IMPROVING OUTCOMES FOR A TIMELY DIAGNOSIS AND MANAGEMENT OF DEMENTIA IN GENERAL PRACTICE

Partners

Alzheimer's Australia

Dementia Training Australia (DTA)

Dementia Collaborative Research Centre (DCRC), UNSW Sydney

Acknowledgements

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Improving outcomes for a timely diagnosis and management of dementia in general practice

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Improving outcomes for a timely diagnosis and management of dementia in general practice

AIMS OF THE ALM

This active learning module (ALM) is designed to assist GPs to:

- Improve early assessment and management of people with dementia within a primary care setting

- Reduce known risk factors that impact on developing dementia

- Improve confidence in the application and interpretation of assessment tools, and have an understanding of the new neuroimaging scans of the brain

- Understand the behavioral changes in patients with dementia and their better management

- Improve referral to Alzheimer's Australia and other community bodies in support of carers

- Recognise dementia as both a social and medical condition

- Improve the team approach in the assessment and management of early dementia

- Assist and advise families/carers with future planning for the patient with dementia

Improving outcomes for a timely diagnosis and management of dementia in general practice

IMPROVING OUTCOMES FOR A TIMELY DIAGNOSIS AND MANAGEMENT OF DEMENTIA IN GENERAL PRACTICE

Predisposing Activity Form

As part of the RACGP ALM requirements, you are required to complete a predisposing activity prior to coming to the workshop. After the workshop you will be asked to complete an ALM reinforcing activity that will ask you to comment on how you may improve your outcomes.

This predisposing activity is designed to help focus your thoughts on the diagnosis and management of dementia in your practice. Please complete the following prior to the meeting.

1. Identify at least <u>one</u> patient from your practice, with either of the following issues:
   a. A patient presenting with possible dementia, or
   b. A patient with dementia and the problems involved in their management.

2. For the patient identified:
   a. Note the patient's history including initial presentation and other relevant information & problems that will impact on patient outcome and treatment success.
   b. Briefly outline your management strategy and treatment goals and outline any problems/challenges you encountered and that you may wish to have addressed

Also read the following material:

- Alzheimer's Australia Key Facts and Statistics – Feb 2017
- Difficulties in disclosing the diagnosis of dementia: a qualitative study in general practice, BJGP, Aug 2012
- Barricades and brickwalls – a qualitative study exploring perceptions of medication use and deprescribing in long-term care, BMC Geriatrics (2016) 16:15

This form is for approved RACGP Category 1 Activity no. 94430

Submission of predisposing activity documentation

The submission of a completed Predisposing Activity and your Certificate of Attendance is required in order to earn the CPD Points for which you have registered.

Predisposing Activities need to be received <u>prior</u> to the commencement of the workshop.
Please print these two pages and submit your case study (over page).

There are two methods of providing your completed Predisposing Activity documentation:

1. ONLINE SUBMISSION <u>(must be done prior to the workshop)</u> –
   Upload an electronic copy of your completed form and email to: L.Nattrass@unsw.edu.au

   OR

2. HARD COPY SUBMISSION (onsite at the workshop) –
   You can bring your completed Predisposing Activity documentation with you and give it to the facilitators prior to the commencement of the workshop.

Note: the facilitators will use a small number of case studies for discussion during the workshop

Improving outcomes for a timely diagnosis and management of dementia in general practice

Predisposing Activity Form – Notes

Surname: _____   First Name: _____

QI&CPD No: _____*(must be filled in)*   Workshop date: /   /

Patient A: a patient presenting with possible dementia
a. Note the patient's history including initial presentation and other relevant information & problems that will impact on patient outcome and treatment success.
b. Briefly outline your management strategy and treatment goals and outline any problems/challenges you encountered and that you may wish to have addressed

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Patient B: a patient with dementia and the problems involved in their management
a. Note the patient's history including initial presentation and other relevant information & problems that will impact on patient outcome and treatment success.
b. Briefly outline your management strategy and treatment goals and outline any problems/challenges you encountered and that you may wish to have addressed

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THE LONG GOODBYE

Our brain makes us who we are, it gives us our memories, our ability to think, to understand the world around us and it gives us our sense of self. All this is slowly stripped away for a person living with dementia. THE LONG GOODBYE follows the journeys of three families living with dementia as they struggle to maintain the identity and dignity of those they love. Filmed over a 3 year period, the documentary celebrates the capacity of the human spirit to search for meaning and hope when the end is known and inescapable.

The three families are at different stages of the condition and they each offer a different perspective. *Michael*, a criminal barrister with four teenage children was diagnosed with early onset Alzheimer's disease at the age of 49. Three years on and still in the early stages of his condition, Michael retains insight and articulately shares his thoughts and feelings from within the disease. Although adamant he will fight on with a positive attitude and a sense of humour, Michael struggles with the loss of his professional identity and the shifting relationship dynamics within the family home. As his condition deteriorates, Michael and his family bravely strive to maintain as normal a family life as possible and to live each day as it comes.

The second strand is from the perspective of *Myrle*, an elderly carer committed to looking after her husband of 60 years until his dying day. Well into the mid stages of his Vascular dementia, Ken requires constant care and supervision. A fiercely independent woman, Myrle knocks back all offers of help, she sees it as her duty and is determined to carry out the caring responsibility alone. Although Myrle maintains control over all aspects of Kens care she is unable to control the decline of her beloved. As Ken's condition deteriorates, Myrle is faced with the fact that she is losing the love of her life. The burden of care continues to build and Myrle's health is significantly threatened. Forced to relinquish control over Ken's care Myrle must find a new way to stay with her man.

The final strand is from the perspective of *Tom*, a 72 year old carer who is desperately struggling to look after his wife Brenda who is in the latter stages of her Alzheimer's disease. No longer able to care for Brenda at home, Tom very reluctantly opts for dementia specific residential care. Racked with guilt and loneliness, Tom struggles to cope with his new life separated from his wife. As Brenda's memory and speech continue to diminish and she slowly withdraws from the world they shared, Tom refuses to let her go. He finds a new way to remain connected with his soul mate, the woman who loves him yet no longer remembers his name.

Every week 1000 more Australians are diagnosed with dementia and the numbers continue to escalate in line with our ageing population. There are currently 300,000* Australians living with dementia and it's estimated that there will be over 1.0 million by 2050. Raised in the unparalleled optimism and prosperity of the '50s and '60s, the baby boomers are accustomed to controlling their own destiny. As the dementia epidemic looms, it is unknown whether science will save them this time.

For our three families the end is known and inescapable, and yet they refuse to despair. Their insight, humour and wisdom will provide comfort and hope to thousands of Australians facing a similar fate. A very intimate and ultimately uplifting documentary, THE LONG GOODBYE celebrates the best the human spirit has to offer.

as at 2009

Kaye Harrison – Director

© 2010 produced by Luminous Films in association with Screen Australia, Screen NSW and the Australian Broadcasting Corporation. Distributed by Ronin Films.

Topic 39: Thinking clearly about the anticholinergic burden

Older people can be particularly sensitive to the anticholinergic effects of medicines.[1] Adverse effects may arise from an individual anticholinergic medicine, and from the cumulative effects of multiple medicines with varying degrees of anticholinergic properties.[2-4]

The anticholinergic burden may be unintentionally increased by medicines prescribed with other mechanisms of action intended, but also having anticholinergic effects, such as antihistamines, tricyclic antidepressants and antipsychotics.[2] In addition, medicines not typically thought of as having anticholinergic effects, such as citalopram, mirtazapine and metoclopramide, when added to other strongly anticholinergic medicines, may tip the balance of the cumulative anticholinergic burden and result in significant adverse effects.[2, 4, 5]

Older Australians commonly use medicines with anticholinergic effects; at any point in time 21-33% of Australians aged over 60 years use at least one medicine with anticholinergic effects.[6-8] A cumulative anticholinergic burden in older people with co-morbidities who are taking multiple medicines is associated with an increased risk of confusion, cognitive and physical decline, delirium, hospitalisation and death.[2, 3, 9-11]

This therapeutic brief provides information on anticholinergic adverse effects and outlines steps to take to reduce the anticholinergic burden.

INSIDE

- Ask yourself and your patient: What are the adverse effects and potential outcomes?
- Ask: What is the burden?
- Ask: Can the burden be reduced?
- Insert: Potential strategies to reduce the anticholinergic burden.

KEY POINTS

- **Medicines that contribute to an anticholinergic burden are medicines:**
  - **prescribed for their anticholinergic effects**
  - **prescribed with other mechanisms of action intended but also having anticholinergic effects and,**
  - **not typically thought of as having anticholinergic effects.**

- **A high anticholinergic burden in older people is associated with an increased risk of cognitive decline.**

- **Be alert to anticholinergic adverse effects in your older patient.**

- **Consider reducing the anticholinergic burden where possible.**

Veterans' Medicines Advice and Therapeutics Education Services

Topic 39: Thinking clearly about the anticholinergic burden. Sept 2014.

Ask yourself and your patient: What are the adverse effects and potential outcomes?

