somewhat irregularly for his hypertension and peripheral vascular disease. He denies any memory loss or difficulties, but his wife says he forgets the names of their grandchildren, leaves lights and gas on, has lost interest in sex and is often cranky. She is now becoming afraid to leave him when she goes to bowls.

A full clinical history should be taken. This should include interviews with the patient and their family or carer conducted together and separately. Patients may be unaware of or refuse to admit they have symptoms; carers may be defensive or simply reluctant to upset the patient, or occasionally wanting to 'dump' the problem.

Asking carers to keep a diary of the patient's behaviour, or giving them checklists to fill in, can help assess the patient's decline and allow the progression of the condition to be monitored. However, GPs should be aware that the quality of the information about the patient will depend on how much time the carers and/or family members spend in the patient's household. Useful instruments to assist in this are available (*see p33*).

Functional assessment

It is important to assess the extent to which the patient's problems with memory, cognition and communication are interfering with his or her ability to undertake daily activities (*see p17*). Health Assessment checklists may be useful (*Appendices A1 and A2*).

Physical examination

A complete and thorough clinical examination is necessary. This should be directed towards finding evidence for:

- specific conditions which may cause dementia eg stroke, Parkinson's disease, cerebrovascular disease, hypothyroidism
- underlying chronic conditions which may aggravate dementia eg hypertension, cardiac failure, renal failure, diabetes, anaemia
- conditions which may cause delirium eg respiratory or renal infection.

It is important to assess specifically the patient's level of consciousness as, if impaired, this may be an important pointer to delirium which may need to be treated as an emergency.

There is often considerable co-morbidity found in people with dementia, and they may benefit from a methodical examination in search of treatable conditions (*see section p14*).

Investigations

Although encountered rarely, potentially reversible causes of dementia are important to detect. This has led to the development of a list of tests which should be undertaken in any person with dementia, to ensure that reversible causes will not be overlooked.

- Hb, WBC, ESR
- renal function/electrolytes
- liver function
- thyroid function
- blood sugar
- serum calcium and phosphate

- urine – WBC, protein, sugar (culture if delirium)
- serum B12, folate levels
- CT scan without contrast
- CXR (if delirium)
- syphilis serology (if specific indications)
- HIV testing (if specific indications) (*see p28*).

Cognitive assessment

Suitable well-recognised tests of cognitive ability are the mini-mental state examination (MMSE) (*Appendix B1*) and the clock-drawing test. A shorter alternative to these is the Australian-developed GPCOG (*Appendix B2*). Limitations in the interpretation of these tests include:

- other issues that may impair performance such as the presence of dysphasia, sight impairment, deafness, poor educational level, cultural factors, an awareness of the fact that the patient is being tested and fear of testing
- factors that may overcome decreased cognition such as better intellect and education (*see p35*).

Home visit

Mrs C, aged 75, lives alone. She has attended frequently for years with hypertension, chronic airways disease, NIDDM and osteoarthritis, all becoming less well controlled. On making a home visit, the GP finds that her medication is scattered around an untidy and dirty house, and there is little food. Neighbours help out, but say her son manages her affairs and never lets her handle money.

Such a situation raises many issues and emphasises the importance of a home visit. One or more home visits by a general practitioner and/or other members of the team will be needed before assessment is complete. This will usually result in additional history prompted by the situation, better assessment of functioning, sometimes a better environment for cognitive testing, and appreciation of the safety and quality of the environment.

Differential diagnosis

Mr E, aged 82, had hypertension, COAD and epilepsy for years, all well controlled on medications, and seemed to cope well living alone. He phoned the ambulance at 6am to take him to hospital because of a fever, but no abnormality was found. He later refused to pay the bill because he said they had not found out what was wrong with him, and became more and more reclusive. The GP was concerned when he did in fact develop a recurrent low grade fever.

Several conditions can present with similar symptoms to those of dementia. These include:

- normal cognitive changes associated with ageing
- delirium
- depression
- drug-induced effects
- mild or moderate intellectual disability
- subnormal cognitive functioning because of a severely impoverished social environment and limited education.

Asking the patient ‘are you depressed?’ and ‘how’s your memory?’ at regular intervals of time may help to differentiate between depression and dementia.

Normal ageing

The perception of failing memory among the elderly is common, with about 25% of non-demented, healthy elderly complaining of memory impairment.

Several features of cognition characterise ‘normal’ ageing. There is a generalised decline in the speed of processing, yet accuracy of response is not affected. Verbal abilities remain stable over the lifespan. Most types of memory also remain stable over life, including immediate memory and long term or remote memory. New learning or recent memory is also relatively resistant to ageing, although not to the same degree.

Description	Person with dementia	‘Normal’ older adult
Forgets	Whole experience	Parts of an experience
Forgets words or names for things or objects	Progressively worsens	Occasional lapses of memory
Delays recall of names	Often	Rarely
Follows written or verbal directions	Gradually unable	Usually able
Ability to use notes, reminders, cues from the environment	Gradually unable	Usually able
Follows a story on TV, in a movie or in a book	Gradually loses ability	Usually able
Calculations	Gradually loses ability	May be slower than before
Self-care capacity (dressing, bathing, cooking etc)	Gradually unable	Usually able

The four ‘D’s – dementia, delirium, depression and drugs

The differential diagnosis should include the four ‘D’s of geriatric practice – dementia, delirium, depression and drugs. Remember that the patient’s age, level of education, cultural background and co-morbid illnesses may affect their assessment.

A comparison of the clinical features of delirium, dementia and depression

Feature	Delirium	Dementia	Depression
Onset	Acute/sub-acute depends on cause, often 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 1 month, seldom longer	Months to years	At least 2 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, marked poor judgement, 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
Stability	Variable hour to hour	Fairly stable	Some variability
Emotions	Irritable, aggressive, fearful	Apathetic, labile, irritable	Flat, unresponsive or sad. May be irritable
Sleep	Nocturnal confusion	Often disturbed. Nocturnal wandering and confusion	Early morning awakening
Other features	Other physical disease may not be obvious		Past history of mood disorder

(Adapted from NZ Guideline 6:22 and LoGiudice 1999)

Delirium

It is essential that delirium be discounted early in the diagnostic process. The underlying physical disorder, together with decline in cognition, may constitute a medical emergency. Immediate evaluation of the underlying causes and initiation of possible treatment is imperative.

Delirium is a confused state precipitated by an underlying organic cause, although this may not always be obvious. Some clues to the diagnosis include:

- sudden change in mental state or behaviour (informant history is of utmost importance)
- recent change in medication
- evidence of infection
- visual hallucinations (which indicate delirium until proven otherwise)
- very old, physically ill, with known dementia
- recent surgery
- looks unwell, perplexed or anxious
- vision and hearing impairment.

Some of the causes include substance abuse, medication effects, infections, vascular changes, hypoxia, metabolic problems, surgery and trauma. Delirium is not always of short duration and of florid symptomatology; a sub-acute confusional state can last for months.

Patients with delirium may have dementia as well, and this needs to be assessed when the cause of the delirium has been treated.

Depression

It can be difficult to differentiate between dementia and depression. Depression can manifest as dementia; conversely, dementia can present with depressive symptoms early in the illness.

Because patients with dementia may also be depressed and have poor insight or ability to express their mood changes, other clues must be sought. Features such as a past history of depression, recent onset in symptoms, poor appetite and loss of weight, depressed mood, thoughts of self-reproach, guilt or suicide, and delusions favour a diagnosis of depression (*see p36*).

Drugs

Many drugs can cause or aggravate cognitive impairment. Problems particularly arise when doses are changed or new drugs are added, and occasionally when drugs are stopped. It is therefore important that a full drug history be obtained.

The following drugs are those which are more commonly involved:

- 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.

Dementia sub-types

Dementia may be of many types. The more common are discussed below. Differentiation may be important for management in some cases eg recognition of early Parkinsonism with dementia may allow improvement with specific treatment, and it is important to avoid neuroleptic drugs with Lewy-body 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 ability to repeat phrases is usually preserved but naming (initially of uncommon words) is impaired. 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 eg miming how to hold a brush and brush one's hair) 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 might include decreased emotional expression, increased stubbornness, diminished initiative and greater suspiciousness. Delusions may occur in about 30% of patients.

Vascular dementia

Vascular dementia is the second most common cause of dementia after AD, with which it may coexist, accounting for 15-20% of cases. A rapid onset with focal deficits and significant somatic complaints may suggest vascular dementia, as may emotional lability, impaired judgement, early neuropsychiatric symptoms and gait disorders. There is relative preservation of personality and verbal memory.

There are several types of vascular dementia. Where it is caused by multiple small infarcts progression is normally stepped (whereas Alzheimer's disease progresses gradually).

However sometimes vascular dementia can have a gradual onset and progression similar to Alzheimer's disease eg when the cause is ischaemic rather than infarction. A computed tomography (CT) scan without contrast may help confirm or exclude a vascular aetiology (*Grey Matters 7:9*).

Dementia of the frontal lobe type

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. These people are prone to angry catastrophic reactions. The apathy may be difficult to distinguish from depression. One 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 coexistent Alzheimer's disease, cerebrovascular disease or other causes.

Lewy-body dementia

This dementia is characterised by cognitive impairment which affects both memory and ability to carry out complex tasks and fluctuates within one day. 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
- repeated unexplained falls
- transient clouding or loss of consciousness.

Alcohol dementia

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

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 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.

Sub-cortical dementia syndrome

In this condition, unlike Alzheimer's disease, there is relative preservation of language, calculation and tasks requiring coordinated 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. (*see p39*).

Ability/disability

Assessment of functional status

Assessment of the patient's ability to manage personal care, such as bathing, dressing and feeding, and other activities of daily living such as using the telephone, shopping and banking, are essential parts of the evaluation of dementia. If the patient is having trouble undertaking such activities – particularly against a background of memory or cognitive problems – then a dementing illness may be suspected.

The use of recognised simple instruments may make such assessment easier and more reliable:

- Activities of daily living (ADL) (*Appendix C4*)
- Instrumental activities of daily living (IADL) (*Appendix C5*).

Assessment of function is also included more briefly in more general instruments:

- Health assessments (*Appendix A1 and A2*)
- GPCOG (*Appendix B2*).

If the patient demonstrates impaired functional ability on these tests, further cognitive testing should be conducted if not already done (*see Appendices B1-B2*), (*Grey Matters 7:6*).

In addition to established physical or intellectual deficits, it is important to be aware that gender and cultural factors may influence the utility of these lists (for instance, men normally do less around the house than women).

The following issues also need to be considered:

- safety issues in the home and on the road (*see below*)
- personal hygiene
- financial competency
- self-monitoring of medications
- ability to attend to adequate nutrition
- present and future legal capacity regarding: advance care directives, Enduring Guardianship or Enduring Power of Attorney (*see below*).

Older road users

Advice from medical practitioners is often heeded by older patients in relation to their ability to drive. Using resources such as the Austroads publication *Assessing fitness to drive* will aid the general practitioner in making an informed decision in relation to this (*Appendix F2*)

Legal capacity for decision-making

Determination of a patient's capacity to make decisions may be an important role of the doctor. This may apply in one of three situations:

- consent for medical treatment
- giving an advance care directive
- making a will.

It may also apply to other tasks such as managing financial affairs or arranging living circumstances (*see p44*).

Co-morbidity

Common conditions which can cause or aggravate dementia need to be thought of and excluded or managed are:

- depression
- drugs
- thyroid disorders (hypo/hyperthyroidism)
- subdural haematoma
- neoplasms
- alcohol
- intracerebral lesions (tumour, normal pressure hydrocephalus)
- vitamin B12 deficiency
- folate deficiency
- metabolic disturbances (hypo/hyperglycaemia, uraemia, hypo/hypercalcaemia)
- water and electrolyte disturbances (dehydration and hyponatraemia)
- infections (urinary tract, respiratory tract)
- renal failure
- hypoxia
- malnutrition.

Not only may these conditions aggravate dementia, but also the onset of dementia may lead to deterioration in such conditions, particularly by reducing compliance with medications.

In order not to avoid overlooking any co-morbidity which should be managed optimally, it may help to use the assessment form checklist developed by the RACGP (*see Appendix A1*).

Family/social support and environment

Assess carer and family

Mrs D, aged 81, has COAD and early dementia which she admits, although denying the seriousness of her problems. She lives alone, helped by a daughter who lives in the next suburb. When her driving licence is cancelled she expects the daughter to take her out every day, and blames her for all difficulties. She complains to the GP that her daughter often becomes explosively angry.

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. Carers are often elderly, or stressed by other family responsibilities. Higher levels of depression, psychological morbidity and use of psychotropic medications are seen in carers of those with dementia.

Difficulties experienced with caring 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.

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 from patient, other family members or community or all three.

Signs of stress need to be looked for, the stress level assessed, and reviewed at least six-monthly; three-monthly would be ideal.

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. The Caregiver Burden Scale may be useful. (*Appendix D1*) (*NZ Guideline 6:32*), (*see p39*).

If the carer has a different GP they should be referred to that GP with an offer of cooperation in management.

Assess environment

Is the home environment safe? Consider:

- floor coverings
- cooking facilities
- bathroom
- toxic substance storage
- heating.

Action plan

Once the question of dementia arises assessment cannot be achieved in one consultation and a plan needs to be agreed with patient and family or carers, together and separately. The Enhanced Primary Care health assessment or care planning items in the Medical Benefits Schedule can be used.

At the initial consultation it is necessary to:

- determine the problems
- sort out priorities with patient and family
- manage urgent problems
- deal with the priority problems
- arrange a plan for further assessment and management.

This will be encouraged by a focus on dealing with the patient and family’s perceived problems, with follow-up to see that the desired goals are achieved.

There is often considerable fluctuation in the patient’s condition and functioning over time and in different places, and this needs to be considered.

The action plan needs to be considered in terms of weeks, months and years, since dementia is a chronic progressive condition, though the rate of progression varies in different people.

What, how and when to tell patient and family

Mrs F, aged 82, lived in a retirement village with her husband. She had been very active with no obvious health problems. She presented with concern about her memory and inability to control her aggressive feelings when things went wrong. Her husband and family felt it was merely ‘old age’ and denied any difficulties. After assessment, the GP was sure she had early dementia.

While the patient, carer and family have a right not to be informed of the diagnosis, where possible it is best to inform them so that they will know what to expect and can begin making any necessary arrangements, such as altering the home environment, changing wills and contacting Alzheimer’s Australia.

Listen first

Before imparting information, it is important to find out what the patient and family already know about dementia, to reinforce what is correct, and to correct what is not.

What to tell

This depends on what the patient and family need and want to know, but consider:

- what the diagnosis is, and its prognosis
- 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
- support and respite care available
- 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
- Enduring Power of Attorney or Guardianship
- making of will.

Be careful not to overload people with too much information at one time.

