Patient presentation

1.1

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.

Assessment

1.2

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.

Management

1.3

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

2.1

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).*

Assessment 2.2

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)
- syphillis 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 transmissable. 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 hydocephalus. 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.

Management

2.3

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 depresssion 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 acetycholinesterase 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 acetycholinesterase 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 calenders 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 domicilary 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.

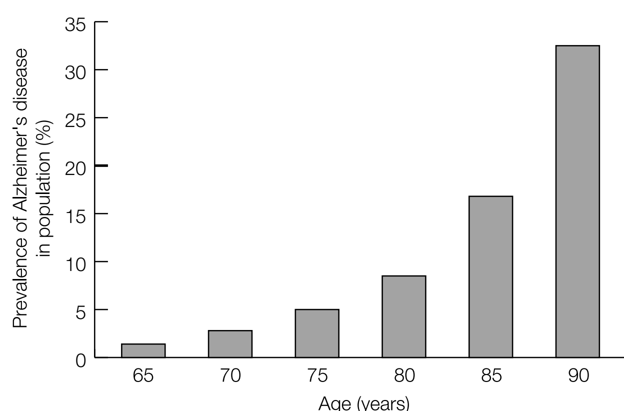
Background and supporting evidence

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)*.