Anticholinergic adverse effects may be subtle or severe (see Figure 1). In older people, the effects may be overlooked and considered part of the natural ageing process or attributed to the progression of underlying disease.[1, 5] Consequences of blurred vision, dizziness or memory loss from an anticholinergic burden may include loss of independence, falls or motor vehicle accidents.[1, 12] Acute confusion or delirium may result in hospitalisation, functional and cognitive decline or aged care facility placement.[13, 14]

Be alert to possible anticholinergic adverse effects in your older patient, as the anticholinergic load differs between medicines, and individuals differ in their ability to tolerate them.[4]

Consider that any worsening of chronic conditions, new symptoms or adverse events may be the result of medicines with anticholinergic effects, especially if they occur after changes in the medicine regimen.[4, 13]

Avoid treating adverse effects with medicines.[13]
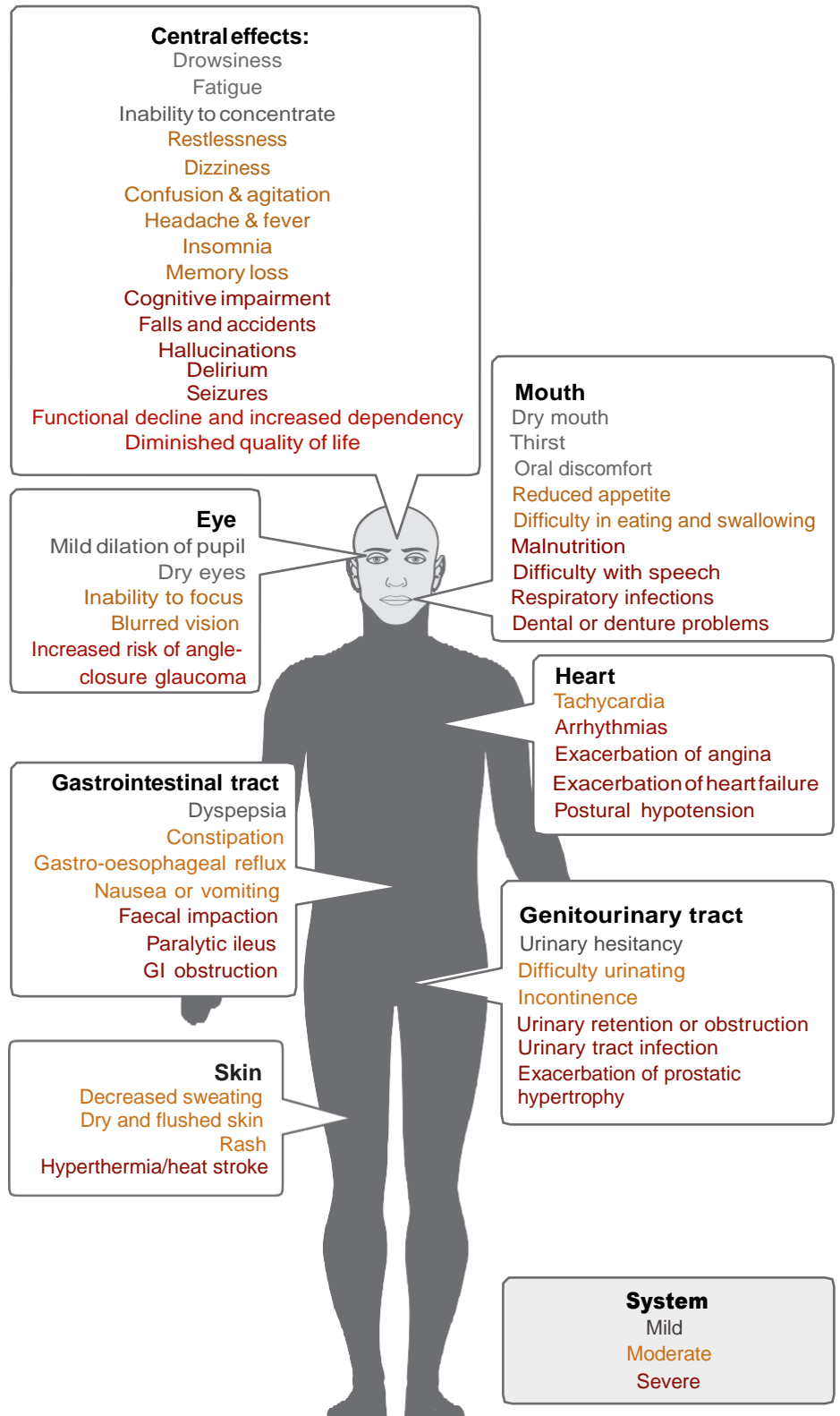
Central effects:
Drowsiness
Fatigue
Inability to concentrate
Restlessness
Dizziness
Confusion & agitation
Headache & fever
Insomnia
Memory loss
Cognitive impairment
Falls and accidents
Hallucinations
Delirium
Seizures
Functional decline and increased dependency
Diminished quality of life

Mouth
Dry mouth
Thirst
Oral discomfort
Reduced appetite
Difficulty in eating and swallowing
Malnutrition
Difficulty with speech
Respiratory infections
Dental or denture problems

Eye
Mild dilation of pupil
Dry eyes
Inability to focus
Blurred vision
Increased risk of angle-closure glaucoma

Heart
Tachycardia
Arrhythmias
Exacerbation of angina
Exacerbation of heart failure
Postural hypotension

Gastrointestinal tract
Dyspepsia
Constipation
Gastro-oesophageal reflux
Nausea or vomiting
Faecal impaction
Paralytic ileus
GI obstruction

Genitourinary tract
Urinary hesitancy
Difficulty urinating
Incontinence
Urinary retention or obstruction
Urinary tract infection
Exacerbation of prostatic hypertrophy

Skin
Decreased sweating
Dry and flushed skin
Rash
Hyperthermia/heat stroke

System
Mild
Moderate
Severe

Figure 1: Anticholinergic adverse effects and potential outcomes [2, 12, 13, 15]

Veterans' Medicines Advice and Therapeutics Education Services

Topic 39: Thinking clearly about the anticholinergic burden. Sept 2014.

Ask: What is the burden?

While exact quantification of a medicine's anticholinergic effect is difficult[16] it is estimated one medicine with strong anticholinergic effects is likely to cause two or more anticholinergic adverse effects in more than 70% of older patients.[17] Additionally, older patients prescribed two or more anticholinergic medicines are at a significantly increased risk of hospitalisation for confusion or dementia.[10] Table 1 lists some of the commonly used medicines with anticholinergic effects in older veterans.

Individual pharmacokinetic and pharmacodynamic variability, the number of medicines, dosages prescribed, drug interactions, and prevalence and severity of co-morbidities may also influence cumulative anticholinergic burden and severity of adverse effects.[4, 18]

The increase in the number of medicines, including prescribed and self-prescribed over the counter medicines used by many older people, may contribute to an unintended high anticholinergic burden.[2, 3, 11] Herbal preparations such as knotweed (*polygonum aviculare*) as well as over the counter medicines for coughs and colds, antihistamines, travel sickness products and antidiarrhoeals may have anticholinergic properties.[4]

Ask your patient specific questions about self-prescribed medicines they may be taking.

Anticholinesterases and anticholinergic medicines

Where possible avoid using anticholinesterases, such as:
- o   donepezil
- o   galantamine
- o   rivastigmine
- o   pyridostigmine

with anticholinergic medicines; anticholinergic medicines antagonise the therapeutic effect of anticholinesterases.[4]

Be alert to the cholinergic effects of anticholinesterases. Avoid prescribing anticholinergic medicines to compensate for the cholinergic effects of anticholinesterases. If an anticholinergic medicine is prescribed, and you stop the anticholinesterase, the effects of the anticholinergic medicine may be magnified.[12]

Table 1: Commonly used medicines with anticholinergic effects in older veterans[12, 16]

	Antipsychotics	Antidepressants	Bladder antispasmodics	Antihistamines	Opioids	Inhaled medicines	Other medicines
Higher anticholinergic effects	chlorpromazine clozapine trifluoperazine	amitriptyline clomipramine dothiepin doxepin imipramine nortriptyline	darifenacin* oxybutynin propantheline solifenacin* tolterodine*	cyproheptadine promethazine	tapentadol	aclidinium glycopyrronium ipratropium tiotropium	benztropine homatropine
Lower anticholinergic effects	haloperidol lithium carbonate olanzapine prochlorperazine quetiapine risperidone	citalopram fluoxetine fluvoxamine mirtazapine paroxetine		cetirizine fexofenadine loratadine	codeine fentanyl methadone morphine oxycodone tramadol		alprazolam amantadine baclofen carbamazepine clonazepam colchicine diazepam digoxin disopyramide domperidone entacapone frusemide loperamide metoclopramide ranitidine temazepam theophylline

Note: The list of medicines is based on Duran et al.'s 2013 Systematic review of anticholinergic risk scales in older adults (reviewing 7 studies, one of which was Australian), the Australian Medicines Handbook, Martindale: The Complete Drug Reference and expert opinion.

Note: *these medicines are not available on the PBS/RPBS

Ask: Can the burden be reduced?

Step 1: Assess your patient for adverse effects

Assess your patient for anticholinergic symptoms including dry mouth, constipation, blurred vision, increased heart rate, heat intolerance, sedation and mild confusion or memory loss. In your older patient, these symptoms can develop into serious problems (see Figure 1).[1]

Step 2: Review your patient's medicines

Identify medicines to consider ceasing or substituting: target medicines of lesser benefit to your patient.[19] Assess whether your patient is taking their medicines as prescribed, potential adverse effects, such as risk of falls and cognitive decline, indications, time of benefit and interactions.[20] Consider recommending a Medicines Review (HMR or RMMR) by an accredited pharmacist. Ask the pharmacist to specifically consider the anticholinergic burden. Consider consulting the opinion of a geriatrician in difficult cases.

Step 3: If problematic, ask the question: is a medicine essential?