Encourage all involved to read the excellent resources available from Alzheimer’s Australia.

How and when to tell

Listed below are ways to help minimise the distress that breaking the news of dementia may cause:

- Allow adequate time and ensure privacy.
- Let the patient decide how much they want to know.
- Tell the patient and carer separately.
- Be empathetic and encourage expressions of feelings.
- Break the news in stages over several consultations.
- Assess patient’s understanding frequently.
- Be aware that both patients and carers may suffer reactive depression or anxiety after hearing the diagnosis.
- It is perfectly acceptable to refer the patient to a specialist to hear the diagnosis if you feel that passing on the diagnosis will damage your relationship with the patient and/or family.

Patients and families should be encouraged to contact the Alzheimer’s Australia, which can provide information and support. Its help sheets are a useful resource available on request to general practitioners to give to patients and families (*Appendix F1*).

Prognosis

Most dementia is progressive, but it will affect different individuals in different ways. On average, the time from onset of the disease to diagnosis is about 2-3 years, while from onset to death is usually within 10 years, but varies greatly for individuals. At some time during the dementia, behavioural complications will affect 90% of patients. Psychological/psychiatric complications include depression, anxiety, psychosis or hallucinations, while non-psychological behavioural complications include agitation, wandering, screaming and aggression (*see pp42-3*).

Referral

Most patients with early dementia can be managed successfully in general practice, without the need to refer to specialists (although other groups such as solicitors and community services may be required). However, some reasons for referring patients to (where appropriate) a neurologist, geriatrician, psychogeriatrician, memory clinic or an Aged Care Assessment Team (ACAT) are:

- confirmation of diagnosis
- uncertain diagnosis or unusual/complicated presentation
- rapid deterioration
- significant psychiatric co-morbidity (especially depression)
- access to dementia drugs (under current PBS arrangements)
- patient is less than 60 years old
- possible industrial exposure to heavy metals
- patient or family request a referral/second opinion
- access to multi-disciplinary team to assist in assessment or management
- difficult behavioural problems
- respite care or other community support services needed
- patient or family in denial and at unacceptable risk.

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 general practitioner.

When dementia has been diagnosed, severity determined, abilities and disabilities clarified and family/social support and environment assessed, management can continue.

The management of the patient will be guided by the assessments made. Assessment and management will not necessarily be sequential, but will be undertaken in an iterative way following the priorities determined in formulating an action plan. It is important that patient, family and carers are kept involved as the plan is developed and modified in the light of further assessments and progress in meeting objectives.

Dementia and disability

Treatment of specific causes

Sometimes medical or surgical treatment can be offered for potentially reversible causes of or conditions associated with 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 appearance but can be improved with appropriate treatment.

Drug treatments for dementia

There are currently no drugs proven to prevent dementia or modify the neuropathology of the disease once established. However clinical studies have shown that acetylcholinesterase inhibitors can improve cognitive function and/or delay or lessen the rate of cognitive and functional decline in patients with mild to moderately severe Alzheimer's disease. A number of acetylcholinesterase inhibitors are currently available under the Pharmaceutical Benefits Scheme, provided the patient meets the guidelines (see the PBS Handbook for current guidelines and arrangements). Evidence of benefit is now accumulating for Lewy-body dementia, but not for other types of dementia, including vascular dementia.

Cholinesterase inhibitors

Donepezil and rivastigmine constitute symptomatic treatments with varying degrees of efficacy and safety. So far the longest studies have used donepezil. Side effects were generally mild and transient in nature, usually resolving without dose modification, and were related to the nervous and digestive systems.

Other drugs

- *Aspirin* in vascular dementia is of benefit in preventing vascular events or death in patients with a history of prior transient ischaemic attack or stroke.
- *Vasodilators* – there is no consistent evidence of clinical benefit from vasodilators in dementia.
- *Oestrogen* – evidence of benefit is controversial.
- *Vitamin E* – evidence of benefit is controversial and applies only to very high doses.
- *Nonsteroidal anti-inflammatory drugs (NSAIDS)* – evidence of benefit is controversial.
- *Hydergine* may lead to a small improvement of variable sustainability in some patients, but those who will respond cannot be predicted in advance.
- *Tacrine* has a moderate effect on cognitive function, but this effect does not seem to translate to differences in activities of daily living scores, and it has potentially serious side effects so should not be used.

Psychotropic drugs

- *Antidepressants* – when doubt remains as to the extent of depression in a patient with early dementia, a trial of antidepressant therapy is warranted, with careful monitoring to determine the extent of benefit or adverse effect.
- *Other psychotropic drugs* – 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 continued in parallel with drug treatment.

The golden rule is to start with low doses and increase slowly, whilst carefully monitoring both beneficial and adverse effects.

Adverse effects are unfortunately very common. These include: sedation, confusion, decreased mobility, low blood pressure and Parkinsonism, and paradoxical worsening of behaviour. Psychotropic drugs should not be prescribed indefinitely and their use needs regular review.

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.

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. (*see p42*).

Managing behavioural concomitants of dementia

Some general practical strategies which carers can adopt:

- Establish a simple, regular routine that suits the person with dementia.
- Establish a physical environment that suits the person with dementia (safe, comfortable, familiar, interesting).
- Be prepared for change, understand that dementia is due to a disorder/disease of the brain and that the affected person has reduced ability to control/think/act.
- Ignore unwanted behaviour or walk away; positive reinforcement of adaptive behaviour.
- Expect inconsistencies – patient can sometimes do things, sometimes not (like faulty wiring).
- Distract – try to focus attention away from what is upsetting the person with dementia.
- Use empathy and humour to defuse tension.
- Maintain respect, avoid infantilisation, don't say to the person 'I just told you that'.
- Slow pace, avoid rush.

- Give repeated explanation and reassurance.
- Use clear, direct, short and simple communication; importance of eye contact, gestures and appropriate touch.
- Break tasks down into small steps.
- Look at activities in terms of the steps required to perform them. The person may be able to do some but not all of these eg get dressed, if clothes are selected and put out by someone else.
- If resistance encountered with task, try again later.
- Tolerate the behaviour (avoid arguing or scolding).
- Ensure consistency and avoid change wherever possible.

An important principle in minimising the difficulties that dementia will cause is to change the environment, not the person:

- Install a whiteboard near the telephone to write messages on.
- Display clocks prominently.
- Use calendars where the current date is obvious.
- Remove loose rugs and low furniture which may cause falls.
- Provide the patient with frequent reminders, explanations and orientation cues (*see p43*).

Co-morbidity

The patient's general medical problems and treatments should be managed optimally and reviewed regularly to minimise adverse effects on mental functioning, particularly medications which may produce central nervous system side-effects. 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. This may require the use of aids such as the Webster pack, and domiciliary medication reviews from time to time.

Depression

Social stimulation, appropriate activities, plus counselling when appropriate are first-line strategies for depressed mood. Antidepressant drugs are often worth trying, newer antidepressants such as selective serotonin re-uptake inhibitors (SSRI's) usually being preferable to tricyclics.

Anxiety states

High anxiety levels may respond to social or environmental manipulation. If not, patients may benefit from behaviour modification, counselling, or anti-anxiety, anti-panic or anti-phobic drug treatment.

Cerebrovascular disease

The medical management of vascular dementia is the same as for stroke disease.

Other conditions

Other medical conditions particularly needing optimum treatment are: dehydration, diabetes (particularly, avoidance of hypoglycemia), hypoxia, anaemia, postural hypotension, epilepsy, infective illness, pain and urinary or faecal retention.

Health promotion

It is important to focus on the remaining strengths, skills and resources of people with dementia, and work toward the maintenance of these, encouraging customary activities. Support groups such as those run by Alzheimer's Australia under its Living With Memory Loss Program may improve insight and coping skills and assist patients and carers in coming to terms with disability. Regular review and care planning, with referral on to counselling support groups or other support agencies, is vital.

Diet

Adequate diet is very important, particularly to avoid obesity or unwanted loss of weight, and to ensure an adequate dietary intake of vitamins and other essentials. Meals-on-Wheels should be considered for those living alone.

Exercise

'Use it or lose it' applies to physical as well as mental activity. Patients need to be encouraged to maintain physical activity appropriate to their interests and physical state, and this needs to be built into their routine.

Drug Use

The patient's consumption of alcohol and other potential drugs of abuse (especially minor tranquillisers) should be reviewed since usual doses (previously tolerated) may produce more obvious toxic effects once dementia ensues.

Prevention

This most commonly needs to be directed towards preventing:

- worsening of co-morbid conditions (*see p22*)
- falls and other accidents
- preventable infections.

Falls

Prevention of falls requires recognition and alteration of environmental risks, modification of risk behaviours, and appropriate physical assistance.

Immunisations

Routine immunisations such as tetanus should be checked, and updated if necessary, for all patients. Annual influenza immunisation should be given, and many may need pneumococcal vaccine every five years.

Patient/family and social support

This is probably the area of management which will make most impact on the quality of life for both patient and family or carer.

Providing information

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. Carers need to be able to access information in small, manageable ‘bites’, checking their understanding frequently and reviewing and updating information at each consultation.

People with dementia living alone will usually need support. There are complex ethical issues involved in ensuring that a person’s wish to continue living alone is balanced with their safety and that of others.

Decision making capacity

The patient’s capacity to make decisions about matters such as consent to treatment, living circumstances and financial arrangements needs to be determined (*see pp44-5*).

Risk management assessment

An early priority is to assess whether there is any evidence of danger to the person with dementia or to others. Falls, accident risks in the home (eg stove, appliances, open fires), impaired driving, malnutrition, suicide threats or apparent abuse or neglect may require urgent action.

Dementia and driving

The issue of fitness to drive must be assessed. Even mild dementia increases the risk of traffic accidents; the risk increases with concomitant morbidities and as the disease advances.

Writing ‘DO NOT DRIVE’ on a prescription pad may help. If there is a dispute, the patient should be referred to the local office of the Roads

and Traffic Authority. Options for alternatives should be discussed including the offer of a second opinion or the suggestion of a formal driving assessment or a simulated test (*Appendix F2*).

Financial support

The patient may be eligible for superannuation on medical grounds, sickness benefits or a disability support pension.

The carer may be eligible for a carer payment or carer allowance. The latter is not means-tested but based on the severity of the dementia being at a level where the patient would be approved for nursing home admission. Information can be obtained from Centrelink Tel. 13 27 17.

Carer and Patient Support

Further support for carers can be obtained via the Commonwealth Carer Resource Centre, which has a Carer Information Pack Support Kit that provides information about the support and services available to carers, and offers practical assistance. A copy of the information kit can be obtained by phoning the Commonwealth Carer Resource Centre on 1800 242 636 (toll free from anywhere in Australia). Community services can be accessed via Carelink on 1800 052 222, and respite services via Commonwealth Carer Respite Centres on 1800 059 059.

In addition, Alzheimer’s Australia coordinates a large number of support groups throughout Australia and also offers free specialist counselling services for both carer and patients (*Appendix F1*). These services can be accessed through the National Dementia Helpline on 1800 639 331.

Aged Care Assessment Teams are also an avenue for further resources for carers and patients.

Other assistance may be obtained via Community Health teams, community nursing services, specialist services (eg psychogeriatricians) and community support services such as Meals-on-Wheels, community transport, personal home nursing care and home help and specialists.

Legal issues

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. Testamentary capacity, Enduring Power of Attorney or Enduring Guardianship, and advanced care directives should be considered (*see pp44-5*).

Leaving home

Institutionalisation offers the best duration of survival for people with dementia, survival in this context meaning time until death rather than quality of life. However most patients would prefer to remain living in the community, and usually their carer agrees. A patient should not be assessed for optimal home care independently of the carer, and often both patient and carer prefer a formal care package while remaining at home.

Ultimately the requirements of caring become too much for carer and family, and often adversely affect their health. The decision to relinquish full-time care is rarely easy, particularly for spouses, and usually involves emotional turmoil, grief and guilt. Carers need support at this time, available from the Carer Resource Centre, Alzheimer's Australia or face-to-face counselling. Institutional care needs to be considered early because it often takes considerable time to arrange a placement. ACAT assessment is required for admission to a residential aged care facility.

The carer: the 'second patient'

Patients sometimes make life very difficult for their carers.

Mrs B, aged 82, woke one morning and turned to her husband in alarm. 'What are you doing there? Get out of the bed. I don't know you.' The husband's distress was compounded when the GP arrived and Mrs B greeted him warmly: 'How nice to see you doctor. Why are you here?'

GPs need to be vigilant about the health of the carer as well as the patient with Alzheimer's disease even if the carer is not their patient. Encourage carers

to join the Alzheimer's Australia and to contact the Carer Resource Centre for education and support. Suggest alternative or respite care arrangements rather than waiting for carers to mention them.

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. Spouses are generally more stressed than other kin. Problems may be exacerbated by grief at the loss of the relationship that previously existed.

Carers' stress can be worsened if other family members or close friends have differing views about management. Such difficulties should be sought out and dealt with tactfully.

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.

There is a great deal of descriptive and anecdotal data indicating that support services are helpful in many ways to carers and people with dementia. Training programs for carers have been shown both to relieve strain and to delay institutional placement.

Respite care

Consideration of respite care is an essential part of a long-term plan. This can give carers the opportunity to have a break, and allow the patient to experience another environment without it being a permanent break. However it must be planned carefully, as respite care in a unit with severely demented patients may be traumatic for a patient with early dementia. Respite care needs to be planned well in advance as it is rarely available at short notice. It must usually be arranged through an Aged Care Assessment Team.

Abuse

Recognition of abuse may be difficult and requires awareness of the possibility and tactful inquiring about the stresses of caring. Abuse can be physical, psychological, financial or sexual. The person with dementia can sometimes be the abuser (*see p48*).

Initial stage management

Management of dementia – the early stage

Management priorities and urgency will vary from patient to patient, but in the early stages there will be a need to address:

- assessment
- diagnosis
- deficits
- assets
- other health issues
- counselling and education
- patient
- carer
- medical management of dementia, behaviour and co-morbidity
- extended family interview
- legal planning
- driving
- financial planning
- support from others.

As these are dealt with, a long-term plan needs to be developed with formulation of potentially achievable objectives against which progress can be measured.

Long-term management plan

The long-term plan needs to be modified as time goes by to take into account changes in the patient, family, carer and social situation.

Areas to consider include:

- support for the person with dementia
- support for the carer
- increasing dependence
- personality changes
- behavioural disturbances
- psychiatric co-morbidity
- aged care services
- social services.

Follow-up

As dementia is a progressive disease, ongoing follow-up and continuity of care are essential. Management should aim to anticipate developments and therefore minimise difficulties they might cause. During follow-up visits with the patient and their carer, it is important to explore:

- cognitive function, including any changes (especially if they are acute)
- functional ability, especially alterations in daily living skills such as shopping or travelling
- behaviour, including mood and motivation
- general health, including sleep, nutrition, continence, balance and mobility/gait.