If a medicine is not essential, can it be ceased? Ceasing a medicine with anticholinergic effects may not always be possible. Consider, in consultation with your patient, their goals and expectations, co-morbidities and individual preferences when making a decision.[4, 19]

Once you have confirmed the medicines to be ceased and a plan has been developed with your patient, begin by ceasing one medicine at a time. Monitor your patient closely and gradually taper the medicine.[19] Talk to your patient about possible withdrawal effects, such as anxiety, nausea, vomiting, headache and dizziness. Advise your patient to talk to you if any of these symptoms worry them.[21]

If a medicine is essential, ask these questions:

- **Is there a safer alternative treatment option? (see Insert)**
- **If not, can the dose, frequency or duration of the medicine be reduced?**

When a medicine with anticholinergic effects is essential and the dose, frequency or duration cannot be reduced, advise your patient of non-pharmacological measures to minimise the impact of adverse effects. Examples include artificial tears for dry eyes and increased water intake and a high fibre diet for constipation.[5]

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Insert: Potential strategies to reduce the anticholinergic burden[4, 12]

Urinary incontinence

* Consider potential contributing factors, such as disease or pharmacological causes.
* Consider lifestyle and physical or behavioural therapies before using medicines.
* If prescribing anticholinergics, monitor for adverse effects, especially cognitive function, and cease after 4 weeks if no improvement in urinary symptoms.
* Darifenacin and solifenacin may be less likely to cause cognitive impairment or dry mouth than oxybutynin, but may contribute to constipation.
* For further information contact the Continence Foundation of Australia at: www.continence.org.au
* See Module 26: The impact of commonly used medicines on urinary incontinence at:
  www.veteransmates.net.au/TB_urinaryincontinence

Depression

* Treat mild to moderate depression with psychotherapies such as cognitive behavioural therapy, mindfulness and interpersonal therapy, supportive counselling and problem - solving techniques as first line therapies where possible.
* If prescribing medicines, consider escitalopram or sertraline: they have less potential for drug interactions.
* If prescribing a tricyclic antidepressant (TCA), consider nortriptyline as there is a lower incidence of anticholinergic adverse effects than for other TCAs.[22]

Behavioural and psychotic disorders including those associated with dementia

* Exclude secondary causes of behavioural disturbances such as pain, infection, faecal impaction or depression.
* Initiate behavioural therapies and changes to the environment before considering medicines.
* If antipsychotics are indicated, consider one with low anticholinergic effects such as risperidone or haloperidol. NOTE: haloperidol is for short term use only.

COPD

* Assess for and treat comorbidities commonly associated with COPD, such as cardiovascular disease, anxiety, depression and osteoporosis.
* Encourage and support smoking cessation: it is the single most effective way to improve long term outcomes and reduce mortality in COPD patients.
* Consider multidisciplinary rehabilitation programs such as exercise training, advice about nutrition and psychosocial support programs.
* Consider annual influenza vaccinations: they reduce serious illness and mortality in COPD patients.
* If prescribing anticholinergics and your patient is experiencing adverse effects, consider ipratropium before tiotropium as it may not have as many anticholinergic adverse effects.
* Avoid prescribing short and long acting anticholinergic medicines in combination as the anticholinergic effects will be magnified.
* Consider combined long acting beta2 agonists with inhaled corticosteroids to reduce exacerbations.
* See Module 6: COPD for further information at:
  www.veteransmates.net.au/TB_COPD

Allergies

* Antihistamines are effective in relieving itch due only to histamine release.
* Intranasal corticosteroids are the most effective treatment for allergic rhinitis.
* Consider loratadine or fexofenadine for chronic urticaria: they have reduced anticholinergic effects.

Pain

* Consider physical, psychological and social factors that may be contributing to pain.
* Consider non-pharmacological therapies and a multidisciplinary approach to management.
* If amitriptyline is prescribed for neuropathic pain and causing adverse effects, consider gabapentin or pregabalin Instead.
* See Modules 35: Managing neuropathic pain: a stepwise approach at: www.veteransmates.net.au/TB_neuropathicpain
* See Module 38: Chronic musculoskeletal pain: Changing the way we think about pain at:
  www.veteransmates.net. au/TB_musculoskeletalpain

A case for Medicine Review

Scenario: Dorothy, aged 85, has been a patient of the practice for many years. She has recently been diagnosed with mild cognitive impairment (MCI) and is considering a move into a local residential aged care facility. You review her medications and, if indicated, consider 'deprescribing' some of these prior to her move to a well-managed hostel facility.

PH: Dorothy's BP is 145/75, pulse rate is regular at 72 bpm. Her urinary incontinence bothers her, as does her arthritis. She sleeps poorly despite the night sedation, partly because of the pain from her arthritis.

Recent blood test results had her cholesterol level at 6.2, a mildly reduced GFR at 50, with other results, including LFTs, thyroid function and Calcium all in the 'normal' range.

Current medications:

- Serepax (Oxazepam) - 15mg. nocte for sleep.

- Ditropan (Oxybutynin) - 5mg. t.d.s. for urinary incontinence.

- Panadeine forte (Paracetamol 500mg + Codeine 30mg) - 2 nocte for arthritis.

- Panadol Osteo (Paracetamol SR 665mg) - 2 b.d. for arthritis.

- Cardizem CD (Diltiazem 180mg) - 1 daily for hypertension.

- Lasix (Frusemide) 40mg - 1 daily for hypertension/mild CCF.

- Slow K (Potassium) - 1 daily.

- Movicol - 1 packet daily for constipation.

- Zocor (Simvastatin) 10 mg – 1 daily.

Q. What medications would you target and why? Discuss

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Workshop Program

08.30 - 09.00	**Registration and refreshments**
09.00 - 09.15	**Welcome and Predisposing Activity**
09.15 - 10.45	**Session 1 - Recognising dementia in general practice:** The Barriers to Diagnosis Diagnostic / Assessment tools / new biomarkers and scans
10.45 – 11.00	**MORNING TEA**
11.00 – 12.30	**Session 2 - The early to middle stages:** Risk Factors Medications – pharma. or non-pharma. management of dementia
12.30 – 13.15	**LUNCH**
13.15 – 14.45	**Session 3 - Complications of dementia:** BPSD, Depression and management issues
14.45 – 15.00	**AFTERNOON TEA**
15.00 – 16.30	**Session 4 – The end stages:** Carer Stress, Support Service Community and Practice Nurses Legal Issues End of life issues / advanced directives / palliative care
16.30 - 17.00	**Final Discussions** **Post evaluation**
17.00	**END**

Improving outcomes for a timely diagnosis and management of dementia in general practice

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- Speakers' Competing Interests: None

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- ❑ Ronin Films – The distributor of *The Long Goodbye* documentary

Our Aim

- What we aim to do:

  Break down the barriers to making the dementia diagnosis

- How we will do it:

  Skill-based workshop series using videos, case discussion, resource materials

Objectives

To assist GP participants:

- In the better assessment and management of patients with dementia
- By providing information to help reduce risk factors that impact on developing dementia
- In the better understanding of behavioural changes in patients with dementia
- To refer dementia patients to Alzheimer's Australia and other community bodies in support of carers
- In recognising that dementia is both a social and medical condition


Session 1
Recognising Dementia and the better use of Assessment Tests and Scans

- What assessment tests should we do, to better identify the person with dementia?

- Understand that mild cognitive impairment (MCI) is not dementia

- Review and appreciate the new scans and biomarkers used in research of dementia today

- Consider NH&MRC Clinical Practice Guidelines for Dementia

MJA - Clinical practice guidelines for Dementia in Australia. Laver, K et al 2016.pdf

Changes in Age Structure Australia - 2009 -2050
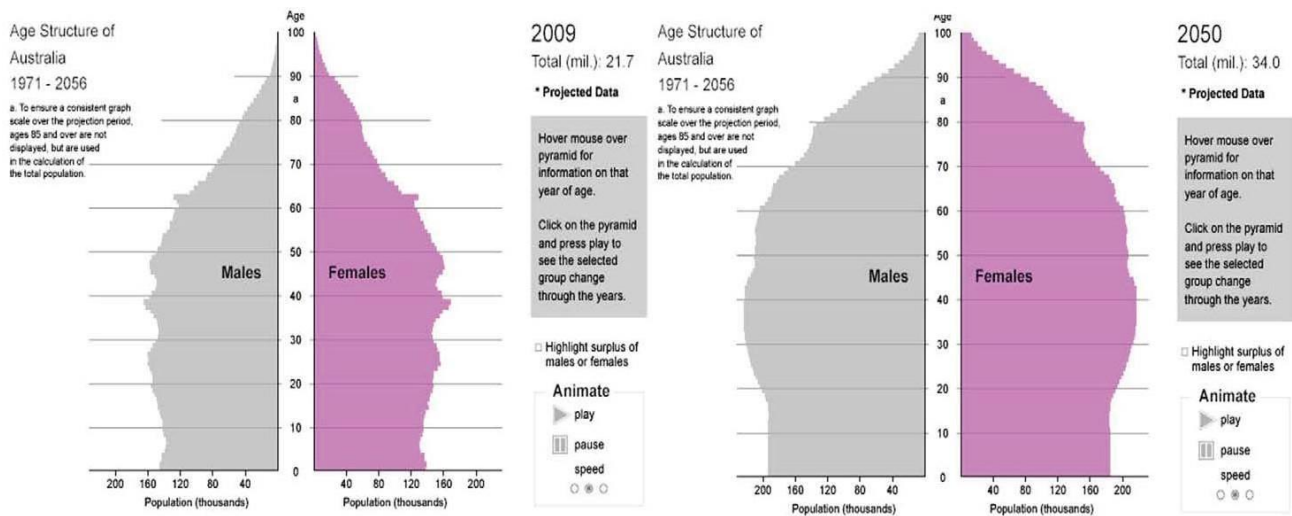
Source: Australian Bureau of Statistics 2013

Case Presentations - Part 1
Michael, Ken and Brenda

Defining dementia

- Characterised by a decline in multiple areas of cognitive function (i.e. memory, intellect and personality) in an alert (non-delirious) patient[1]

- Most dementias are progressive and irreversible

- Must cause significant impairment in social or occupational functioning for diagnosis to be made

- Dementia is a both a social and medical condition

- Prevalence – there are an estimated 342,800 Australians living with dementia – including Younger Onset of around 26,000 - and projected to increase to around 900,000 by 2050 (AIHW Dementia in Australia. 2015)

1. American Psychiatric Assoc. DSM IV TR. – now replaced by the DSM5 definition

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New Clinical Practice Guidelines

Recommendations approved by the NH&MRC (2016)

https://www.clinicalguidelines.gov.au/portal/2503/clinical-practice-guidelines-and-principles-care-people-dementia

- Details the optimal diagnosis and management in community, residential and hospital settings

- Emphasises a more timely diagnosis

- In order to help people live well with their dementia

- Assist in delaying their functional decline

- Using non-pharma. approaches in the first instance

- Better management of symptoms through training staff in how to provide person-centered care

- Training and supporting families and carers to provide optimal care at home

Early warning signs

- Memory problems:
  - ☐ Trouble recalling time or date
  - ☐ Impaired ability to recall events or conversations
  - ☐ Losing items
  - ☐ Repetitive questioning

- Cognitive problems:
  - ☐ Abandonment of complex problems - finances
  - ☐ Difficulty recognising familiar objects or people
  - ☐ Cannot follow the plot or story
  - ☐ Language problems
  - ☐ Delirium

Early warning signs cont'd

- Behavioural problems:
  - ☐ Withdrawal and / or inertia
  - ☐ Inflexible attitude or stubbornness
  - ☐ Irritability, Agitated
  - ☐ Reduced competence in making decision & plans
  - ☐ Lack of attention to detail

- Specific incidents:
  - ☐ Confusion or unhappiness while on holidays
  - ☐ Neglect of long-established behaviour, such as writing Xmas cards to family and friends

Identifying the type of dementia[2]

Dementia syndromes may overlap in individual patients, and there may be as many as 100 different types

- Alzheimer's disease - accounts for ~50% dementia cases
  - ❑ Insidious onset, slow progression, fluctuating symptoms
  - ❑ Impairment of memory, attention and language; apathy or irritability; apraxia
  - ❑ Neuroimaging may show cortical atrophy and β-amyloid deposits
- Vascular dementia – now accounts for ~20% dementia cases
  - ❑ Onset may be sudden following stroke, or a stepwise deterioration after TIAs
  - ❑ Cognitive impairment variable; early markers are emotional lability, gait abnormalities, Parkinsonian features

2. Brodaty, H. 14 essentials in the diagnosis and management of dementia, 2014

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Identifying the type of dementia[2] cont'd

- Mixed dementia will become more common – now at ~20%
- Other Dementias account for ~10% of cases, importantly:
  - ❖ Dementia with Lewy Bodies (LBD):
    - ❑ Patients must have at least two of the following key features to indicate probable LBD:
      - ➢ Visual and auditory hallucinations
      - ➢ Significant fluctuations in cognition
      - ➢ Extrapyramidal features – Parkinsonism
  - ❖ Neuroleptic sensitivity is common - important to avoid older drugs, Haloperidol or Serenace, or higher doses of the newer atypical antipsychotics
- Fronto-temporal – often an early onset of disinhibition, poorer executive function and changes in social behavior before other physical signs appear

2. Brodaty, H. 14 essentials in the diagnosis and management of dementia, 2014

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Barriers to recognising dementia

Discussion

Barriers to diagnosis[3]

Carer's perception:

- Stigma associated with the diagnosis
- Delay in treatment through a misunderstanding of symptoms by doctors
- Families arranged 'support' rather than seeking medical advice
- Stoicism – perceived need to cope with a difficult situation

3. Philips J, Pond CD, Shell AM, in *No time like the present*. Alzheimer's Australia 2010

Barriers to diagnosis[3,4] cont'd

GP's limitation:

- Differentiating between normal ageing and dementia
- A perceived lack of need to make a specific diagnosis
    - no cure, not enough drugs
- Lack of confidence and training
- Risk of misdiagnosis – which tests really help
- Paucity of specialist or memory clinics available
- Lack of time
- Other chronic conditions to treat

3. Philips J, Pond CD, Shell AM, in *No time like the present*. Alzheimer's Australia 2010

4. Phillips J, et al. *Difficulties in disclosing the diagnosis of dementia*. BJGP 2012

Consumers

Person with dementia:

- may live alone (about 25% of older Australians)
- may lack insight into their problems
- belief that there is nothing that can be done

Consequence:

GP cannot identify problems until they are obvious

(Draper, B. 2014)

Consequences of not recognising dementia

- Missed reversible causes
- Failure to intervene symptomatically
- "Prescription" for positive lifestyle changes
- Failure to provide assistance/community support for ADL dysfunction
- Missed opportunities re AChEI* and or Memantine*
- Dangerous decision making – e.g. still driving?
- Struggling families, misunderstanding
- Placement and long term planning issues

*Refer to the full PI for approved indications, dosages, adverse events and drug interactions for medicines used in Australia.

Population Screening vs Case finding

Population screening
- Do we screen all patients over 75 yr + over?
- GP Guidelines recommend against population screening
- Problems –
  - ❑ False positives
  - ❑ Screening instruments do not always perform well
  - ❑ Frustration/overwhelms system – e.g. GP spends time/effort before referral to memory clinic

Case finding
- Instead
  - ❑ Consider screening as part of a package of enhanced care
  - ❑ Guidelines recommend case finding - applying screening instrument to someone who reports symptoms, or whom you observe or about whom relatives report symptoms > lower rate of false positives

(Le Couteur et al. 2013)

Assessment Tests

- MMSE
- GPCOG - www.gpcog.com.au
- RUDAS
- KICA / KICA Cog
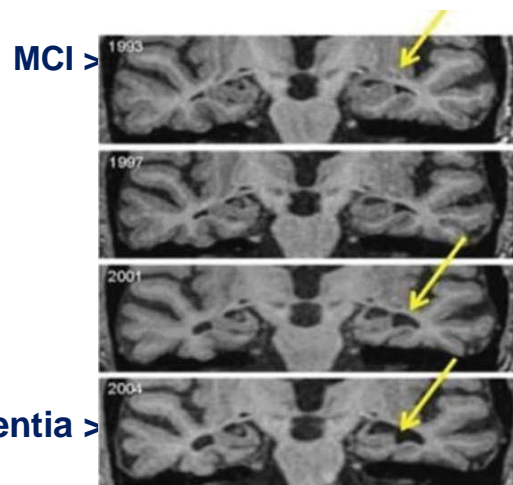
Others:

- MoCA
- CAMCOG
- ADASCog

+ Clock Test

The GPCOG test

What tests to do?

- FBC, ESR or CRP
- clinical chemistry including Calcium
- Thyroid function tests
- B12, Folate
- micro-urine
- fasting glucose, lipids
- serology for HIV, syphilis
- neuropsychological assessment
- ECG CXR EEG
- CT scan of brain (without contrast)

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Advances in Biomarkers

- Cerebrospinal fluid (CSF)
  - Amyloid β Protein (Aβ42)
  - Tau Protein (tt and tp)
- MRI scans - serial *
- SPECT scans + dopamine label
- PET Scans + amyloid ligands

MCI >

Dementia >

*Serial changes seen in the hippocampus – MCI progressing to dementia over 11 yrs.

http://yassermetwally.wordpress.com/dementia-alzheimer-type-and-others/neuroimaging-of-dementia

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Biomedical Imaging

- Pittsburgh compound B (11C-PIB) is a radioactive biomarker used in Positron Emission Tomography (PET) to stain Aβ plaques and highlight Aβ deposits

- PIB binds to insoluble species of Amyloid, crosses the blood-brain barrier and is cleared rapidly

- Fluorodeoxyglucose (18FDG) PET imaging and Magnetic Resonance Imaging (MRI) are other comparatives used

- MRI can assess cortical atrophy associated with the progressive neuro-degeneration seen in Alzheimer's disease

(van Gool 2015)

CSF and Scanning biomarkers

- Neurochemical Dementia Diagnosis (NDD) tools:

  ☐ Amyloid Aß pathology – decreased CSF concentration of Aß42 and / or positive Aß PET imaging for Alzheimer's

  ☐ Neurodegeneration – increased CSF Tau, decreased uptake of FDG on FDG-PET, and

  ☐ Cerebral atrophy on MRI – see high quality anatomical details of brain tissue

- CSF and Aß PET changes may occur some years before onset of clinical symptoms of Alzheimer's disease