Ask the carer:

- How they are coping with looking after the patient
- Whether they need assistance or respite care
- How their own health is and how they are looking after themselves.

Audit of care for persons with dementia

An audit checklist for the general practice management of a person with dementia is useful (*see p7*).

Referral

Referral should be considered when:

- progress with any of the problems is unsatisfactory to doctor, patient, family or carer
- there are multiple unresolved problems
- symptoms are causing acute distress
- there are difficult behavioural problems
- respite care or other community support services are needed.

Referrals should be made with specific stated objectives.

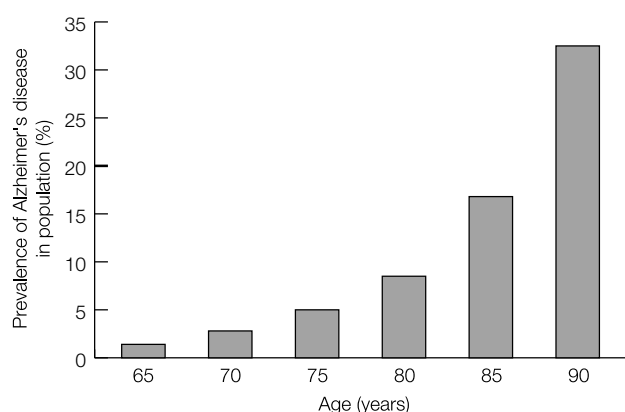
Background and supporting evidence

General background

Prevalence

For every 1,000 patients that an Australian GP sees, he or she can expect to find 10 patients with moderate to severe dementia and another 10 patients with mild dementia. The incidence of Alzheimer's disease is dependent on age, with the prevalence doubling every 5 years from the age of 65 (figure 1). It is estimated that 5–10% of elderly people and up to 50% of those aged over 85 years have some degree of Alzheimer's disease (Katzman 1994).

Figure 1. Prevalence of dementia in the population



Source: Livingstone G. *The scale of the problem*. In Burns A, Levy R, eds. *Dementia* London: Chapman and Hall Medical, 1994: 21–25.

Dementia in general practice in Australia

The BEACH study of morbidity and treatment in general practice 1998–2000 contains information from 2,031 GPs who each recorded information about 100 consecutive encounters. There were 863 encounters (0.4%) with patients with dementia, with 7% of these encounters being a new diagnosis. The encounters were reported by only 431 of the GPs (21%); 39% occurred in nursing homes.

Most (82%) of the patients with dementia were over 75 years of age, and 69% were female. At their encounters they presented 154 reasons for encounter per 100 encounters, of which 28% were dementia, 15% were check-up, 13% were memory disturbance, and 9% were psychological or behavioural symptoms. Apart from check-up, these were uncommon reasons for encounter overall.

Other problems were dealt with in 96% of patients, most often hypertension (7%), heart disease (8%), diabetes (4%), depression (2%), and cerebrovascular disease (2%). Other problems in general, and all those mentioned except hypertension, were much more common in patients with dementia than in patients overall.

Prescriptions were issued much less frequently for patients with dementia (29 per 100 encounters) than for patients overall (64 per 100 encounters) and most were for psychotropic drugs (Bridges-Webb 2002).

Genetics

Genetic factors are important in the development of dementia, particularly Alzheimer's disease, but most cases are sporadic; it is familial in less than 10% of cases (Panegyres 2000).

The presence of the apolipoprotein E4 (ApoE4) allele on chromosome 19 increases the probability that a patient with dementia has Alzheimer's disease, while its absence makes it less likely.

Although the ApoE4 allele and Alzheimer's disease are closely linked, not everyone with ApoE4 develops the disease and, conversely, not all patients with Alzheimer's disease carry the allele. Therefore, although it is a risk factor, the use of ApoE4 genotyping to predict future risk of Alzheimer's disease is currently not recommended (National Institute on Ageing 1996), (Grey Matters 7:3).

Neuropathology

The most characteristic neuropathological features of Alzheimer's disease are amyloid plaques, neurofibrillary tangles, neuronal loss and cortical and central atrophy. Amyloid protein is believed to play an important role in the pathogenesis of Alzheimer's and may be critical for the formation of amyloid plaques, which appear to reflect damage to the surrounding nerve endings. This neuronal damage causes impaired neurotransmission and results in the cognitive deficits associated with Alzheimer's (*Grey Matters 7:3*).

Risk factors

There are multiple risk factors for Alzheimer's disease. Almost certainly a variety of factors, both genetic and environmental, can contribute concurrently to its development; however, a number of specific risk factors have been associated with its onset, and should be inquired about.

Risk factor	Comments
Increasing age	The prevalence of Alzheimer's disease doubles every 5 years in the elderly
Family history	A family history of Alzheimer's disease increases risk 2 to 4 times
Sex	Women appear to be at greater risk than men, but this may be linked to the longer life expectancy of women
Head trauma	Repeated trauma increases the risk of developing Alzheimer's disease
Down's syndrome	All patients with Down's syndrome develop the neuropathological (although not necessarily the clinical) features of Alzheimer's disease by the age of 40
Education	Patients with a lower level of formal education are more likely to develop Alzheimer's disease

The links between Alzheimer's disease and other potential risk factors such as aluminium and environmental pollutants have not yet been proven (*Grey Matters 7:3*).

Other risk factors may be important in other sub-types of dementia, such as arteriosclerotic vascular disease for vascular dementia (*see the section on the sub-types of dementia pp38-9*).

Ageing and cognitive decline

During normal ageing the speed at which individuals acquire information gradually declines, but their ability to recall information remains relatively preserved. In Alzheimer's disease, there is a progressive decline in learning and the ability to recall information. There is also an intermediate state – cognitive impairment without dementia – which is in fact twice as prevalent as dementia in elderly populations (*Graham 1997*). Such individuals have lower than normal cognitive ability but it is insufficient to cause functional decline (*refer to Appendix E1 for DSM IV criteria for Alzheimer's disease*).

The usual diagnostic standard for dementia consists of detailed assessment of mental status and careful investigation to rule out other causes of cognitive impairment. A variety of abbreviated instruments have been examined for their ability to screen for dementia in the outpatient setting (*see Appendix B*).

Advantages of early recognition of dementia

1. Opportunity to discuss concerns and feelings and gain some control of the situation.
2. Treatment issues – effective therapy, including drugs and behavioural therapy, is more likely to be of use in the early stages of the condition. The newer specific drug treatments for Alzheimer's disease are most effective if used in the early stages. Treatment of conditions that may cause dementia, such as hypothyroidism or vitamin B12 deficiency, is essential, and optimal treatment of other co-existent conditions can improve the patient's functioning.
3. Medico-legal issues – an early diagnosis allows for the following:
 - an Enduring Power of Attorney and Enduring Guardianship can be arranged
 - any advance directives can be discussed
 - car driving safety can be assessed
 - safety around the house can be assessed.

4. 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 (*NZ Guidelines 6:15*).

'Use it or lose it' applies to physical as well as mental activity. Patients need to be encouraged to maintain physical activity appropriate to their interests and physical state, and this needs to be built into their routine.

Recognition of dementia

The GP may become aware of the possibility of dementia in three ways:

- presenting problems
- noting early pointers when treating other conditions
- screening.

Presenting problems

A 'typical' presentation of early dementia

The patient:

- is brought to the doctor by a spouse, family member or friend
- tends to look at his or her carer when asked a question (the 'head-turning sign')
- has difficulty recalling the present date and finding words
- may forget recent events but immediate and long-term memory tend to be intact
- tends to minimise or rationalise problems
- has had a 'memory problem' for at least six months, with insidious onset and gradual progression
- shows mild impairment on cognitive screening, including impaired recent memory and difficulty drawing a clock.

With Alzheimer's disease (the commonest type of dementia), the patient:

- is unlikely to have a history of cerebrovascular events, headaches or seizures
- is unremarkable on medical and neurological examination apart from higher cortical functions (*Grey Matters*).

There are, however, other less common types of dementia which may present in different ways. These are discussed in the section on the sub-types of dementia (pp38-9).

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*)

- 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; indicates poor prognosis.

Depressive symptoms (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% of cases*)

Dementia may occasionally present with a syndrome which is indistinguishable from hypomania: overactivity, sleep disturbance, talkativeness, disinhibition, and cheerfulness or irritability.

* At some stage in the course of dementia.

(Source: NZ Guideline 6:24)

Non-psychotic behavioural disorders

An association exists between acute underlying medical illness and outbursts of aggressive behaviour in people with dementia. A placebo response is seen in 67% of people treated with neuroleptic agents for the control of behavioural disorders in dementia; there is no difference between neuroleptic agents used and no identifiable differences between responders and non-responders. *A high proportion of people with dementia of the Lewy-body type are sensitive to neuroleptic agents, and appreciable number of these experience a severe reaction.* Delusions or misidentifications are associated with a high number of aggressive episodes.

- Any underlying causes of behavioural disorder, eg an acute physical illness, environmental distress, or physical discomfort, should be excluded.
- Where underlying causes are identified they should be managed before prescribing drugs for the behavioural disorder.
- Tranquillisers should not be used routinely to control behaviour disorders in dementia. In crisis situations, the short-term use of neuroleptic drugs may be appropriate.
- *Patients with dementia of the Lewy-body type should not be treated with neuroleptics.*

There is a relation between delusions and aggressive behaviour; aggressive behaviour should be assessed with this in mind.

The care setting and the attitudes of carers (or care teams in an institutional setting) may influence the emergence of behavioural problems (*Eccles 1998*).

Early pointers

Case-finding and warning signs

Up to half of all cases of Alzheimer's disease may remain undiagnosed and may become apparent only when the individual's carer dies or becomes unable to cope.

GPs may note early pointers to dementia when treating other conditions. Early diagnosis is important because drug treatment is now available, and much can be done at this stage to improve lifestyle and reduce risks, and provide information and support for carer and family.

It is important to be alert to cognitive impairment in elderly patients and this should be kept in mind during routine appointments.

Warning sign	Examples
Memory problems	<ul style="list-style-type: none"> - trouble recalling time or date - impaired ability to recall recent events or conversations - losing items - repetitive questioning.
Cognitive problems	<ul style="list-style-type: none"> - abandonment of complex activities (eg finances) - difficulty recognising familiar objects or people - cannot follow the plot of a story - language problems - delirium.
Behavioural changes	<ul style="list-style-type: none"> - withdrawal and/or inertia - inflexible - attitude or stubbornness - irritability - reduced planning and decision making - lack of attention to detail.
Specific incidents	<ul style="list-style-type: none"> - confusion or unhappiness while on holiday - inability to recognise familiar faces at family/social gatherings - neglect of long-established behaviours (eg writing Christmas cards).

These changes are likely to have developed slowly and have no clear date of onset.

(*Grey Matters 7:4*)

Screening

There is insufficient evidence to recommend for or against routine screening for dementia with standardised instruments in asymptomatic persons (*Canadian Consensus Conference 1998, p3*).

The routine physical examination and patient history is not sensitive for dementia, especially if family members are not present to corroborate patient self-report. The most commonly used short test of cognitive functioning, the MMSE, applied to a population of asymptomatic 65 to 74-year-old people would yield false positive rate of 93% (*Canadian Consensus Conference 3:57*).

The inability to recall the correct date or place is reasonably specific (92-100% – few false positives), but highly insensitive (15-53% – many false negatives) for dementia.

In dementia due to Alzheimer's disease, neurologic findings, such as release signs, gait disorders, and impaired stereognosis, are usually late findings and are not sufficiently sensitive or specific to screen for dementia.

History and functional assessment

As the dementing process progresses, awareness of memory problems decreases, leading to less reliable histories from patients. People with dementia cannot be relied on to complain of memory difficulties. The short mental questionnaire is a screening tool that is sensitive to mild dementia. It can be completed by the carer and may have a useful place in identifying people with dementia. Memory complaints by patients correlate with depression. Carers' complaints about the memory of their relatives correlate with dementia.

Recommendations and important points:

- Insight diminishes as dementia progresses, making the patient's history less reliable.
- In assessing a person with cognitive impairment, a history of memory problems should be sought from the carer as well as the patient.
- Dementia and other psychiatric symptoms (delusions or hallucinations, or both, usually persecutory in nature and simple in type) may coexist (*Eccles 1998*).

Remember that the patient must be asked whether he or she consents to others being consulted about his/her health. If an interpreter is required, it is preferable to use an independent person as members of the patient's family may (consciously or unwittingly) compensate for the patient's problems (*Grey Matters 7:5*).

History from the patient and a reliable informant

The history should include:

- general medical (including vascular risk factors)
- neurological history
- neuropsychiatric history, including behavioural changes
- drugs, alcohol
- family history, particularly in younger onset
- description of onset and progression of cognitive deficits

- initial depression screen (eg 'Are you feeling sad/down?') (*LoGiudice 1999*).

Questions to ask both the patient and the carer include the following:

- Who first noticed a problem?
- What changes have been noticed?
- How and when did it start? Can a specific date or period be given?
- How is the situation progressing? Are the changes slow and smooth or sporadic?
- Is there a family history of behavioural or memory problems in old age? (*Grey Matters 7:5*)

When consulting the carer or family members alone, ask whether the patient has:

- changed their behaviour (eg become irritable, withdrawn, unhappy)
- become forgetful
- become lost in familiar surroundings
- failed to recognise – or shown a lack of interest in – family members
- exhibited difficulties driving, shopping or using the telephone
- not been performing well in their usual work or home duties
- suffered any delusions or hallucinations.

Giving carers checklists to fill in, or asking them to keep a diary of the patient's behaviour, can help assess the patient's decline and allow the progression of the condition to be monitored (*Grey Matters 7:5*). The Neuropsychiatric Inventory Questionnaire (NPI-Q) is one such useful instrument. (*Appendix C3*) (*American Academy of Family Physicians Guidelines 2002, 1*).

Functional assessment

It is important to assess the extent to which the patient's problems with memory and cognition are interfering with his or her ability to undertake daily activities (*See p17*).

Physical examination

A small proportion of people with dementia have an underlying abnormality, and when this is treated cognitive function improves. The exact number of people thus affected is uncertain because of problems of study populations. People with Alzheimer-type dementia do not complain of common physical symptoms, but experience them to the same degree as the general population.

Recommendations and important points:

- Health care professionals should be aware of the existence of reversible causes of dementia.
- People with dementia experience physical morbidity to the same degree as the general population, but are likely to under report their symptoms.
- General practitioners should ensure that the following routine tests are performed:
 - haematology (including erythrocyte sedimentation rate)
 - biochemistry
 - serum calcium and phosphate
 - thyroid function
 - simple urine analysis (*Eccles 1998*).