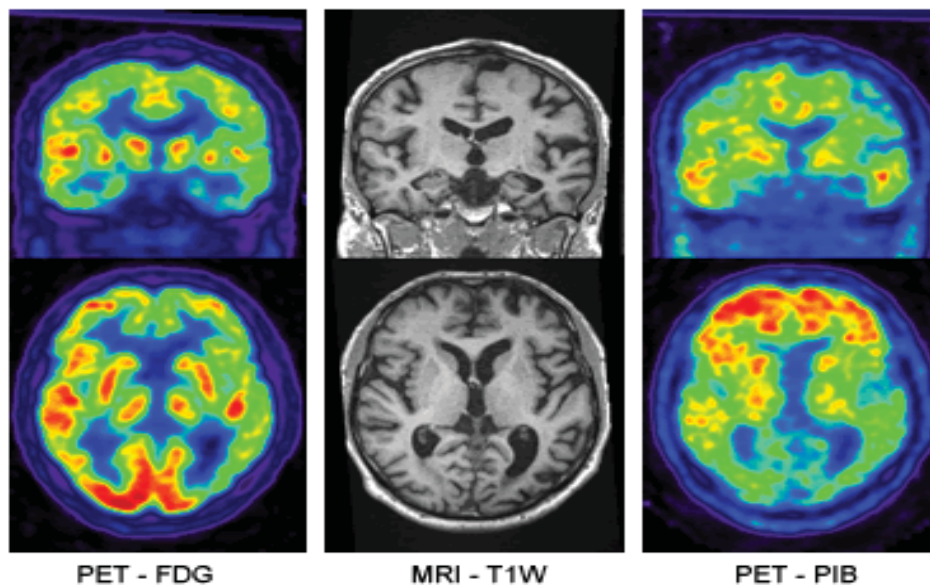(Lewczuk, P. et al. 2014)

Imaging samples

Control	AD Patient
Non specific binding in white matter, thalamus and brainstem	Specific binding in frontal, posterior cingulate, parietal and lateral temporal areas

Source: CSIRO - Australian e-Health Research Centre 2009; www.aehrc.com

PET - FDG   MRI - T1W   PET - PIB

Multimodality imaging provides complimentary information.
From left to right on the same patient: PET-FDG (neuronal activity),
MRI-T1W (anatomical delineation), PET-PIB (Aβ plaques deposition).
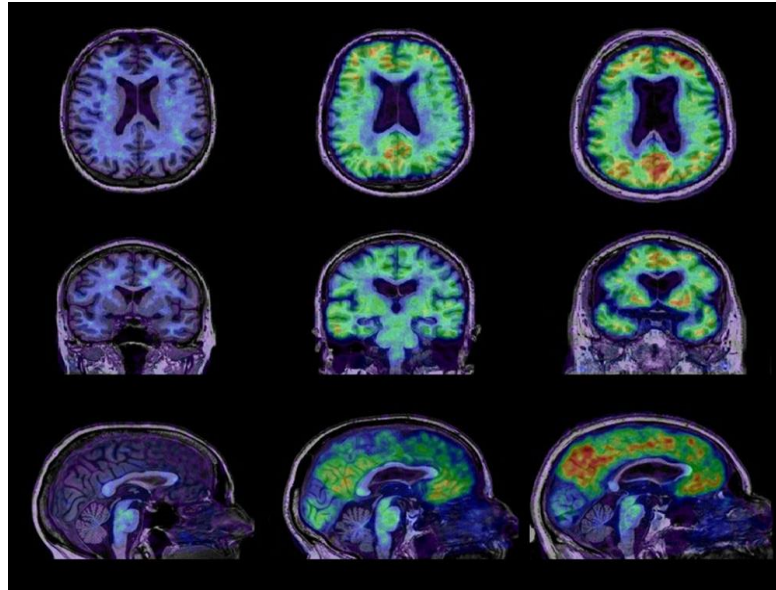
MRI views superimposed with Amyloid PET scans:
1. Healthy brain   2. Mild cognitive impairment - MCI
3. Alzheimer's disease patient   (Prof C Rowe, 2015)

What is MCI?

- Mild Cognitive Impairment – is it a prodrome to dementia?

- A cognitive complaint (self-reported or informant-based)

- Preserved basic ADLs, intact or min. impaired complex instrumental ADLs (e.g. finances, driving)

- Cognitive Impairment - not normal for age or education

- A decline in cognition evidenced by performance in objective testing

- Preserved general cognitive functioning

- Not dementia - but need to discuss with patient, family and carer re: complex finances, relationships, support of ADLs

Conversion of MCI to dementia

- Conversion rates for MCI vary – about 3-12% p.a.
  - ➤ Recent paper (Brodaty, H. 2014) suggests 10% p.a.

- Some studies higher – depends on definition used and the population that you follow-up
  - ❑ Community screened versus Clinic presentations

- It's NOT Bad News - not invariable, some studies show 50% remain stable, or 40% revert to normal

- No role for AChEI's – manage Risk Factors

Vascular dementia

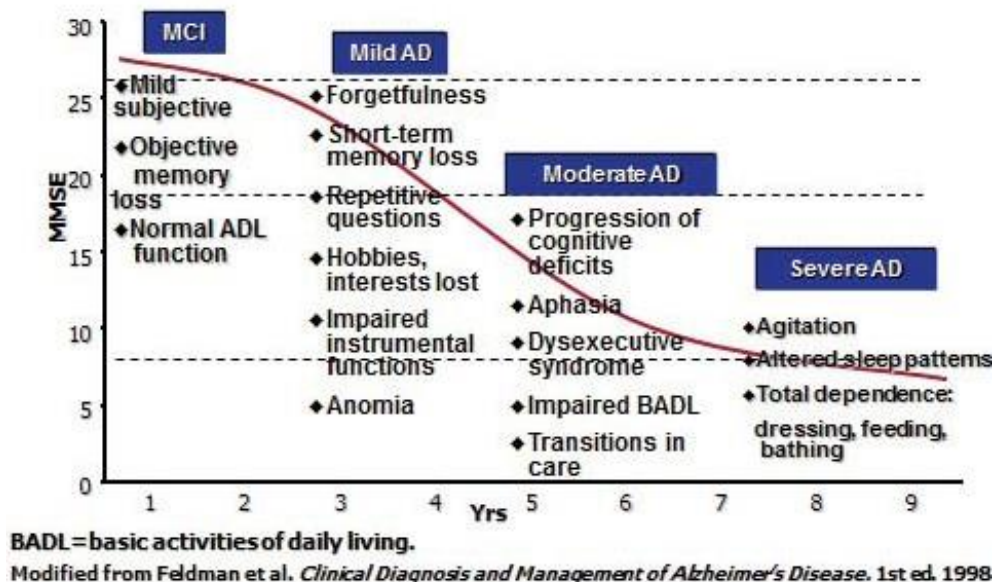Most vascular dementias have a slow gradual progress

- More slowing of mentation
- Step-wise progression
- Difficulty with retrieval rather than learning
- Evidence of cardiovascular risk factors
- Gait disturbance and falls
- MRI scan
  - ➤ Dense white matter hyperintensity ++
  - ➤ Lacunae
  - ➤ Presence of Stroke – single strategic or multiple small
  - ➤ Usually preserved hippocampi

Giving the diagnosis

- Group discussion – carer, family, patient

- Doctor - Patient relationship
  - ❑ Barriers in making the diagnosis

- [Breaking bad news](#)

- Other practical issues – are there Genetic Tests?

  - ❑ ApoE genotype?
  - ❑ Twin studies
  - ❑ 20% of younger onset Alzheimer's Disease – type usually familial
  - ❑ 50% passed onto next generation   (Ahmed, R. 2015)

Symptom Progression in AD

BADL = basic activities of daily living.

Modified from Feldman et al. *Clinical Diagnosis and Management of Alzheimer's Disease.* 1st ed. 1998

Source: Brodaty, H. 14 essentials in the practice & art of diagnosis & management of dementia, 2011

Session 2
Risk Factors and Medication

- Risk factor management: Primary and secondary prevention

- Pharmacy review

- What else can we do?

  ☐ Needs assessment- ADL dysfunction
  ☐ Positive lifestyle changes
  ☐ Diet / Nutrition
  ☐ Medical, dental, sensory co-morbidities
  ☐ Care planning

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Risk factors for dementia prevention[5]

- Vascular dementia risk factors

  - ❑ Hypertension

  - ❑ Diabetes

  - ❑ Smoking

  - ❑ Atrial fibrillation (AF)

  - ❑ Hypercholesterolaemia

- ➢ **Higher LDL** variability, assoc.↑↑ hyperintensity on scans (Mayor, S 2016. BMJ)
- ➢ **European Heart guidelines** in high-risk patients, recommend target LDL cholesterol of less than 2.6mmol/L (100 mg/dL) with diet and lifestyle changes, before Statins are used (2016)

  - ❑ Diet / Nutrition

- ➢ **Mediterranean diet** – primarily plant-based foods, such as fruits and vegetables, whole grains, legumes and nuts, healthy fats such as olive oil, and herbs and spices instead of salt to flavour foods. Less red meat, more fish.