Does the cognitive loss affect more than one part of the brain?

If the dementia symptoms cannot be attributed to delirium, depression or drugs then a neurological evaluation should be undertaken. In particular, the following should be assessed:

- focal deficits – gait disturbance, motor deficit, sensory deficit
- abnormalities of muscle tone, movement or reflexes.

The neurological history and examination should look for current or past conditions which may produce signs of dementia, including cerebrovascular events, head trauma, epilepsy or infections of the central nervous system such as syphilis or human immunodeficiency virus (HIV) (*Grey Matters 7:9*).

Investigations

CT scan

The principle reason for conducting a CT scan is to eliminate non-Alzheimer's disease causes of dementia, such as mass lesions or subdural haematomas (*Chan 1997*). Although the detection of diffuse cerebral atrophy on CT may suggest Alzheimer's disease, its diagnostic specificity is low. A CT scan without contrast should be ordered at some stage in the dementia, but is of more use early in the disease. A CT scan becomes more urgent if the patient with dementia is under 60 years of age, has had a recent head trauma, is using anticoagulants or has undergone a rapid, unexplained decline (*Grey Matters 7:9*).

Potentially reversible dementia

This refers to syndromes that are, at least partly, reversible following early recognition and treatment of the underlying condition. 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 a list of tests which should be undertaken in any person with dementia (*see p8*), to ensure that reversible causes will not be overlooked. However these are encountered rarely when the case is typical of Alzheimer's disease. The use of such tests may reveal abnormalities, which can be corrected and can lead to total reversibility if the dementia is only related to these abnormalities. However there may not be any improvement in cognition if the abnormalities are aggravating a dementia which is fundamentally caused by another disease process (*NZ Guideline 6:12-13*).

Cognitive assessment

Short assessment tests for cognitive impairment

Mini-mental state examination (MMSE)

(Appendix B1)

At present the full mini-mental state examination should be used for assessment though, there is some evidence that it can be shortened for use in primary care with only a small reduction in specificity. Four items of the mini-mental state examination are predictors of dementia:

- orientation to day
- spell WORLD backwards
- recall three words
- write a sentence.

Reducing the mini-mental state examination to two items – recall and orientation for place – reduces the specificity only slightly. The mini-mental state examination may be influenced by verbal fluency, age, education, social grouping and cultural background.

Clock drawing test

In the clock drawing test, the accuracy of the fourth quadrant of the clock face shows the greatest sensitivity (87.5%) and specificity (82.3%) for dementia.

GPCOG (Appendix B2)

This Australian-designed test for use in general practice includes elements of both the above plus an informant interview, and has the advantage of brevity and efficiency. (Brodaty et al. 2002)

(Rowland) Universal Dementia Assessment Scale

This Australian-designed version of the mini-mental state examination is a brief, administratively simple dementia assessment tool that is designed to be culturally and linguistically fair. (Accepted for publication in *International Psychogeriatric Association (IPA) Journal*, 2003)

Activities of daily living (Appendix C5)

Deterioration in four domains of instrumental activities of daily living are significantly associated with cognitive impairment. These domains are:

- managing medication
- using the telephone
- coping with a budget
- using transportation.

Recommendations

Health care professionals should consider using the following instruments to identify cognitive impairment:

- the mini-mental state examination
- the clock drawing test
- the GPCOG
- (Rowland) Universal Dementia Assessment Scale
- an instrument for assessing activities of daily living (Eccles 1998).

The most widely studied of these instruments is the mini-mental state examination, a short, structured examination that takes 5-10 minutes to administer. The MMSE contains 30 items and is reproducible using a standardised version. Various studies suggest that an MMSE score of less than 24 out of 30 has a reasonable sensitivity (80-90%) and specificity (80%) for discriminating between dementia cases and normal controls. There are only limited data, however, on its performance as a screening test for early dementia among a representative population of outpatients. The positive predictive value (PPV) of MMSE for dementia depends on the definition of an abnormal score and the prevalence of dementia. Based on its performance in one community study, a MMSE score of 20 or less has a PPV of only 48% when the prevalence is 10% (eg a population of 75-84 year olds), but a much higher PPV (73%) when prevalence of dementia is 25% (eg age over 85).

The predictive value of intermediate MMSE scores (21-25) appears to be low (21-44%) for dementia in most populations (Guide to Clinical Preventive Services, 1996).

Home visit

(Refer to Guidelines p12)

Delirium

Delirium in the elderly is often a first warning sign that dementia may develop within the next three years and may highlight underlying Alzheimer's disease (*Grey Matters 7:8* and *NZ Guidelines 6:23*).

Some of the causes include medication effects, infections, vascular changes, hypoxia, metabolic problems, surgery and trauma. Delirium has an increased mortality, increased rate of institutionalisation and increased likelihood of readmission to hospital. One source of diagnostic confusion between delirium and dementia is caused by the mistaken belief that delirium is always of short duration and of florid symptomatology. A sub-acute confusional state can last for months. Recent research has shown that 'quiet signs' are common in delirium, such as plucking at bedclothes, poor attention, incoherent speech, slow vague thought and fluctuating mental state (*LoGiudice 1999*).

Depression

Depression can manifest as dementia; conversely, dementia can present with depressive symptoms early in the illness. To differentiate between depression with cognitive impairment and dementia consider using the Geriatric Depression Scale (*Appendix C1*), or the short EBAS-DEP (*Appendix C2*). If in doubt, psychiatric referral is required.

Depression is common in the elderly. The longer the depression is left untreated, the less likely it is to get better. Failure to recognise and treat depression can lead to long-term suffering, disability and even suicide.

In the elderly depression is often overlooked or under treated; major depression occurs in 20-30% of people diagnosed with Alzheimer's disease (*Ames 1994*). The criteria for making a clinical diagnosis of major depression are noted in following table.

Depression is common, especially in the physically ill, those in hospital, attendees at GP surgeries, alcoholics, the socially isolated and residents of aged care facilities.

Criteria for major depressive disorder

Before a diagnosis of depression can be made, one of the following two symptoms must be present:

- low (sad, miserable, depressed) mood most of the time which is not relieved by pleasant circumstances
- loss of interest and the capacity to take pleasure in things which the sufferer previously enjoyed (that is not due to circumstances only).

Other symptoms may be:

- loss of energy, tiredness, fatigue and ability not due to other physical factors
- unreasonable feelings of guilt or self reproach
- suicidal behaviour or recurrent thought of death or suicide
- subjective impairment of concentration or thinking ability
- agitation or psychomotor retardation
- excessive or disturbed sleep (especially early waking)
- loss of appetite and/or weight (increase in appetite or weight can occur)
- loss of self esteem and confidence.

The diagnosis of major depression is made when five or more symptoms are present for two or more consecutive weeks.

(*American Psychiatric Association 1994*)

Depression in patients with dementia

Depressive illness is commoner in people with dementia than those without. Mortality is increased in people with dementia and depression. The prevalence of depression in patients with dementia varies widely according to the study population. In a general population, the prevalence varies from 10-40% of patients with dementia. Depression is more commonly diagnosed or recognised in early dementia. Treatment is likely to be of value, with reported response rates of up to 85%. Depression commonly leads to difficulties in communication and independent activities of daily living and has a less common effect on cognitive function. Presenting symptoms relate to inner feelings (anxiety, mood, loss of interest, helplessness, hopelessness and worthlessness) and less to vegetative symptoms.

Recommendations and important points:

- Depression can occur in patients with dementia at any stage in the dementing process.
- the history should be gathered from both the patients and their carers.
- Relevant risk factors for depressive illness, such as personal or family history of depression, or recent adverse events, such as bereavement or relocation, should be considered.
- Consider a trial of antidepressant medication evaluated against explicit criteria such as activities of daily living, level of functioning, behavioural disturbance, and biological features of recent onset (*Eccles 1998*).

Differential diagnosis

The most common cause of dementia is Alzheimer's disease, which accounts for about half of the cases seen. Other types of dementia are listed below.

Features that may distinguish depression from dementia

Feature	Primary depression	Primary dementia
General features	<ul style="list-style-type: none"> – family aware of illness – onset more acute and can be dated – symptoms of short duration – rapid progression – family history of affective disorder 	<ul style="list-style-type: none"> – family often unaware of illness – insidious onset, only vaguely dated – symptoms of long duration – slow progression – possible family history of dementia
Patient's history	<ul style="list-style-type: none"> – past history of depression – seeks help with complaints of memory loss – complaints given in great detail – cognitive deficits emphasised – failings highlighted by patient 	<ul style="list-style-type: none"> – no history of depression – few complaints of memory loss – vague, non-specific complaints – cognitive deficits concealed – accomplishments highlighted by patient
Mental state observations	<ul style="list-style-type: none"> – 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 	<ul style="list-style-type: none"> – 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	<ul style="list-style-type: none"> – '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-R pattern 	<ul style="list-style-type: none"> – frequent 'near miss' answers – orientation tests poor – recent memory worse than concentration – consistently poor test performance – WAIS-R performance scores worse than verbal scores
Neurological	<ul style="list-style-type: none"> – no primitive frontal release reflexes – no dyspraxias or agnosias – no language difficulties, corrects paraphasic errors – CT head scan more commonly normal 	<ul style="list-style-type: none"> – frontal reflexes may be present – dyspraxias and agnosias common – word finding problems and paraphasia common – CT head scan usually abnormal, with cerebral atrophy

(NZ guidelines 6:23)

Types of dementia

Alzheimer's disease	40%
Vascular dementia	20%
Lewy-body dementia	20%
Frontal lobe dementia	
Parkinson's disease with dementia	
Normal pressure hydrocephalus	
Post-traumatic, toxic (particularly alcohol) or anoxic encephalopathy	20%
Prion diseases eg Creutzfeldt Jakob disease	
Multi-infarct dementia	
Down's syndrome	
AIDS	
Other	

(LoGiudice, 1999)

Dementia sub-types**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 in 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 (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 (NZ Guidelines 6:11).

Vascular dementia

Risk factors include hypertension, diabetes, atrial fibrillation and a history of myocardial infarction. A computed tomography (CT) scan without contrast may help confirm or exclude a vascular aetiology (Grey Matters 7:9).

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. Cognitive decline tends to be discontinuous and deficits are often patchy (NZ Guidelines 6:11).

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. 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 cause of this syndrome is Pick's disease which is associated with focal atrophy of one or both frontal and/or temporal lobes. (NZ Guidelines 6:11).

Lewy-body dementia

The clinical course of dementia of the Lewy-body type differs from that of Alzheimer's disease, showing clear fluctuations with the following clinical features:

- complex visual hallucinations (48%)
- auditory hallucinations (14%)
- paranoid delusions (57%)
- clouding of consciousness (81%)
- falls or collapses (38%)
- depression (38%)
- extrapyramidal features (9.5%).

There is high neuroleptic sensitivity (61.5%) and a high risk of increased morbidity and mortality if neuroleptic drugs are prescribed.

Recommendations and important points:

- Differential diagnosis of dementia of the Lewy-body type is important because of the high risk of increased morbidity and mortality with neuroleptic agents in these patients.

- Doctors should be aware of the importance of avoiding neuroleptic drugs in people known to have dementia of the Lewy-body type (*Eccles 1998*).

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 (*NZ Guidelines 6:11*).

Ability/disability

Older road users – issues for general practitioners

Advice from medical practitioners is often heeded by older patients in relation to their ability to drive. Using resources such as the Austroads publication *Assessing Fitness to Drive and Medical examinations of commercial vehicle drivers* will aid the GP in making an informed decision in relation to this (*Appendix F2*).

Co-morbidity

(Refer to *Guidelines p18*).

Family/social support and environment

Assess carer and family

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.

The ability to cope with caring depends on the:

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

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.

The Caregiver Burden Scale is a self-administered 22-item scale that is a useful tool for measuring the distress of caregivers (*Appendix D1*) (*American Academy of Family Physicians Guidelines 2002, 1*).

Action plan

Overarching principles for the general practitioner:

- not all dementias are the same
- quality of life for the person with dementia
- the hidden second patient
- dementing not demented – the evolving, ever-changing picture
- dementia – the long haul
- vulnerability of people with dementia
- liaising with other services
- treating patients who can’t consent – medico-legal issues
- advances in knowledge (*Brodsky 1996*).

What, how and when to tell patient and family

Giving patients a diagnosis of Alzheimer’s disease is often seen by many as equivalent to giving a diagnosis of incurable cancer (*Grey Matters 7:11*).

Prognosis

As Alzheimer’s disease is a progressive neurodegenerative disease, it will affect different individuals in different ways. Throughout the dementing process, changes will continue to occur; some problems may become exaggerated, others will paradoxically subside.

On average, the time from onset of the disease to diagnosis is about 2-3 years, while from onset to death is usually 10 years. Although the progress of Alzheimer’s disease is gradual, the following table gives some indication of the changes that will occur as the disease progresses. (*Grey Matters 7:12*).

At some time during the dementia, behavioural complications will affect 90% of patients with Alzheimer’s disease. Psychological/psychiatric complications include depression, anxiety, psychosis or hallucinations, while non-psychological behavioural complications include agitation, wandering, screaming and aggression. These problems warrant treatment when they impair self-care or social interactions, or when they are likely to lead to institutionalisation. Patients with these behaviours can be difficult to manage but they are often over-medicated; as these behaviours change over time, medication for such complications should be reviewed at least every 6 months (*Grey Matters 7:12*).

Referral

(Refer to *Guidelines p18*).

Typical stages in the development of Alzheimer’s disease; each individual will be affected differently

Moderate Alzheimer’s disease	Severe Alzheimer’s disease
<ul style="list-style-type: none"> – Approximately 4-7 years from onset. – Deficits in working memory, attention span and language comprehension. – Personality traits become flattened or exaggerated (eg lack of inhibition, impulsiveness, coarseness). – Problem behaviours emerge (eg wandering, shouting, clinging). – Psychiatric complications (eg hallucinations, delusions, paranoid ideation, suspiciousness). 	<ul style="list-style-type: none"> – Approximately 7-10 years from onset. – Loss of most memories and inability to use or comprehend language. – Motor symptoms become more pronounced: extrapyramidal signs and gait abnormalities. – Problem behaviours may abate; patient may become easier to care for. – Increasing dependence on others for basic needs; residential care and eventually death.

Dementia and disability

Drug treatments for dementia

This is a rapidly developing area of research, and changes are occurring quickly. Two recent reviews are recommended for more detailed information (*American Academy of Neurology 2001, 4; Brodaty H et al. 2001*).

Cholinesterase inhibitors

The evidence that cholinesterase inhibitor drugs benefit patients with Alzheimer's disease by delaying the onset and rate of functional decline and preserving the ability to perform certain activities of daily living has recently been reviewed (*American Academy of Neurology 2001, 4; Brodaty H et al. 2001*). Although an improvement in cognition has been correlated with plasma drug concentrations and the level of acetylcholinesterase inhibition in red blood cells, there has been no direct evidence to show that these drugs specifically alter the neuropathology of the disease process.