5 Alzheimer's Australia. Towards a National Dementia Preventative Health Strategy, August 2010

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Other Risk factors[5]

- Depression

- Head injury

- Excessive alcohol

- Sedentary lifestyle - lack of any exercise

- Lack of mental stimulation

- Limited social interaction

- Stress

5. Alzheimer's Australia. Towards a National Dementia Preventative Health Strategy, August 2010

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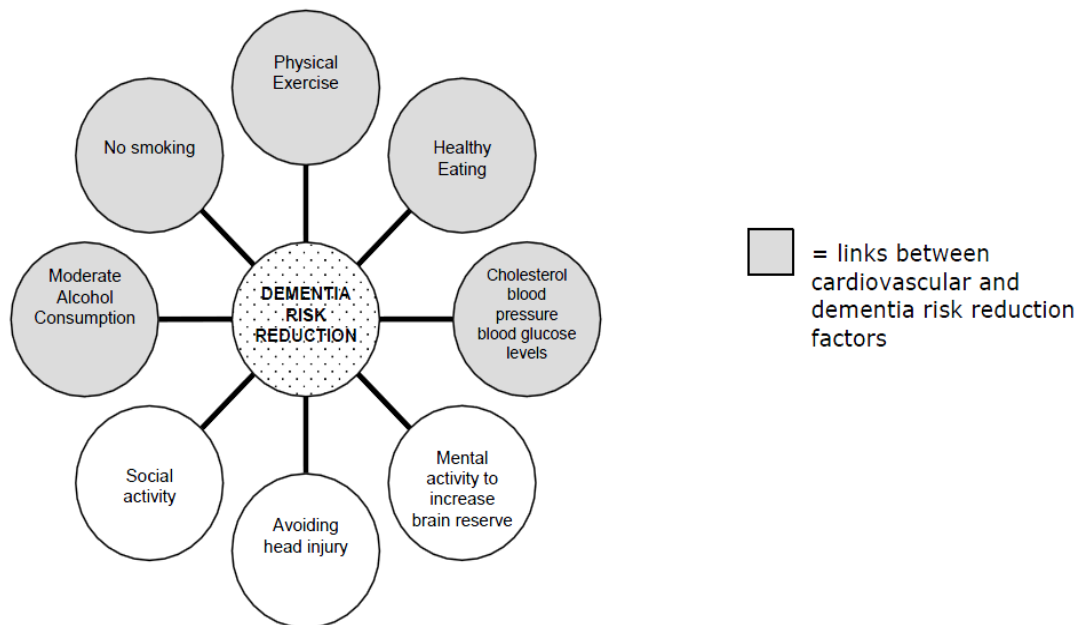
Source: 5. Alzheimer's Australia. Towards a National Dementia Preventative Health Strategy, August 2010

Established dementia - what can we do?

- Evidence for risk factor management includes:

  ❑ Hypertension

  ❑ Control diabetes – not as clear for Alzheimer's disease

  ❑ Regular exercise

- Managing other medical, dental and sensory co-morbidities - and try to reduce 'stressors'

Pharmacy Review

- Age >65 – 90% taking at least one medication with 3-5 medical conditions being treated
- Value of medication review in dementia patient
    - ❑ Polypharmacy - Assess impact of current chronic disease management medicines and side-effects
- Which drugs should we watch out for?
    - ❑ Acetylcholine is main neurotransmitter for new memories
    - ❑ Potential for 'Anticholinergic load' - - Veterans - Reducing the anticholinergic load - 2014.pdf – "Deprescribing"
- Acetylcholinesterase inhibitors (AChEIs) and other CNS (neuroleptic) agents
    - ❑ Cognitive function - may impact on BPSD

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Polypharmacy

- Polypharmacy - which drugs should we watch out for?

JOURNAL OF THE ROYAL SOCIETY OF MEDICINE

Table 1 *In-vitro* anticholinergic activity (at 10 nmol/L) of the 25 medications most commonly prescribed to elderly people in the USA (Adapted from Ref. 7)

Detectable atropine-like activity (ranked from high to low)	No detectable atropine-like activity
Cimetidine	Hydrochlorothiazide
Prednisolone	Propranolol
Theophylline	Salicyclic acid
Digoxin	Nitroglycerin
Nifedipine	Insulin
Frusemide	Methyldopa
Ranitidine	Ibuprofen
Isosorbide dinitrate	Diltiazem
Warfarin	Atenolol
Dipyridamole	Metoprolol
Codeine	Timolol
Dyazide	
Captopril	

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Acetylcholinesterase inhibitors* (AChEIs)

- AChEIs* established as first-line pharmacotherapy in mild-moderate Alzheimer's disease (AD)[6]
- Available in Australia: donepezil*, rivastigmine*, galantamine*
- Do not provide a cure
- Provide modest benefit in
  - ❑ Cognitive function
  - ❑ Activities of daily living
  - ❑ Behaviour
- Assess clinical state

6. Birks J. Cochrane Database Syst Rev. 2006; CD005593

*Please refer to the full PI for approved indications, dosages, adverse events and drug interactions for medicines used in Australia.

AChEIs* cont'd

- Adverse events include nausea, vomiting - even GI bleed - and diarrhoea
- 23% of Australians with mild-moderate AD use AChEIs[7]
- PBS criteria for reimbursement are complex[8]

  - Specialist initial diagnosis and MMSE results
    (PBS Restrictions on further prescribing lifted in 2013)
- Also available – Memantine (NMDA) in moderate-severe and can be combined in some cases

7. Alzheimer's Australia. The dementia epidemic: Economic impact and positive solutions for Australia.
8. Schedule of Pharmaceutical Benefits 2013

*Please refer to the full PI for approved indications, dosages, adverse events and drug interactions for medicines.

Session 3
Complications of dementia

- BPSD - what is it?

- Addressing BPSD and carer issues

- Assessment of concerns

- Behaviours of concern assessment

- How do we treat?

- How do we manage 'a change in behaviour'?

Case Presentation – Part 3

What is BPSD?

- **Behavioural & Psychological Symptoms of Dementia**
- <u>Symptoms</u> of disturbed perception (hallucinations), thought content (delusions) and mood (depression), anxiety
- <u>Behavioural</u> changes frequently occurring in patients with dementia
    - ❑ Wandering
    - ❑ Aggression
    - ❑ Sexual disinhibition
    - ❑ Screaming
    - ❑ Agitation
    - ❑ Shadowing

www.frontiersin.org/Dementia/10.3389/fneur.2012.00073/abstract
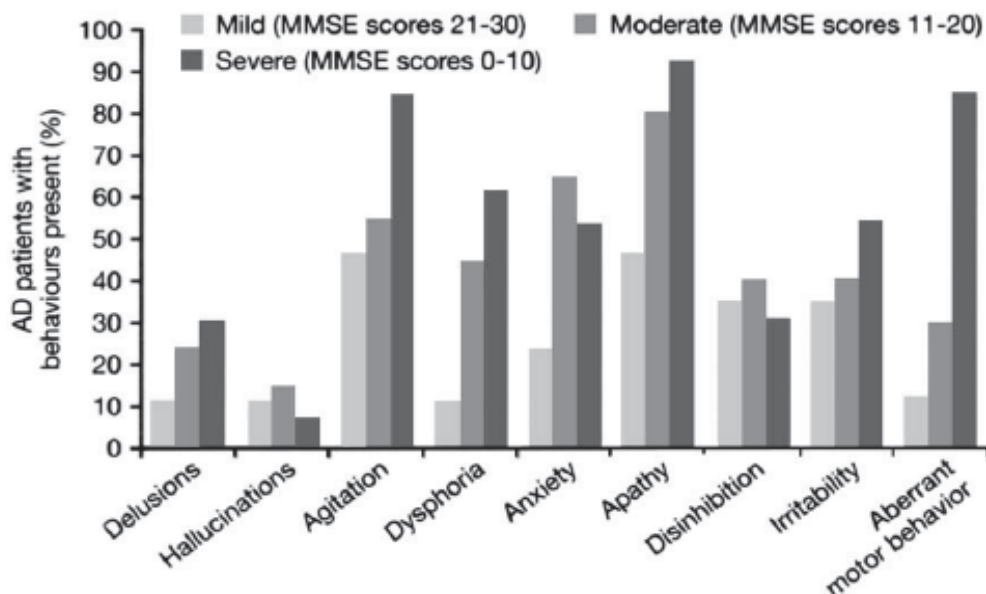

Figure 1. Presence of neuropsychiatric symptoms in patients with AD according to severity of disease (Adapted from Mega et al., 1996).

From: Grossberg. Int. Psychogeriatrics, 14:27-49

Behavioural and Psychological

Behavioural Symptoms
- *Physical and Verbal Aggression*
- *Agitation*
- Pacing
- Wandering
- Disinhibition
- Sexual disinhibition
- Screaming
- Tearfulness
- Swearing/Cursing
- Resistance to care
- Night time disturbance
- Physical violence

Psychological Symptoms
- *Delusions*
- *Hallucinations*
- Depression
- Apathy
- Sleeplessness
- Anxiety
- Shadowing
- Repetitive questioning/complaining
- Catastrophic reactions

Differential diagnosis of BPSD

- Delirium
  - Infection, constipation, pain, medication

- Medication
  - Anti-Parkinson medication
  - ACh medications

- Changes to the environment or routine
  - Institutional
  - Too much stimulation

Diagnosis of delirium

Characteristics	Delirium	Dementia
Onset	Acute to sub-acute	Insidious
Course	Fluctuation	Stable and progressive
Duration	Hours to days	Months to years
Attention	Fluctuates	Steady
Sensorium	Often impaired, can fluctuate rapidly	Clear until later stages
Etiology	Usually immediate cause	No immediate cause
Psychomotor activity	Increased, decreased or unpredictable	Usually normal
Cognitive function	Impaired, poor attention	Poor memory > attention
Perception	Hallucinations (visual), delusions – fleeting, not systematised	Simple delusions and hallucinations
Sleep/wake cycle	Disrupted or reversed	Fragmented

Adapted from: Manepalli N., et al., Primary Psychiatry Vol 14, No 8, 2007

Physical comorbidities of dementia

The following conditions occur significantly more frequently in people with dementia (particularly Alzheimer's disease) than in people of the same age without dementia:

- ❑ epilepsy
- ❑ falls
- ❑ delirium
- ❑ frailty
- ❑ malnutrition
- ❑ dental disease
- ❑ visual impairment
- ❑ sleep disorders
- ❑ urinary and faecal incontinence   (Kurrle, S. 2010, DCRC)

Aetiology of BPSD

- Biological
  - ❑ Alterations in neurotransmitter systems – Ach, Dopamine
  - ❑ Neuronal loss, tangles and plaques – VaD, CVA

- Unmet needs model

- ABC model -
  - ❑ Antecedents - Behaviour – Consequences*

- Stress threshold model:- under and over stimulation

www.dementiamanagementstrategy.com/Pages/ABC_of_behaviour_management.aspx *

# Underlying cause of disturbing behaviours

- Need to know past personality, occupation, etc.