Cholinesterase inhibitor drugs including donepezil, rivastigmine and galantamine stop the breakdown of acetylcholine in the brain to reduce the apparent loss of cholinergic neurotransmitter activity in individuals with Alzheimer's disease. Most patients benefit to some extent, but only 50–60% show a measurable response to treatment, and it is not possible to predict which ones before treatment is started. Four to eight patients need to be treated for one to show measurable benefit (*Brodaty H et al.*).

Some patients, 15–50% in various studies, experience predictable cholinergic adverse effects, predominantly gastrointestinal – nausea, vomiting, diarrhoea – but also including many others such as bradycardia, muscle cramps, fatigue, dizziness, headaches, agitation and insomnia. These are dose-related and usually occur within the first few weeks of treatment. The side effect profile of the different drugs varies somewhat, but there is no direct evidence as to their relative merits.

The drugs' effects on cognition equate to about 6–9 months of preserved cognitive function. There are no known patient or disease characteristics that predict a positive response to treatment.

These treatments have an as yet undefined role in the overall management plan for individuals with Alzheimer's disease. Treatment should be initiated only for patients with 'probable' Alzheimer's disease of mild to moderate severity (ie MMSE scores of >10), and where there is a family member or other caregiver available to monitor compliance, effectiveness and adverse effects. There is now increasing evidence of benefit in Lewy-body dementia, but no evidence of benefit for patients with other types of dementia. Availability of the drugs under the Pharmaceutical Benefits Scheme is restricted.

Treatment should be initiated with clearly defined treatment goals and with an ability to assess effectiveness. The chosen measures and outcomes for monitoring should be meaningful to the patient and/or caregiver.

Treatment should be initiated at low dosages and titrated according to tolerability up to the maximum recommended by the manufacturer. Patients should be monitored for adverse effects in the first 6 weeks of commencing treatment or after dosage adjustment. Effectiveness should be assessed after 3 months of treatment at the highest tolerated dosage.

Treatment for longer than 6 months should be based on a clear response, which may include stabilisation of symptoms, preferably as assessed by objective measures. Treatment should be discontinued if there are significant adverse effects, poor compliance, failure to meet the chosen treatment outcomes, or a significant deterioration in the patient's condition. All patients on long-term treatment should be reassessed at least every 6 months and consideration should be given to the cessation of treatment in order to judge the adequacy of response.

Other drugs

- Anti-inflammatory drugs – epidemiological evidence suggests that these may prevent or delay the onset of Alzheimer's disease, but there is insufficient evidence that they are effective in its treatment, and their side effect profile means that their use is not recommended.
- Vitamin E – one randomised controlled trial supports epidemiological evidence that delays clinical decline, but more evidence is needed.
- Selegiline has beneficial effects, but the evidence is as yet insufficient to recommend routine clinical use.
- Many other drugs have been thought to be beneficial, including ginkgo biloba and oestrogen, but the evidence is as yet unconvincing.

(*American Academy of Neurology 2001, 1; Brodaty H et al. 2001; National Guidelines Committee for Anticholinesterase Inhibitors 2000*)

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. Haloperidol and thioridazine are the most commonly used. Other neuroleptics include pericyazine, loxapine, thiothixene and pimozide. However these drugs are not recommended for treatment of Lewy-body dementia. In addition, a prospective study 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 judgment in the use of these drugs.

The place of newer neuroleptics (olanzapine, risperidone) is being evaluated. They have a lower incidence of extrapyramidal side effects and may be more efficacious (*Canadian Consensus Conference 3:10*). These drugs are not currently PBS listed and so if used patients would be charged the full cost.

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 (*NZ Guideline 6:26*).

Managing behavioural concomitants of dementia

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 a 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.

Recent reports 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; eg aggression may be attributable to psychosis. 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 (see section on *Co-morbidity* below) (NZ Guidelines 6:25).

Non-drug management strategies

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.

Social work support and other counselling interventions such as those listed below, 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.

Specific activities or therapies which may be available from aged care services:

- reality orientation
- reminiscence
- validation therapy
- behaviour modification
- cued recall
- music therapy and dance
- motivational therapy
- doll therapy
- water therapy (NZ Guidelines 6:26).

Co-morbidity

Depression

Many clinicians feel that the newer antidepressants such as selective serotonin reuptake inhibitors (SSRI’s) 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 SSRI’s. Moclobemide also has proven efficacy and is generally well tolerated (NZ Guidelines 6:24).

Anxiety states

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 (NZ Guidelines 6:24).

Cerebrovascular disease

The medical management of vascular dementia is the same as for stroke disease. There should be careful treatment of hypertension (whilst avoiding hypotensive episodes), hyperlipidemia, carotid atherosclerosis and atrial fibrillation (NZ Guideline 6:19). Aspirin (75mg) may reduce the risk of further vascular events (Eccles 1998).

Other conditions

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 (NZ Guideline 6:19).

Health promotion

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 (NZ Guidelines 6:19).

Diet

Adequate diet is even more important in patients with dementia than in other older patients. Special attention needs to be paid to avoid or dealing with obesity or loss of weight, and ensuring an adequate dietary intake of vitamins and other essentials, since dementing patients may become difficult about taking their meals. Regular inquiry about what is being eaten should be made.

Prevention

Falls

Fracture of the hip is the commonest fracture in falls associated with dementia. Medication increases the risk of falling in people with dementia.

Falls are not associated with the severity of the dementia but are associated with wandering and reversible confusion. Those people who fall are more likely to fall again and falls are associated with their doing too much, eg wandering, restlessness. Falls are increased in the more capable groups of people with dementia (*Eccles 1998*).

Prevention of falls requires when possible recognition and alteration of environmental risks, modification of risk behaviours and appropriate physical assistance. This usually requires a multifactorial approach, but specific interventions may be needed in individual patients, such as recommending against the use of bifocals, awareness of appropriate footwear or use of hip protectors (*Monagle 2002*).

Patient / family / social support

Not all people with dementia will have a carer available, and some will have family members who do not wish to take on the care-giving 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 issues involved in ensuring that a person's wish to continue living alone is balanced with their safety and that of others (*NZ Guideline 6:32*).

Legal issues

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.

Advance care directives relate to advance decisions about the level of medical care to be adopted in specified circumstances when the patient is unable to make decisions. Enduring Guardianship provides for nomination of a person or persons who are to make decisions about personal care on behalf of the patient when the patient is unable to make decisions. Enduring Power of Attorney is similar, but relates only to financial and business matters.

Advance care directives, enduring guardianship, and enduring power of attorney are three aspects of legal decision-making which need to be considered in early dementia while the patient may still be able to make legal decisions. If not done, later there may arise a need for a medical decision about the patient's capacity to make decisions about medical and personal care, and financial and testamentary matters.

Decision making capacity

(see Appendix B3)

Determination of a patient's capacity to make decisions may be an important role of the doctor. This usually applies in one of three situations:

1. Consent for medical treatment.
2. Arranging enduring guardianship or giving an advance care directive.
3. Making a will or giving power of attorney.

It may also apply to other tasks such as managing financial affairs or arranging living circumstances.

Whatever the task, it is important that:

- capacity is task-specific, and must be assessed separately for each decision
- assessment is best made over time, rather than at only one interview, because determination of consistency of response is important
- information from others, with the patient's consent, is desirable.

Records should be kept as fully as possible, with emphasis on information that explains the basis for the decision.

The following factors need to be considered in determining capacity:

- Attention – can the patient maintain attention for long enough? Maintaining conversation for at least one minute is a minimum.

- Language – comprehension, by hearing or reading; this can be tested by conversation and/or with suitable simple multi-choice questions given orally and/or in writing.
- Language – reply, may be made by the patient in speech or writing, or by gesture, pointing or other understandable means. These forms of communication should not be overlooked when speech or writing is not possible.
- Memory – short and long-term memory need not be perfect, but should be relevant to the task.
- Awareness of the significance of the interview: does the patient understand who is doing it, what it is about and the likely consequences?
- Judgement – can the patient appreciate likely outcomes of decisions made?

Consent to medical treatment

In assessing capacity to consent to medical treatment the following factors must be clear:

- what are the options?
- the benefits and risks of each
- the values the patient wants to uphold or goals they wish to reach
- the stability of the decision over time; the consent must be given on at least two different occasions
- the patient must always be included in the decision process to the extent possible
- there must be no coercion or undue pressure from others.

If the patient does not have the capacity to consent, then the decision **MUST** be made by someone other than the treating team members.

Capacity to arrange Enduring Guardianship or advance care directives

In making such arrangements the patient must understand that:

- the choices being made are for the future
- it will be used only if the patient has become incapable
- some choices are about future treatment
- some choices are about who will then decide
- the choices made could threaten life

- coma or dementia means that no choice in the future will be possible
- choices may change over time
- directives should be updated and changed if necessary each year
- choices made in the directive override later choices if the patient has become incapable.

Capacity to make a will

In determining capacity to make a will, there are a number of specific requirements:

- the patient's lawyer should first be consulted
- assessment should occur on two different occasions, the second preferably on the day of executing the will
- the presence or absence of witnesses to the assessment, and if any, who they should be, should be considered
- the patient must be free of undue influence, such as from family member or carer
- the patient must not have delusions or hallucinations which could influence the decisions.

In the assessment, the patient must:

- understand the nature and purpose of the interview, and what he/she is doing
- understand what a will is and when it would come into effect
- be able to describe the extent and nature of his/her property
- be able to understand and state the claims of potential heirs
- state who is to benefit, in what way each will benefit, and give a sensible explanation of why that benefit to that person is desired.

Dementia and driving

The issue of fitness to drive is an easier issue for GPs to tackle than some others because there are specific guidelines to be followed that are widely recognised in the community (though not always by the patient with dementia).

Even mild dementia increases the risk of traffic accidents; the risk increases with concomitant morbidities and as the disease advances.

Mildly impaired patients should be asked to stop driving or confine themselves to familiar routes; those with moderate to severe disease should be instructed not to drive at all. In some states it is mandatory to report patients whom one considers unfit to drive; if there is a dispute, the patient should be referred to the local office of the Roads and Traffic Authority. Many of these strategies also apply to patients who could endanger others if they continue working (eg doctors, engineers) (*Grey Matters 7:12*).

The practitioner, in making the notification, must be satisfied not only about the person's medical unfitness to drive, but also be aware that the licence holder may 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 patients. 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
- suggestion of a formal driving assessment or a simulated test available in occupational therapy departments in some hospitals
- use of mobility vouchers to reduce taxi costs (*see Appendix F2*) (*NZ Guidelines 6:29*).

Leaving home

Factors in patients that lead to an increased risk of institutionalisation are physical dependence, irritability, nocturnal wandering and incontinence. Stress in carers can lead to an increased risk of institutionalisation. Institutionalisation offers the best duration of survival for people with dementia followed by a formal care package at home. Survival in this context means time until death rather than quality of life. Day care for people with dementia can delay institutionalisation.

A patient should not be assessed for optimal home care independently of the carer (*Eccles 1998*).

The carer: the 'second patient'

Many patients with a dementing illness have a primary carer. Carers may suffer physical, social and financial burdens associated with caring for the patient, as well as depressive disorders that can affect as many as 30% of them. Carers are often called the 'second patient' and GPs need to be vigilant about the health of the carer as well as the patient with Alzheimer's disease. Encourage carers to join Alzheimer's Australia for education and support. Suggest alternative or respite care arrangements rather than waiting for carers to mention them, and – when appropriate – remind carers that in the later stages of Alzheimer's disease, a patient's quality of life may actually improve in a nursing home. This will also allow the carer to spend more quality time with the patient as they will no longer be completely preoccupied with, or exhausted by, caring for the patient (*Grey Matters 7:12*).

Epidemiology

At least 80% of people with dementia are cared for at home, only 10–20% reside in facilities. 75% 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. A substantial minority suffers 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 in carers**Factors related to dementing illness**

Neither severity of cognitive impairment nor duration of dementia seems 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
- 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
- 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 of stress.

Caregiving factors

Dysfunctional caregiving is characterised by:

- inability to set limits when the cared-for person behaves unreasonably
- inability to leave the cared-for person, even when adequate arrangements are made

- difficulty engaging with outside agencies when help is offered
- 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. This appears to be mainly related to attitudinal factors and differences in coping style.

What can be done to relieve carer strain and distress?

Carer surveys have shown carers would like GPs to:

- include them in care planning and decision-making
- provide plain language information about the patient’s condition, prognosis and treatment
- refer to support groups such as carer associations, health care services and respite care providers
- discuss and assess the carer’s own physical and psychosocial health needs
- engage other family members in understanding and sharing care responsibilities
- recognise grief and loss on cessation of caring (Nankervis *et al.* 2002).

Training programs for carers have been shown both to relieve strain and to delay institutional placement, and are therefore cost-effective. Such programs can include the above and provide a group within which the carer can be encouraged to come to terms with losses involved through expression of feelings.

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) (*NZ Guidelines 6:27*).

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 person 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 inquiring about the stresses of caring.

The prospect of financial gain may sometimes be a source of abuse. As one GP said ‘One of the saddest things is watching the family come in like a pack of sharks for the will’ (*NZ Guidelines 6:31*).

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Appendix A.