- May be multifactorial e.g. insomnia
  - ❑ Can't find way back after going to toilet
  - ❑ Napping during the day

- May include issues relating to the family or carer
  - ❑ Limited understanding of dementia
  - ❑ Depression

Assess the Behaviour

Characterize the behaviour:

- Consider whether there is an underlying goal (e.g. exit-seeking) or misperception (e.g. misperceiving the corner of a room as a urinal, or another person's bed as one's own)
- Review the patient's psychiatric history, social history and premorbid personality
- Review the medication list
- Inquire about life events and the quality of premorbid relationships between carer and patient
- Examine the patient with attention to changes in mental status from baseline
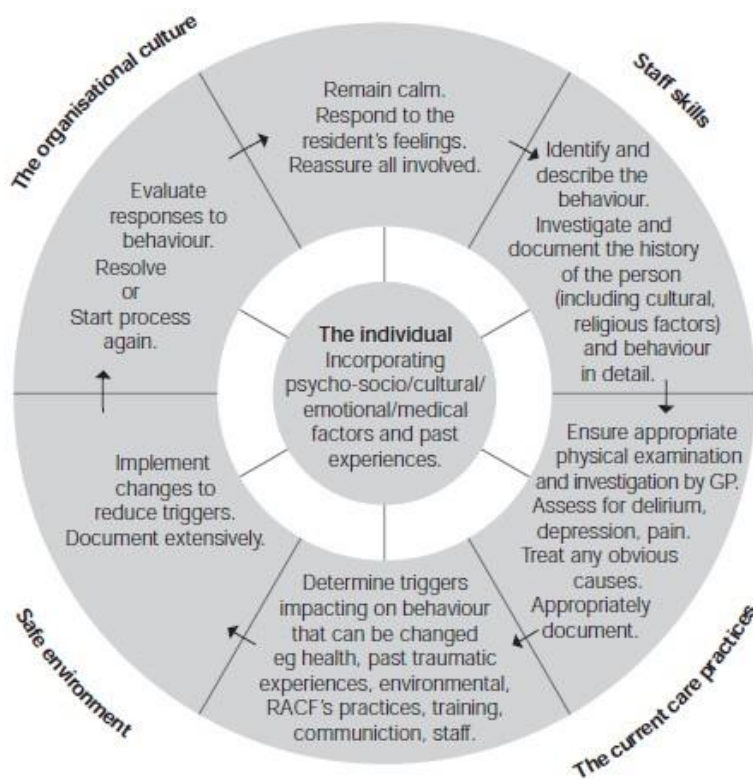
From NSW Health: Guidelines for working with people with challenging behaviours in residential aged care facilities, 2006
www.health.nsw.gov.au/policies/gl/2006/GL2006_014.html

Managing behavioural & psychological symptoms of dementia (BPSD) and co-morbidities

- Regular review and optimal management required
- Avoid polypharmacy where possible
    - ❑ Supervision of medication-taking will be required
    - ❑ Start low dose, titrate slowly, monitor for beneficial/adverse effects
- Depression
    - ❑ First line: social stimulation, activities and counselling
    - ❑ Antidepressant drugs may be appropriate
- Agitation / aggression / psychosis
    - ❑ First line: social or environmental manipulation, behaviour modification
    - ❑ Anxiolytic / Neuroleptic* drug therapy may be appropriate

    *not in patients with Dementia with Lewy bodies

Non-pharmacological management of dementia

- Education on non-pharmacological strategies is important:
    - ❑ Nursing and residential home staff
    - ❑ Informal carers and family

- Behavioural strategies
    - ❑ Regular routine
    - ❑ Reminders and repetition
    - ❑ Social activity, sensory stimulation

- Environmental strategies
    - ❑ Message systems
    - ❑ Clocks & date - though may not be of benefit
    - ❑ Home modifications (safe, comfortable, familiar, interesting)

Psychosocial treatments

Challenging behaviours[9]

- Evidence for aromatherapy, person-centred bathing, individualised music, gentle sounds, muscle relaxation training in managing agitation
- The "BPSD Guide" – a free iPhone / iPad app. for GPs and for Carers as "Care4Dementia"

  www.dementiaresearch.org.au/bpsdguide.html

Psychological symptoms

- Carer education, music, gentle exercise, recreation and validation therapy useful for psychological symptoms of dementia
- Humour therapy: SMILE Study - 20% reduction in agitation[10]

9. O'Connor et al., 2009   10. Low, L.F et al, BMJ Open, 2013

Behavioural symptoms

	Psychosocial Interventions	Medication*
Insomnia	Limit napping, exercise, cut out caffeine,	Give existing psychotropics in evening, melatonin
Wandering	Environmental change, exercise	Little evidence for medication
Aggression	Consider needs, stimulation and ABC models, communication, caregiver support	Antipsychotics, AChEIs, SSRIs, carbamazapine, memantine
Sexual disinhibition	Use needs model, access, privacy, redirection, tactile soothing, caregiver support	SSRIs, AChEIs, antipsychotics
Agitation	Reduce crowding, stimulation, exercise, distraction	Antipsychotics, carbamazapine, antidepressants

*Please refer to the full PI for approved indications, dosages, adverse events and drug interactions for medicines used in Australia.

Psychological symptoms

	Psychosocial	Medications*
Depression	CBT (mild - mod)	SSRIs
Psychosis	Clear communication, reassure	AChE inhibitors, Antipsychotics
Anxiety	CBT, exercise, diversion, reassure	SSRI Avoid benzodiazepines

*Please refer to the full PI for approved indications, dosages, adverse events and drug interactions for medicines used in Australia..

Pharmacological* treatment

- Antipsychotics – little evidence for long term (>3 /12 months) treatment
- AChEIs
- Memantine (NMDA)
- Antidepressants
- Anxiolytics - use of short-acting Benzodiazepines in acute cases, for short term only

    ❑ Oxazepam or Lorazepam   (Yaffe, K. et al. 2014)

- Medications used in BPSD – *start low and go slow*

*Please refer to the full PI for approved indications, dosages, adverse events and drug interactions for medicines used in Australia.

Who you can call

- Dementia Behaviour Management Advisory Service (DBMAS)
  - to assist GPs and carers of people with BPSD living in the community, or residential aged care facilities
  Tel: **1800 699 799** (24/7)

- National Dementia Helpline (Alzheimer's Australia)
  - various State Dementia and Memory Community Centres
  Tel: **1800 100 500** (Mon-Fri - business hours)

Session 4
The Patient, the Carer and the Burden of Care - Legal issues

- The Carer and the patient

- Driving

- Decision making & Legal issues

- Distress and palliation in dementia

- Practice and Community Nurse

- Who to call for help

Case Presentations – Part 4

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The Carers

- Carers as patients

  - ❑ Identifying distress

  - ❑ Options of self-report forms (Caregiver burden scale)
  - ❑ Counselling
    - ➢ Recognising carer as equal focus of treatment
    - ➢ Acknowledging and giving permission
    - ➢ Taking into account premorbid relationship – what is driving the care?
  - ❑ Drug treatment / referral

- Community support

  - ❑ Practice and Community Nurses

  - ❑ State Health, local community, other respite centres

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Carers as patients cont'd

- About 30% of Carers will develop a depressive disorder

- Carers experience physical, social and financial burdens

- Behavioural problems of patient can be very stressful

  - ❑ Sleep disturbance
  - ❑ Incontinence
  - ❑ Immobility/ falls
  - ❑ Repetitive / demanding behaviour
  - ❑ Aggression

- Spouse often more distressed than other family members

- High rates of anxiety, stress and burnout, with reduced life expectancy[11]

  11. Butler, R. Carers of people with dementia. *BMJ* 2008; 336

Education and support

- Carers may require:

  - ❑ Education with regard to the illness and its impact on families and carers
  - ❑ Assessment and management of physical and mental health problems
  - ❑ Assistance with organisation of respite care for patients or transition to residential care
  - ❑ Assistance with practical strategies to manage behavioural or cognitive problems

- Cognitive behavioural therapy:

  - ❑ Reduces burden of care
  - ❑ Delays institutionalisation and improve survival
  - ❑ Improves skills in managing patient behavioural problems

Assisting with care

- The Practice Nurse has become an invaluable team member, often identifying patients who have early dementia - when doing a house visit or in assisting the GP with a care management plan:

  - ❑ Assessing family or carer's ability to cope at home
  - ❑ Liaising with Community Nursing services
  - ❑ Helping with access to community support services to provide support to family / carers
  - ❑ Assisting with other medical needs of the patient

Functional Assessment

- Targeting services to ADL dysfunction

- Carer needs

- Driving ability

Activities of daily living (ADL)	Instrumental activities of daily living (IADL)
• Choosing appropriate clothes	• Competently performing usual roles (at work or home)
• Dressing	• Managing finances
• Bathing	• Keeping appointments
• Grooming	• Handling correspondence
• Toileting	• Travelling alone
	• Using household appliances
	• Participating in hobbies

Source: Directly reproduced from International Advisory Group, 1997.