Patient health assessments



A1. Royal Australian College of General Practitioners (RACGP) assessment form checklist

People with dementia and behaviours of concern – assessment form

Patient's name: _____ Date of birth: _____

Presenting behaviour and characteristics
 (include duration, frequency, antecedents, consequences) _____

Physical/psychological health status

Exclusion of delirium	Considered	Systems review	Reviewed	
Infections		Eyes (spectacles, reduced acuity)	<input type="checkbox"/>	_____
Respiratory	<input type="checkbox"/>	Ears (hearing aid, wax, audiology)	<input type="checkbox"/>	_____
Urinary	<input type="checkbox"/>	Nutrition (vitamin deficiency, dentition, oral hygiene, swallowing, appetite, hydration, diet, aspiration)	<input type="checkbox"/>	_____
Neurological	<input type="checkbox"/>	Continenence (bladder distension, faecal impaction)	<input type="checkbox"/>	_____
Metabolic disorders		Mobility	<input type="checkbox"/>	_____
Electrolyte disturbance	<input type="checkbox"/>	Level of functioning	<input type="checkbox"/>	_____
Renal failure	<input type="checkbox"/>	Pain	<input type="checkbox"/>	_____
Hepatic failure	<input type="checkbox"/>	Sleep patterns	<input type="checkbox"/>	_____
Vascular disease				
Hypertensive encephalopathy	<input type="checkbox"/>			
Shock	<input type="checkbox"/>			

Medication review
 (drug interactions, compliance, usage or non prescription medication medicines)

Hypoxia	
Hypotension	<input type="checkbox"/>
Cardiac failure	<input type="checkbox"/>
Carbon monoxide poisoning	<input type="checkbox"/>
Endocrine disorders	
Hypo- or hyper- thyroidism	<input type="checkbox"/>
Hypo- or hyper- adrenocorticism	<input type="checkbox"/>
Diabetes	<input type="checkbox"/>
Drugs	
Alcohol	<input type="checkbox"/>
Withdrawal	<input type="checkbox"/>
Cholinergic drugs	<input type="checkbox"/>
Psychotropics	<input type="checkbox"/>
Cardiac drugs (beta blockers)	<input type="checkbox"/>
Toxins	
Heavy metals	<input type="checkbox"/>
Pesticides	<input type="checkbox"/>
Trauma	
Head trauma	<input type="checkbox"/>
Subdual haematoma	<input type="checkbox"/>
Heat stroke	<input type="checkbox"/>
Postoperative	<input type="checkbox"/>

Mental state

Appearance (stance, facial expression, dishevelled) _____

Behaviour (general behaviour apart from focal problem eg early morning awakening) _____

Form of speech (thoughts slowed) _____

Content of speech (hallucinations sad and hopeless thoughts) _____

Mood (anxious, agitated, depressed, unresponsive) _____

Diurnal variation in mood _____

Awareness _____

Pre dementia personality, hobbies, occupation, education

Social assessment
 (support network, physical supports, financial support, lifestyle/cultural issues, social activities)

Carer assessment
 (dementia knowledge, coping skills, stress levels, physical, social supports; including Alzheimer's Association)

Physical environment	Reviewed	Comment
Safety considerations (restraints, wandering, smoking, night, time lighting)	<input type="checkbox"/>	_____
Environmental stimulation (level of interest orienting, cues mouse level individual alternation)	<input type="checkbox"/>	_____



COMMONWEALTH DEPARTMENT OF
VETERANS' AFFAIRS

A2. Health Assessment Checklist

A Guide for General Practitioners

Health Assessments - Medicare items 700 to 706

This assessment checklist utilises a series of key questions identified as being useful from the DVA Preventive Care Trial for older persons. However, the information from these questions are to be used in conjunction with clinical assessment. Support for this assessment process is available in a DVA internal publication "*Clinical Supplement - Screening Tools to Support Health Care Planning and Assessment*". The information provided may also be used for the progressive validation of the checklist.

A health assessment means the assessment of a patient's health and physical, psychological and social function and whether preventative health care and education should be offered to the patient, to improve that patient's health and physical, psychological and social function.

Who qualifies for an assessment?

All Australians aged 75 and over and Aboriginal and Torres Strait Islanders aged 55 and over.

Assessment Guidelines

The assessment must include keeping a record of the health assessment, signed by the patient and giving the patient a written report about the health assessment, with recommendations about the matters covered by the health assessment.

These items do not apply to in-patients of a hospital or day hospital facility or residents of a nursing home.

For items 704 and 706, a person is of Aboriginal or Torres Strait Islander descent if the person identifies himself or herself as being of that descent.

The annual health assessment should not take the form of a health screening service, in particular the assessment should not include category 5 (diagnostic imaging) services or category 6 (pathology) services. See General Notes 13.3.

The information collection component of the assessment may be rendered 'on behalf of' a medical practitioner in accordance with accepted medical practice, acting under the supervision of the medical practitioner. The other components of the health assessment must include a personal attendance by the medical practitioner.

Practitioners should establish a register of their patients seeking annual health assessments and remind registered patients when their next health assessment is due.

DVA health assessment enquiries may be directed to **1300 301 610**.

What do I do with the completed form?

- You should provide a copy of the health assessment to the patient/veteran/carer.
- Retain the health assessment in your patient's record for your future reference and referral resource.
- Consider attaching a copy of the health assessment to referrals to other health care providers.
- Do **NOT** send this completed Health Assessment Checklist to DVA. Send your claim for payment to the HIC in the usual manner.

Name

Date

Date of birth

Medicare/DVA No.

D677 - 5/00 - P1

1 Are you living:

Alone As a couple With others

Self Rated Health

2 In general, would you say your health is:

Excellent Very Good Good
Fair Poor

3 Current health problems

4 Community services currently provided:

Daycare Respite care
HACC - Home Help Community nursing
Meals on Wheels Podiatry
Physiotherapy Other (please specify)

5 Vaccinations

Influenza Date / /
Pneumococcus Date / /
Tetanus Date / /

Comments

6 Medications including OTC items (including OTC & complementary items)

Preparation	Strength	Dose	Expiry date
			/ /
			/ /
			/ /
			/ /
			/ /
			/ /

Manages own medicine
No Yes

Compliance difficult
No Yes

Comments

7 Smoking

Currently smokes
No Yes

Wishes to quit
No Yes

Comments

8 Alcohol Consumption

How often do you have a drink containing alcohol?
Never 2 - 4 times a week

Monthly 5+ times a week
Once a week

How many standard drinks do you have on a typical day when you are drinking?

How often do you have 6 or more standard drinks on one occasion?

Never 2 - 4 times a week
Monthly or less 5+ times a week

Once a week

9 Mental Status

a. What is the -
year, season, date, day, month?
Score 1 point for each correct answer

b. Where do you live?
State, country, town, street number, street name
Score 1 point for each correct answer

c. Repeat 3 objects - house, bus, dog
Score 1 point per word on first trial only

d. Spell 'world' backwards
Score 1 point for each correct letter

TOTAL score

Scale: 14 - 18 indicates no cognitive difficulty

Comments

10 Social Support

During the last 4 weeks.... Was someone available to help you if you needed and wanted help? For example if you:

- felt very nervous, lonely or blue
- got sick and had to stay in bed
- needed someone to talk to
- needed help with daily chores
- needed help just taking care of yourself

Yes, as much as I wanted

Yes, quite a bit

Yes, some

Yes, a little

No, not at all

11 Feelings

During the last 4 weeks.... How much have you been bothered by emotional problems such as feeling anxious, depressed, irritable or downhearted or blue?

- Not at all 1
- Slightly 2
- Moderately 3
- Quite a bit 4
- Extremely 5

12 Nutrition

- a. Do you have an illness or condition that made you change the kind and/or amount of food you eat?
Yes 2 No 1
- b. Do you eat at least 3 meals per day?
Yes 0 No 3
- c. Do you eat fruit or vegetables most days?
Yes 0 No 2
- d. Do you eat dairy products most days?
Yes 0 No 2
- e. Do you have 3 or more glasses of beer, wine or spirits almost every day?
Yes 3 No 0
- f. Do you have 6 - 8 cups of fluids most days?
Yes 0 No 1
- g. Do you have teeth, mouth or swallowing problems that make it hard to eat?
Yes 4 No 0
- h. Do you always have enough money to buy food?
Yes 0 No 3
- i. Do you eat alone most of the time?
Yes 2 No 0
- j. Do you take 3 or more prescribed or over the counter medicines every day?
Yes 3 No 0
- k. Without wanting to, have you lost or gained 5kg in the last 6 months?
Yes 2 No 0
- l. Are you always able to shop, cook and/or feed yourself?
Yes 0 No 2

TOTAL score

0 - 3 'good', 4 - 5 'moderate risk', 6 - 29 'high risk'

Comments

13 Home Safety

- a. Can you get up from your lounge chair easily?
Yes No
- b. Can you get in and out of bed easily and safely?
Yes No
- c. Can you switch a light on easily from your bed?
Yes No
- d. Are your loose mats securely fixed to the floor?
Yes No
- e. Do you use slip resistant mats in the bath/bathroom/shower recess?
Yes No
- f. Can you carry meals easily and safely from the kitchen to your dining area?
Yes No
- g. Difficulty gripping utensils/handrails?
None
A little
A lot
- h. Are the edges of the steps/stairs easily identifiable?
Yes No

Comments

14 Mobility

- a. Difficulty climbing one flight of stairs?
None
A little
A lot
- b. Difficulty bending, kneeling or stooping?
None
A little
A lot
- c. Difficulty walking 100 metres?
None
A little
A lot
- d. Difficulty bathing or dressing self?
None
A little
A lot

e. Have you had a fall inside/outside the home in the past 6 months?

Yes No

Comments

15 Feet

a. Problems with one or both feet?

Yes No

Comments

16 Vision

Acuity (*with glasses*)

Comments

17 Hearing

a. Whisper test

Heard Not heard

b. Hearing aid

N/A
 Adequate
 Poor

Comments

18 Continence

a. Leaking urine?

Never
 Sometimes
 Often

b. Is this related to coughing or sneezing?

Yes No

c. Faecal incontinence/change of bowel habit?

Yes No

d. Family history of bowel cancer?

Yes No

Comments

19 BP/Pulses

a. Blood Pressure

b. Pulse

Regular Irregular

Comments

20 Urine analysis

Clear

Glucose

Blood/protein

21 Other areas for examination and/or follow up (*eg skin, breast, prostate*)

22 Future plan of action (*include agreed action/goals of patient and/or carer*)

23 Patient and Doctor declaration

I agree with this plan

Patient's signature

Doctor's signature

24 General Practitioner/Local Medical Officer details

Provider No.

Name

Address

Postcode

Phone No.

Appendix B.

Cognitive functioning

B

B1. Mini-mental state examination

(Folstein et al. 1975)

This test could not be included for copyright reasons. It is available from:

Psychological Assessment Resources Inc (PAR) 16204 North Florida Avenue, Lutz, Florida 33549

Website: www.parinc.com

Email: custserv@parinc.com

B2. GPCOG patient examination

This is a new screening test developed in Australia for use in general practice. It is shorter than the MMSE and incorporates the clock drawing test (*Appendix 2.2*). Only if the test result is in the doubtful area does it need to include some additional information to be obtained from a suitable informant.

The test is set out on next page.

Scoring

Add correct scores from items 2-6:

9 = cognitively intact – no need for informant interview

4 or less = cognitively impaired – no need for informant interview

5-8 = uncertain – needs informant interview

Informant interview score:

No, 3 or less = cognitively impaired

Reference: Brodaty H, Pond D et al. The GPCOG: a new screening test for dementia designed for general practice. J Am Geriatric Soc 2002; 50: 530-34

Appendix

GPCOG Patient Examination

Unless specified, each question should only be asked once.

Name and address for subsequent recall test

1. "I am going to give you a name and address. After I have said it, I want you to repeat it. Remember this name and address because I am going to ask you to tell it to me again in a few minutes: John Brown, 42 West Street, Kensington." (Allow a maximum of 4 attempts but do not score yet)

Time Orientation

2. What is the date? (exact only)

Correct

Incorrect

Clock Drawing (visuospatial functioning) - use page with printed circle

3. Please mark in all the numbers to indicate the hours of a clock (correct spacing required)
4. Please mark in hands to show 10 minutes past eleven o'clock (11:10)

Information

5. Can you tell me something that happened in the news recently? (recently = in the last week)

Recall

6. What was the name and address I asked you to remember?

John

Brown

42

West (St)

Kensington

Scoring guidelines

Clock drawing: For a correct response to question 3, the numbers 12, 3, 6, and 9 should be in the correct quadrants of the circle and the other numbers should be approximately correctly placed. For a correct response to question 4, the hands should be pointing to the 11 and the 2, but do not penalize if the respondent fails to distinguish the long and short hands.

Information: Respondents are not required to provide extensive details, as long as they demonstrate awareness of a recent news story. If a general answer is given, such as "war," "a lot of rain," ask for details—if unable to give details, the answer should be scored as incorrect.

GPCOG Informant Interview

Ask the informant: "Compared to a few years ago,

	Yes	No	Don't Know	N/A
I. Does the patient have more trouble remembering things that have happened recently?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
II. Does he or she have more trouble recalling conversations a few days later?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
III. When speaking, does the patient have more difficulty in finding the right word or tend to use the wrong words more often?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
IV. Is the patient less able to manage money and financial affairs (eg paying bills, budgeting)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
V. Is the patient less able to manage his or her medication independently?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
VI. Does the patient need more assistance with transport (either private or public)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

B3. Decision making capacity

C Bridges-Webb, RACGP NSW Projects, Research and Development Unit.

Determination of a patient's capacity (a word preferred to the more strictly legal one of competency [1]) to make decisions may be an important role of the doctor. This usually applies in one of three situations:

- consent for medical treatment
- giving an advance care directive
- making a will.

It may also apply to other tasks such as managing financial affairs or arranging living circumstances.

Whatever the task, there are a number of important principles to be observed:

- Capacity is task specific, and must be assessed separately for each decision.
- Assessment is best made over time, rather than at only one interview, because determination of consistency of response is important.
- Information from others, with the patient's consent, is desirable.
- There are no studies which define threshold, and only modest correlation between scores on scales such as MMSE or IADL and capacity to make decisions (2).

Records should be kept as fully as possible, with emphasis on information that explains the basis for the decision.

Factors to be considered

The following factors need to be considered in determining capacity (3):

- **Attention** – can the patient maintain attention for long enough? Maintaining conversation for at least 1 minute is a minimum. Assess using subtraction of serial 7's from 100 (need 7 correct responses), or ability to count forward by 3's from 1 (no more than one error in 30 seconds), or counting backwards from 20 (finishing within 20 seconds) (3).

- **Language – comprehension**, by hearing or reading. This can be tested by conversation and/or with suitable simple multi-choice questions given orally and/or in writing.
- **Language – reply**, may be made by the patient in speech or writing, or by gesture, pointing or other understandable means. These forms of communication should not be overlooked when speech or writing is not possible.
- **Memory** – short and long term memory need not be perfect, but should be relevant to the task.
- **Awareness** of the significance of the interview: Does the patient understand who is doing it and why? How does it relate to the patient's social situation, family, interests, activity? What are the likely consequences?
- **Judgement** – can the patient appreciate outcomes, control impulses? How does what they say compare with what they do? How consistent are their responses? History from others is important for this.

Consent to medical treatment

In assessing capacity to consent to medical treatment the following factors must be clear (1):

- what are the options?
- the benefits and risks of each
- the values the patient wants to uphold or goals they wish to reach
- the stability of the decision over time; the consent must be given on at least two different occasions
- the patient must always be included in the decision process to the extent possible
- there must be no coercion or undue pressure from others.

If the patient has not the capacity to consent, then someone other than the treating team members **MUST** make the decision.

Even in the presence of an advance care directive it is important to 'try to understand also the present subjective experiences' of the patient (1).

Advanced care directives

In making an advanced care directive the patient must understand that (4):

- the choices being made are for the future
- it will be used only if the patient has become incapable
- some choices are about future treatment
- some choices are about who will then decide
- the choices made could threaten life
- coma or dementia means that no choice in the future will be possible
- choices may change over time
- directives should be updated and changed if necessary each year
- choices made in the directive override later choices if the patient has become incapable.

A protocol to ensure a patient centred approach for the assessment of competence to complete advance care directives, using two vignettes of hypothetical medical problems and ten questions in a semi-structured interview, has been found to be valid and reliable in one British trial (5).

Making a will

In determining capacity to make a will there are a number of specific requirements (2):

- The patient's lawyer should first be consulted.
- Assessment should occur on two different occasions, the second preferably on the day of executing the will.
- The presence or absence of witnesses to the assessment, and if any, who they should be, should be considered.
- The patient must be free of undue influence, such as from family member or carer.
- The patient must not have delusions or hallucinations that could influence the decisions.

In the assessment the patient must:

- understand the nature and purpose of the interview, and what he/she is doing. Ask them to explain what a will is
- be able to describe the extent and nature of his/her property
- be able to understand and state the claims of potential heirs
- state who is to benefit, in what way each will benefit, and give a sensible explanation of why that benefit to that person is desired.

Corroborative information should be sought, with permission of the patient and his/her lawyer, from medical records, other clinicians, family or others involved with the patient.

References

1. Fellows LK. *Competency and consent in dementia*. Journal of the American Geriatrics Society 1998; 46:922-26.
2. Peisah C, Brodaty H. *Dementia and the will making process: the role of the medical practitioner*, Med J Aust. 1994; 161:381-4.
3. Freeman M, Stuss T, Gordon M. *Assessment of competency: the role of neurobehavioural deficits*. Annals of Internal Medicine 1991; 115:203-8.
4. Silberfeld M, Nash C, Singer PA. *Capacity to complete an advance care directive*. Journal of the American Geriatrics Society 1993; 41:1141-3.
5. Fazel S, Hope T, Jacoby R. *Assessment of competence to complete advance care directives: validation of a patient centred approach*. British Medical Journal 1999; 318:493-7.

Appendix C.

Emotional state and behaviour



C1. The geriatric depression scale

Choose the best answer for how you felt over the past week

1. Are you basically satisfied with your life?	yes/no	N*
2. Have you dropped many of your activities and interests?	yes/no	Y*
3. Do you feel that your life is empty?	yes/no	Y*
4. Do you often get bored?	yes/no	Y*
5. Are you hopeful about the future?	yes/no	N
6. Are you bothered by thoughts that you just cannot get out of your head?	yes/no	Y
7. Are you in good spirits most of the time?	yes/no	N*
8. Are you afraid that something bad is going to happen to you?	yes/no	Y*
9. Do you feel happy most of the time?	yes/no	N*
10. Do you often feel helpless?	yes/no	Y*
11. Do you often get restless and fidgety?	yes/no	Y
12. Do you prefer to stay at home, rather than go out and do new things?	yes/no	Y*
13. Do you frequently worry about the future?	yes/no	Y
14. Do you feel that you have more problems with memory than most?	yes/no	Y*
15. Do you think it is wonderful to be alive now?	yes/no	N*
16. Do you often feel downhearted and blue?	yes/no	Y
17. Do you feel pretty worthless the way you are now?	yes/no	Y*
18. Do you worry a lot about the past?	yes/no	Y
19. Do you find life very exciting?	yes/no	N
20. Is it hard for you to get started on new projects?	yes/no	Y
21. Do you feel full of energy?	yes/no	N*
22. Do you feel that your situation is hopeless?	yes/no	Y*
23. Do you think that most people are better off than you are?	yes/no	Y*
24. Do you frequently get upset over little things?	yes/no	Y
25. Do you frequently feel like crying?	yes/no	Y
26. Do you have trouble concentrating?	yes/no	Y
27. Do you enjoy getting up in the morning?	yes/no	N
28. Do you prefer to avoid social gatherings?	yes/no	Y
29. Is it easy for you to make decisions?	yes/no	N
30. Is your mind as clear as it used to be?	yes/no	N

This scale can be self-administered or read in an interview

Count 1 point for each depressive answer (as indicated by N or Y)

Scores 0-10: normal range 11-20: mild depression 21-30: moderate to severe depression

Cut of points: usually 10/11 but 13/14 and 14/15 have also been used

* = items to include in an abbreviated version to reduce problems of fatigue and lack of focus

Scores 0-4: normal range 5-9: mild depression 10-15: moderate to severe depression

[Measuring Health: A guide to rating scales and questionnaires. Ian McDowell and Clare Newell. 2nd Ed. New York: OUP. 1996]

C2. A screening instrument for depression in later life

EBAS DEP (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.

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, 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 which may need treatment and the patient should be assessed in more detail or referred for psychiatric evaluation.

(Source: Allen N, Ames D, Ashby D, Bennetts K, Tuckwell V, West C. (1994) A brief sensitive screening instrument for depression in late life. *Age and Ageing*. 23:213-218.)

C3. Neuropsychiatric inventory questionnaire (NPI-Q)

Name of patient: _____ Date: _____

Informant: Spouse: _____ Child: _____ Other: _____

Please answer the following questions based on changes that have occurred since the patient first began to experience memory problems. Circle "yes" only if the symptom has been present in the past month. Otherwise, circle "no".

For each item marked "yes":

Rate the severity of the symptom (how it affects the patient):

1 = Mild (noticeable, but not a significant change)

2 = Moderate (significant, but not a dramatic change)

3 = Severe (very marked or prominent; a dramatic change)

Rate the distress you experience because of that symptom (how it affects you):

0 = Not distressing at all

1 = Minimal (slightly distressing, not a problem to cope with)

2 = Mild (not very distressing, generally easy to cope with)

3 = Moderate (fairly distressing, not always easy to cope with)

4 = Severe (very distressing, difficult to cope with)

5 = Extreme or very severe (extremely distressing, unable to cope with)

Please answer each question honestly and carefully. Ask for assistance if you are not sure how to answer any question.

Delusions	Does the patient believe that others are stealing from him or her, or planning to harm him or her in some way?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Hallucinations	Does the patient act as if he or she hears voices? Does he or she talk to people who are not there?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Agitation or aggression	Is the patient stubborn and resistive to help from others?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Depression or dysphoria	Does the patient act as if he or she is sad or in low spirits? Does he or she cry?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Anxiety	Does the patient become upset when separated from you? Does he or she have any other signs of nervousness, such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Elation or euphoria	Does the patient appear to feel too good or act excessively happy?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Apathy or indifference	Does the patient seem less interested in his or her usual activities and in the activities and plans of others?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Disinhibition	Does the patient seem to act impulsively? For example, does the patient talk to strangers as if he or she knows them, or does the patient say things that may hurt people's feelings?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Irritability or lability	Is the patient impatient and cranky? Does he or she have difficulty coping with delays or waiting for planned activities?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Motor disturbance	Does the patient engage in repetitive activities, such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Nighttime behaviors	Does the patient awaken you during the night, rise too early in the morning, or take excessive naps during the day?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			
Appetite and eating	Has the patient lost or gained weight, or had a change in the food he or she likes?	Severity: 1 2 3	Distress: 0 1 2 3 4 5
Yes No			

FIGURE 3. Neuropsychiatric Inventory Questionnaire. This tool provides a reliable assessment of behaviors commonly observed in patients with dementia.

Adapted with permission from Kaufer DI, Cummings JL, Ketchel P, Smith V, MacMillan A, Shelley T, et al. Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. *J Neuropsychiatry Clin Neurosci* 2000;12:233-9. Copyright© J.L. Cummings, 1994.

C4. Activities of daily living (ADL)

Name of patient: _____ Date: _____

For each area of function listed below, check the description that applies. (The word 'assistance' means supervision, direction or personal assistance.)

Bathing – sponge bath, tub bath, or shower

- | | | |
|---|---|---|
| <input type="checkbox"/> Receives no assistance (get in and out of tub by self, if tub is usual means of bathing) | <input type="checkbox"/> Receives assistance in bathing only one part of the body (such as back or a leg) | <input type="checkbox"/> Receives assistance in bathing than one part of the body (or not bathed) |
|---|---|---|

Dressing – gets clothes from closets and drawers, including underclothes and outer garments, and uses fasteners (including braces, if worn)

- | | | |
|--|--|---|
| <input type="checkbox"/> Gets clothes and gets completely dressed without assistance | <input type="checkbox"/> Gets clothes and gets dressed without assistance, except for help in trying shoes | <input type="checkbox"/> Receives assistance in getting cloths or in getting dressed, or stays partly or completely undressed |
|--|--|---|

Toileting – going to the 'toilet room' for bowel and urine elimination, cleaning self after elimination and arranging clothes

- | | | |
|--|--|--|
| <input type="checkbox"/> Goes to 'toilet room', cleans self, and arranges clothes without assistance (may use object for support, such as cane, walker, or wheelchair, and may manage night bedpan or commode, emptying same in morning) | <input type="checkbox"/> Receives assistance in going to 'toilet room'. Or in cleaning self or arranging clothes after elimination, or in use of night bedpan or commode | <input type="checkbox"/> Does not go to room termed 'toilet' for the elimination process |
|--|--|--|

Transfer

- | | | |
|---|---|--|
| <input type="checkbox"/> Moves in and out of bed, as well as in and out of chair, without assistance (may use object for support, such as cane or walker) | <input type="checkbox"/> Moves in and out of bed or chair with assistance | <input type="checkbox"/> Does not get out of bed |
|---|---|--|

Continence

- | | | |
|--|---|---|
| <input type="checkbox"/> Controls urination and bowel movements completely by self | <input type="checkbox"/> Has occasional 'accidents' | <input type="checkbox"/> Supervision helps keep urine or bowel control; catheter is used, or person is incontinent. |
|--|---|---|

Feeding

- | | | |
|--|--|---|
| <input type="checkbox"/> Feeds self without assistance | <input type="checkbox"/> Feeds self except for cutting meat or buttering bread | <input type="checkbox"/> Receives assistance in feeding or is fed partly or completely by using tubes or intravenous fluids |
|--|--|---|

Scoring

Score '0' for each box checked in column 1 or 2, and score '1' for each box checked in column 3. Total score: _____

SCORING Key: 0 = independent in all 6 functions; 1 to 5 = independent in 1 to 5 function; 6 = dependent in all 6 functions.

FIGURE 1. Activities of Daily Living scale. This Instrument evaluates the degree of assistance the patient received during set period (eg the previous week) for each of six basic activities.

Adapted with permission from Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. Studies of illness in the aged. The index of ADL. a standardized measure of biological and psychosocial function. JAMA 1963; 185:914-9.

C5. Instrumental activities of daily living (IADL)

Name of patient: _____ Date: _____

This form may help you assess the functional capabilities of your older patients. The data can be collected by a nurse from the patient or from an informant such as a family member or other caregiver. (I = independent; A = assistance required; D = dependent)

Obtained from:		Activity	Guidelines for assessment
Patient	Informant		
I A D	I A D	Using telephone	I = Able to look up numbers, dial telephone, and receive and make calls without help A = Able to answer telephone or dial operator in an emergency, but needs special telephone or help in getting numbers and/or dialing D = Unable to use telephone
I A D	I A D	Traveling	I = Able to drive own car or to travel alone on buses or in taxis A = Able to travel, but needs someone to travel with D = Unable to travel
I A D	I A D	Shopping	I = Able to take care of all food and clothes shopping with transportation provided A = Able to shop, but needs someone to shop with D = Unable to shop
I A D	I A D	Preparing meals	I = Able to plan and cook full meals A = Able to prepare light foods, but unable to cook full meals alone D = Unable to prepare any meals
I A D	I A D	Housework	I = Able to do heavy housework (ie scrub floors) A = Able to do light housework, but needs help with heavy tasks D = Unable to do any housework
I A D	I A D	Taking medicine	I = Able to prepare and take medications in the right dose at the right time A = Able to take medications, but needs reminding or someone to prepare them D = Unable to take medications
I A D	I A D	Managing money	I = Able to manage buying needs (ie write checks, pay bills) A = Able to manage daily buying needs, but needs help managing checkbook and/or paying bills D = Unable to handle money

FIGURE 2. Instrumental Activities of Daily Living scale. This instrument evaluates the patient's ability to perform the more complex activities that are necessary for optimal independent functioning.

Adapted with permission from Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist 1969;9:179-86.

Appendix D.

Caregiver coping



D1. Caregiver burden scale

Caregiver's name: _____ Date: _____

The following questions reflect how people sometimes feel when they are taking care of another person. After each question, circle how often you feel that way: never, rarely, sometimes, frequently, or nearly always. There are no right or wrong answers.

	Never	Rarely	Sometimes	Frequently	Nearly always
1. Do you feel that your relative asks for more help than he or she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative, you do not have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid about what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you do not have as much privacy as you would like, because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over, because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one he or she could depend on?	0 0	1 1	2 2	3 3	4 4
15. Do you feel that you do not have enough money to care for your relative, in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Total score: _____

SCORING KEY:

0 to 20 = little or no burden; 21 to 40 = mild to moderate burden; 41 to 60 = moderate to severe burden; 61 to 88 = severe burden.

FIGURE 4. Caregiver Burden Scale. This self-administered 22-item questionnaire assesses the "experience of burden."

Adapted with permission from Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist 1980;20:649-55.

Appendix E.

Diagnostic criteria

E

E1. Diagnostic criteria for dementia of the Alzheimer's type (DSM-IV)

A. The development of multiple cognitive deficits manifested by both

1. Memory impairment (impaired ability to learn new information or to recall previously learned information).
2. One (or more) of the following cognitive disturbances:
 - a. aphasia (language disturbance)
 - b. apraxia (impaired ability to carry out motor activities despite intact motor function)
 - c. agnosia (failure to recognise or identify objects despite intact sensory function)
 - d. disturbance in executive functioning (planning, organising, sequencing, abstracting).

B. The cognitive deficits in criteria A1 and A2 each cause significant impairment in occupational and social functioning, and represent a decline from previous higher levels of functioning.

C. The course is characterised by gradual onset and continuing cognitive decline.

D. The cognitive deficits in criteria A1 and A2 are not due to any of the following:

1. Other CNS conditions that cause progressive deficits in memory.
2. Systematic conditions known to cause dementia (e. hypothyroidism).
3. Substance-induced conditions.

E. The deficits do not occur exclusively during the course of a delirium.

F. The disturbance is not better accounted for by another disorder (eg major depression).

(DSM1V, American Psychiatric Association, 1994)

E2. Criteria for the clinical diagnosis of Alzheimer's disease (NINCDS-ADRDA)*

1. The criteria for the clinical diagnosis of PROBABLE Alzheimer's disease include:
 - dementia established by clinical examination and documented by the Mini-Mental Test, Blessed Dementia Scale or some similar examination and confirmed by neuropsychological tests
 - deficits in two or more areas of cognitive functions
 - no disturbance of consciousness
 - onset between ages 40 and 90, most often after age 65: and absence of systemic disorders or other brain diseases that in and of themselves could account for the progressive deficits in memory and cognition.
2. The diagnosis of PROBABLE Alzheimer's disease is supported by:
 - progressive deterioration of specific cognitive functions such as language (aphasia), motor skills (apraxia) and perception (agnosia)
 - Impaired activities of daily living and altered patterns of behavior
 - Family history of similar disorders. Particularly if confirmed neuropathologically; and

Laboratory results of:

 - Normal lumbar puncture as evaluated by standard techniques.
 - Normal pattern or non-specific changes in EEG, such as increased slow-wave activity.
 - Evidence of cerebral atrophy on CT with progression documented by serial observation.
3. Other clinical features consistent with the diagnosis of PROBABLE Alzheimer's disease after exclusion of causes of dementia other than Alzheimer's disease include:
 - plateaus in the course of progression of the illness
 - associated symptoms of depression, insomnia, incontinence, delusions, illusions, hallucinations, catastrophic verbal emotional or physical outbursts, sexual disorders and weight loss
 - other neurologic abnormalities in some patients especially with more advanced disease and including motor signs such as increased muscle lone myoclonus or gait disorder
 - seizures in advanced disease; and
 - CT normal for age.
4. Features that make the diagnosis of PROBABLE Alzheimer's disease uncertain or unlikely include:
 - sudden apoplectic onset
 - focal neurologic findings such as hemiparesis sensory loss, visual field deficits, and incoordination early in the course of the illness; and
 - seizures or gait disturbances at the onset or very early in the course of the illness.
5. Clinical diagnosis of POSSIBLE Alzheimer's disease:
 - may be made on the basis of the dementia syndrome, in the absence of other neurologic psychiatric or systemic disorders sufficient to cause dementia and in the presence of variations in the onset, in the presentation or in the clinical course
 - may be made in the presence of a second systemic or brain disorder sufficient to produce dementia, which is not considered to be the cause of the dementia
 - should be used in research studies when a single, gradually progressive severe cognitive deficit is identified in the absence of other identifiable cause.
6. Criteria for diagnosis of DEFINITE Alzheimer's disease are:
 - the clinical criteria for probable Alzheimer's disease and histopathologic evidence obtained from a biopsy or autopsy.
7. Classification of Alzheimer's disease for research purposes should specify features that may differentiate subtypes of the disorder such as:
 - familial occurrence
 - onset before age of 65
 - presence of trisomy 21
 - coexistence of other relevant condition such as Parkinson's disease.

*NINCDS – ADRDA: National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association

Source: McKhann G, Drachman D, Folstein M, Katzman R, Price D, Stadlan EM (1984) Clinical diagnosis of Alzheimer's disease: Report of the NINCDS-ADRDA Work Group under the Department of Health and Human Services Task Force on Alzheimer's disease. *Neurolog*: 939-944.

Appendix F. Alzheimer's Australia and other services and resources



F1. Alzheimer's Australia list of contacts and help sheets

National

National Secretariat Tel. (02) 6254 4233
Alzheimer's Australia Fax. (02) 6278 7225
PO Box 108 Email. secretariat@alzheimers.org.au
HIGGINS ACT 2615
Frewin Centre
Frewin Place
Scullin ACT 2615

Australian Capital Territory (ACT)

Alzheimer's Australia Tel. (02) 6254 5544
PO Box 108 Fax. (02) 6254 2522
Higgins ACT 2600 Email. alzact@netspeed.com.au

New South Wales (NSW)

Alzheimer's Australia Tel. (02) 9805 0100
PO Box 6042 Fax. (02) 9805 1665
North Ryde NSW 1670 Website. www.alznsw.asn.au
Email. admin@alznsw.asn.au

Macquarie Hospital Campus
Cox's Road Entrance
(1st building on right)
North Ryde NSW 2113

Northern Territory (NT)

Alzheimer's Australia Tel. (08) 8948 5228
PO Box 515 Fax. (08) 8948 5229
Nightcliffe NT 0814 Email. ang.alz@octa4.net.au
1/18 Bauhinia Street
Nightcliffe NT 0814

South Australia (SA)

Alzheimer's Australia Tel. (08) 8372 2100
27 Conyngham Street Fax. (08) 8338 3390
Glenside SA 5065 Website. www.ozemail.com.au/~alzsa
Email. alzsa@alzheimerssa.asn.au

Tasmania (TAS)

Alzheimer's Australia Tel. (03) 6278 9897
PO Box 1606 Fax. (03) 6278 9878
Hobart TAS 7001 Website. www.tased.edu.au/tasonline/tasalz
Email. Debbie.slater@alztas.asn.au

The Old Vickerage
St John's Avenue
New Town TAS 7008

Victoria (VIC)

Alzheimer's Australia Tel. (03) 9815 7800
Locked Bag 3002 Fax. (03) 9815 7801
Hawthorn VIC 3122 Website. www.alzvic.asn.au
Email. alz@alzvic.asn.au

98-104 Riversdale Road
Hawthorn VIC 3122

Western Australia (WA)

Alzheimer's Australia Tel. (08) 9388 2800
PO Box 1509 Fax. (08) 9388 2739
Subiaco WA 6904 Website. www.alzheimers.asn.au/wa
Email. alzwa@alzheimers.asn.au

9 Bedbrook Place
Shenton Park WA 6008

Queensland (Qld)

Alzheimer's Australia Tel. (07) 4434 4501
PO Box 6842 Fax. (07) 5535 4186
Gold Coast Mail Center Email. info@alzgc.asn.au
Qld 9726
40 Lemana Lane
Miami QLD 4220

HELPLINE: 1800 639 331

NATIONAL Website. www.alzheimers.org.au

Help sheets

About Dementia

- What is dementia?
- Diagnosing dementia
- Early planning
- Next steps
- Memory loss
- Progression of dementia
- Research
- Useful resources
- Alzheimer's disease
- Vascular dementia
- Frontal lobe dementia, including Pick's disease
- Dementia with Lewy bodies
- Alcohol related dementia
- AIDS related dementia
- Drug treatments and dementia
- Dementia and heredity
- Diagnosis: Informing the person with dementia
- Information for family and friends
- Down syndrome and Alzheimer's disease

Caring for someone with dementia

- Intimacy and sexual issues
- Continence
- Wandering
- Driving
- Communication
- Eating
- Dressing
- Activities
- Sleeping
- Travelling
- Safety issues
- Hygiene
- Caring for someone who lives alone
- Sundowning
- Nutrition
- Dental care
- Therapies and communication approaches
- Going to hospital
- Later stages of dementia
- Working with doctors
- Pain
- Making the most of Respite Care

Changed behaviours and dementia

- Changed behaviours
- Hallucinations and false ideas
- Depression and dementia
- Changed behaviours: Useful resources
- Changed behaviours: Problem solving
- Agitated behaviours
- Aggressive behaviours
- Anxious behaviours
- Aggressive behaviours
- Disinhibited behaviours

Information for people with dementia

- What is dementia?
- Early planning
- Looking after yourself
- Driving and dementia
- Living alone
- Feelings and adjusting to change
- Keeping involved and active
- Talking about diagnosis
- Talking with your doctor

Residential care and dementia

- Deciding on residential care
- Coping with placement
- What is available and what will it cost?
- Which residential facility?
- Caring partnerships
- Good care in a residential facility
- Accreditation in residential facilities
- Rights and responsibilities
- Further information and support

Taking care of the carers

- Taking care of the carers
- Feelings
- Men and caring
- Useful resources
- Taking a break
- Coping after the death of someone with dementia

The environment and dementia

- At home with dementia
- The kitchen
- The laundry
- The living room
- The bathroom and toilet
- The bedroom
- The building
- Furnishings and décor
- Utilities
- Outside
- New housing and renovations
- Memory aids in the home
- Creating a calming environment
- Pets
- Health and safety for carers
- Useful resources

Young people and dementia

- Information about dementia for young people
- Information about dementia for parents and grandparents
- Young people and dementia: Useful resources

Younger onset dementia

- What is early onset dementia?
- Early planning
- Next steps
- Younger onset dementia: Useful resources

F2. Some relevant services

Dementia Advisory Services (NSW)

These locally-based services promote local awareness of dementia, provide information, education and support, and link people with dementia, their carers and families to assessment and support services.

Aged Care Information Line

The Aged Care Information Line provides information to consumers about aged and community care services, and can forward Aged Care Information Sheets on issues such as community care packages, respite care and other services for carers and residential aged care. Tel. **1800 500 853**.

Commonwealth Carelink Centre

Carelink Centres provide information about services such as meal services, personal and nursing care, home help and other health, aged care, and disability services that help elders stay at home and in the community. Carelink is accessible via a national freecall telephone number. Tel. **1800 052 222**.

Aged Care Assessment Team

Aged Care Assessment Teams (ACATs) are multidisciplinary teams including doctors, nurses, allied health professionals and social workers. Team members can provide an expert assessment of dementia and help to determine the level of care the person will need, and provide information about services such as respite care, community support services and residential care services.

National Dementia Helpline

This freecall national telephone service is provided by Alzheimer's Australia and staffed by professional counsellors and trained volunteers who provide information, support, advice and local referrals. Tel. **1800 639 331**.

Dementia Education and Support Program

Alzheimer's Australia also provides education and support programs for people with dementia and their carers. For information, see Alzheimer's Australia website. **www.alzheimers.org.au** or call the National Dementia Helpline **1800 639 331**.

Commonwealth Carer Resource Centre

Carer Resource Centres provide carers with referral to services and practical information to support them in their caring role. Tel. **1800 242 636**.

Commonwealth Carer Respite Centre

Carer Respite Centres can arrange emergency respite care and specific dementia respite care for carers who need a break. This service is accessible 24 hours a day via a national freecall number **1800 059 059**.

National Dementia Behaviour Advisory Service

This is a national telephone advisory service for respite care staff, carers and relatives or friends who provide care and are concerned about the behaviours of people with dementia and any issues around accessing or providing respite. Tel. **1300 366 448**.

Community Support Services

People with dementia can receive help through services for frail older people such as the Home and Community Care Program, Community Aged Care Packages, day care centres and residential aged care services. These services include dementia monitoring and support services, meal services, personal and nursing care, home help and respite care.

Residential Aged Care Services

Some people with dementia will need residential care (in a hostel or nursing home). There are some dementia-specific services that provide specialised residential care for people with more complex needs.

General information and support for Carers NSW

Tel. 1800 242 636 (*toll free from anywhere in Australia*)

Email. contact@carersnsw.asn.au

Website. www.carersnsw.asn.au

Taxi transport subsidy scheme

This Scheme operates through the NSW Department of Transport and may be appropriate for patients in the later stages of dementia.

Tel. (02) 9268 2800

Application forms are available by calling: (02) 9270 6100 or 1800 623 724.

Similar schemes may operate in other states and information can be obtained from the following offices:

Department of Transport Queensland

Tel. (07) 3253 4700

Customer Service

Tel. (07) 3834 2011

Department of Infrastructure Victoria

Tel. (03) 9655 6666

Department of Transport Western Australia

Tel. (08) 9320 9300

Department of Transport Tasmania

Tel. (03) 6233 5201

Transport SA (for South Australia)

Tel. (08) 8343 2222

Department of Transport and Regional Services (for ACT)

Tel. (02) 6274 7111

Department of Transport and Works Road Transport Branch (Northern Territory)

Tel. (08) 8999 5511

Assessing fitness to drive

Assessing fitness to drive, Sydney. Austroads, 2001.

Available on the Austroads

website www.austroads.com.au

Order free copies on Tel. (02) 9264 7088 or contact the following state offices:

ACT Manager – Licensing Registration
Department of Urban Services
PO Box 582, Dickson ACT 2606
Tel. (02) 6207 7122

NSW Manager – Medical Unit
Driver and Vehicle Administration Section
PO Box K198, Haymarket NSW 1238
Tel. (02) 9218 6888

NT Manager Customer Services
Department of Transport and Works
GPO Box 530, Darwin NT 0801
Tel. (08) 8999 3122
Fax. (08) 8999 3189
email. mvr@nt.gov.au

QLD Executive Director
Land Transport Safety Division
PO Box 673, Fortitude Valley QLD 4006
Tel. (07) 3253 4132

SA Office Manager – Licence Services
Department of Transport
60 Wakefield Street, Adelaide SA 5000
Tel. (08) 8226 7433

TAS Manager – Driver Licensing Policy
Department of Infrastructure Energy and Resources
1 Collins Street, Hobart TAS 7001
Tel. (03) 6233 5389

VIC Medical Review
Registration and Licensing
60 Denmark Street, Kew VIC 3101
Tel. (03) 9854 2666

WA Supervisor Driver Assessment Section
Department of Transport
441 Murray Street, Perth WA 6000
Tel. (08) 9320 9392

F3. Resources for general practitioners (GPs), carers and families

Useful resources for general practitioners

NSW

- *A Dementia Care Guide for General Practitioners* (CD ROM) – Educational tool for GPs on various aspects of dementia care in general practice. Completion of the questions within the CD ROM attracts 6 CME points. Available from Central Coast Dementia Advisory Service
Tel. (02) 4320 3677
Fax. (02) 4320 2088

Australia

- *Dementia: What's it all about?* (video) – Information on dementia including causes and risk factors, types of dementia, the progression of dementia, the early signs and benefits of early diagnosis and assessment, care management and treatment options, and the latest research. Available from the Rural Health Education Foundation.
Tel. (02) 6232 5480
Fax. (02) 6232 5484
Email. rhef@hcn.net.au
Website. www.rhef.com.au

International

- *A Guide to the Diagnosis and Management of Alzheimer's disease* for GPs, including differentiating AD from other forms of dementia; diagnosing AD in primary care, and AD in primary care: the diagnostic process. Available on the International Psychogeriatric Association website www.ipa-online.org

Resources for carers and families

NSW

Produced under the *NSW Action Plan on Dementia 1996-2001*

At Home with Dementia – A practical manual on how to modify the home environment for a person with dementia. The publication includes principles and steps to problem solving, then a room-by-room description of problems, concerns and possible solutions plus a list of useful products. The information is useful for carers as well as for the range of community workers who provide services to people with dementia living at home.

Available free of charge from the NSW Department of Ageing, Disability and Home Care (DADHC), Office for Ageing Tel. (02) 8270 2211

- available on the DADHC website. www.dadhc.nsw.gov.au
- available on audio cassettes from DADHC Tel. (02) 9364 6963
- the information has been summarised into 16 Helpsheets and has been included in the Help Sheets Resource Set of Alzheimer's Australia: 1800 639 331.

Planning Ahead Kit – Resources for managing financial, health and lifestyle decisions into the future.

- available on the DADHC website. www.dadhc.nsw.gov.au
- available on tape from DADHC Tel. (02) 8270 2211.