Driving

1. Engage people with dementia as early as possible after diagnosis

2. Support people with dementia to make informed choice

3. Aim to build on effective partnerships between them, their families and health professionals

4. Introduction of sustained education campaigns by VicRoads report dementia, explanations of conditional licences, medical review requirements: www.racv.com.au/dementia – Dementia and driving ability

5. DriveSafe DriveAware – OT based iPad initiative www.rehabonroad.com.au/drivesafe-driveaware.aspx

6. Discuss all of the options – "to drive or not to drive" https://www.youtube.com/watch?v=4F9z8mPhcTw

Falls injury risks

- Age > 60yr. – 25% injuries due to a fall
  > 70yr. – 40% injuries due to a fall

- Previous falls

- Sensory decline

- Reduced limb strength / Balance

- Comorbidities
  - ❑ Lifestyle changes
  - ❑ Dental
  - ❑ Diet / Nutrition – vit. D, Folate B12 – s/e PPIs
  - ❑ Medicine review - Polypharmacy
  - ❑ Enhanced Primary Care plan

High Risk

Falls injury prevention

Falls injury prevention programs – e.g. iSOLVE project (2014) collaboration of Sydney Uni., Sydney North PHN and NSW Health

Prompted by costs of falls injuries and care ~ 5% of NSW Health budget - $560M. in 2007

Cochrane review:

- Polypharmacy – medicine review
- Home / RACF improvements
- Balance / need for regular exercise

See www.myagedcare.gov.au/healthy-and-active-ageing/preventing-falls-in-elderly

---

Patients in an RACF

- 'Falls' rates are higher ~ 50% of patients in first 6 months
- Increased cognitive impairment
- Polypharmacy
- Continence problems
- Vision / New environment
- Low Vit. D intake – lack of sun, medication
- Lack of exercise
- Wearing the right shoes
- Behaviour Management Care plan

Management Plan - Care Plan[12]

IDENTIFIED PROBLEMS	DETERMINED GOALS	MANAGEMENT TASKS	PERSON RESPONSIBLE
Impact of illness			
• Unsafe at home	Prevent accidents	Environmental intervention	Family/ carer/ GP/ ACAT
• Difficulty managing finances	Avoid long-term problems	Advice on legal issues	GP
• Difficulty driving	Maintain safety	Assessment of capacity	GP/ specialist/ OT
Symptoms of illness			
• Cognitive problems	Improve ADL and IADLs	Initiate acetylcholinesterase inhibitor and	GP/ specialist
• Apathy	Improve motivation	monitor for response/ adverse effects	GP/ specialist
• Problems with behaviour	Improve social skills	Behavioural intervention	ACAT/ GP/ specialist
Lifestyle factors			
• Reduced social contact	Increase social activity	Refer to community programs	GP/ patient/ carer
• Reduced exercise	Regular gentle exercise	Exercise program	GP/ OT/ patient
Capacity to self-manage			
• Reduced capacity to perform social, family and domestic roles	Increase supports	Engage family support/ community services	Family/ patient/ GP/ ACAT

Notes: ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living; ACAT = Aged Care Assessment Team; OT = Occupational Therapist.

12. Australian Government Dept of Health and Ageing. Chronic Disease Management Medicare Items
www.health.gov.au/internet/wcms/publishing.nsf/Content/pcd-programs-epc-chronicdisease.htm.

Things to do: Checklist

RACGP checklist includes:

- Presenting behaviour and characteristics
- Physical / psychological health status
- Systems review
- Medication review - Scenario
- Mental state
- Pre-dementia personality, hobbies, occupation, education
- Social and carer assessment
- Physical environment

Legal issues in dementia

- Goal is to promote autonomy and protect from abuse and exploitation
- Never write "Mrs. X has Dementia and lacks CAPACITY" –capacity is decision specific
- Helps planning, routine care
- Note that there may be State differences with the concept of capacity and other legal definitions
  - NSW Govt. - Capacity Assessment Principles Capacity Toolkit NSW 2015.pdf
  - WA Govt. www.publicadvocate.wa.gov.au/G/guardianship
  - VIC Govt. www.vcat.vic.gov.au
  - SA Govt. www.sahealth.sa.gov.au
  - Australian Govt. www.alrc.gov.au/publications/equality-capacity-and-disability-commonwealth-laws/capacity-and-decision-making
  - QLD Govt. www.qcat.qld.gov.au/matter-types/

FIGHT ALZHEIMER'S SAVE AUSTRALIA
FIGHTDEMENTIA.ORG.AU

dta Dementia Training Australia

UNSW SYDNEY

Advanced Care Planning (ACP)

- Incorporate ACP as part of routine care
- Assess capacity to appoint a representative and complete an advanced care plan
- Support discussion and documentation of ACP
  - ❑ Discuss the person's wishes with relatives/carers, 'guardian'/ legal representative
  - ❑ Enduring Guardian is someone "legally appointed to make lifestyle and health care decisions, when the capacity to make decisions is assessed to be markedly reduced"
- Review plan regularly or when health status changes significantly (can be revoked at any time as long as the person is capable)

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Advanced Care Planning cont'd

- Advanced Care Planning (ACP)
  - ❑ ACP will often lead to the completion of an ACD
  - ❑ Reflects, discusses and enables a person to plan for their future medical treatment and care, e.g. "NFR"
- Advanced Care Directives (ACD)
  - ❑ Functions as an extension of the Common Law right to determine one's future treatment for health and personal care – what you would not like to have
  - ❑ Legally binding documents Australia-wide
    - ➢ www.racgp.org.au/yourpractice/business/tools/support/acp/
    - ➢ www.mywishes.org.au

Palliation and management of severe distress in dementia

- Palliative Care of the dementia patient

- Pain management
  - ❑ Overall balance in managing distress
  - ❑ Identify the causes of distress
    - ➢ Management of pain
    - ➢ Management of depression

Who to call

- Local Aged Care Assessment Team – <u>ACAT</u> (as at Feb 2016)
  - Contact My Aged Care – Tel: **1800 200 422** (Mon-Fri - business hours)
  - Online via the referral portal www.myagedcare.gov.au/

- State Public Hospitals - Geriatric assessment / Memory Clinics

- CDAMS – Cognitive and Dementia Memory Service (VIC.)
  A specialist multidisciplinary approach to dementia care

- Dementia Behaviour Management Advisory Service (DBMAS)
  -to assist carers of people with BPSD living in the community or
  residential facilities. **Tel: 1800 699 799 (24/7)**

- National Dementia Helpline (Alzheimer's Australia)
  -various State Dementia and Memory Community Centres
  Tel: 1800 100 500 (Mon-Fri - business hours)

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Summary notes - NH&MRC Clinical Practice Guidelines for Dementia

www.mja.com.au/journal/2016/204/5/clinical-practice-guidelines-dementia-Australia

- About 9% of Australians aged 65 years and over have a diagnosis of dementia;
- Clinical practice guidelines aim to enhance research by synthesising recent evidence for health and aged care professionals;
- New clinical practice guidelines and principles of care for people with dementia detail the optimal diagnosis and management in community, residential and hospital settings;
- The guidelines emphasise timely diagnosis; living well with dementia and delaying functional decline; managing symptoms through training staff in how to provide person-centred care and using non-pharmacological approaches in the first instance; and training and supporting families and carers to provide care.

IMPROVING OUTCOMES FOR A TIMELY DIAGNOSIS AND MANAGEMENT OF DEMENTIA IN GENERAL PRACTICE

Reinforcing Activity Form

Complete only after you have attended all sessions of the ALM
NB: Both sides of the form must be completed <u>to obtain your RACGP Category 1 points</u>

Surname: _____ First Name: _____

QI&CPD No:_____*(must be filled in)*

1) What did you hope to achieve by attending this activity?

_____

_____

_____

_____

_____

2) What was / were the key message/s you obtained from this activity stream?

_____

_____

_____

_____

3) What changes will you make to your clinical practice as a result of this activity?

_____

_____

_____

_____

_____

4) How will you incorporate these changes into your practice?

_____

_____

_____

_____

_____

5) How will the safety of your practice be improved by you attending this ALM?

_____

_____

_____

_____

_____

PLEASE RETURN THIS COMPLETED FORM WITHIN 2 WEEKS
FROM THE DATE OF THE WORKSHOP:

Email: L.Nattrass@unsw.edu.au

or

Fax: 02 9385-2200

IMPROVING OUTCOMES FOR A TIMELY DIAGNOSIS AND MANAGEMENT OF DEMENTIA IN GENERAL PRACTICE

Evaluation Form

It is a requirement that you demonstrate reflection and reinforcement of the key learning outcomes.
NB: Please complete this form and return it to the workshop organizers to obtain your RACGP Category 1 points

DELEGATE DETAILS:

Surname: _____ First Name: _____

QA No: _____ *(must be filled in)* Email: _____

Please tick the appropriate box

	1. Rate how well the activity's stated learning outcomes were met	Not met	Partially met	Entirely met
a.	Use the current clinical guidelines for the diagnosis and management of dementia in general practice (NH&MRC 2016)			
b.	Distinguish between dementia and other diseases, including delirium			
c.	Implement strategies for family and carers, in dealing with the impact of a patient living with dementia, utilizing local community support and services available			
d.	*Patient safety* - Implement a system in the practice using screening tools for all patients over 75 years with memory problems, cognitive impairment and depression			
2.	Rate the extent to which your learning needs were met			

3. **Rate the extent to which this activity is relevant to your general practice**

❑ Not relevant

❑ Partially relevant

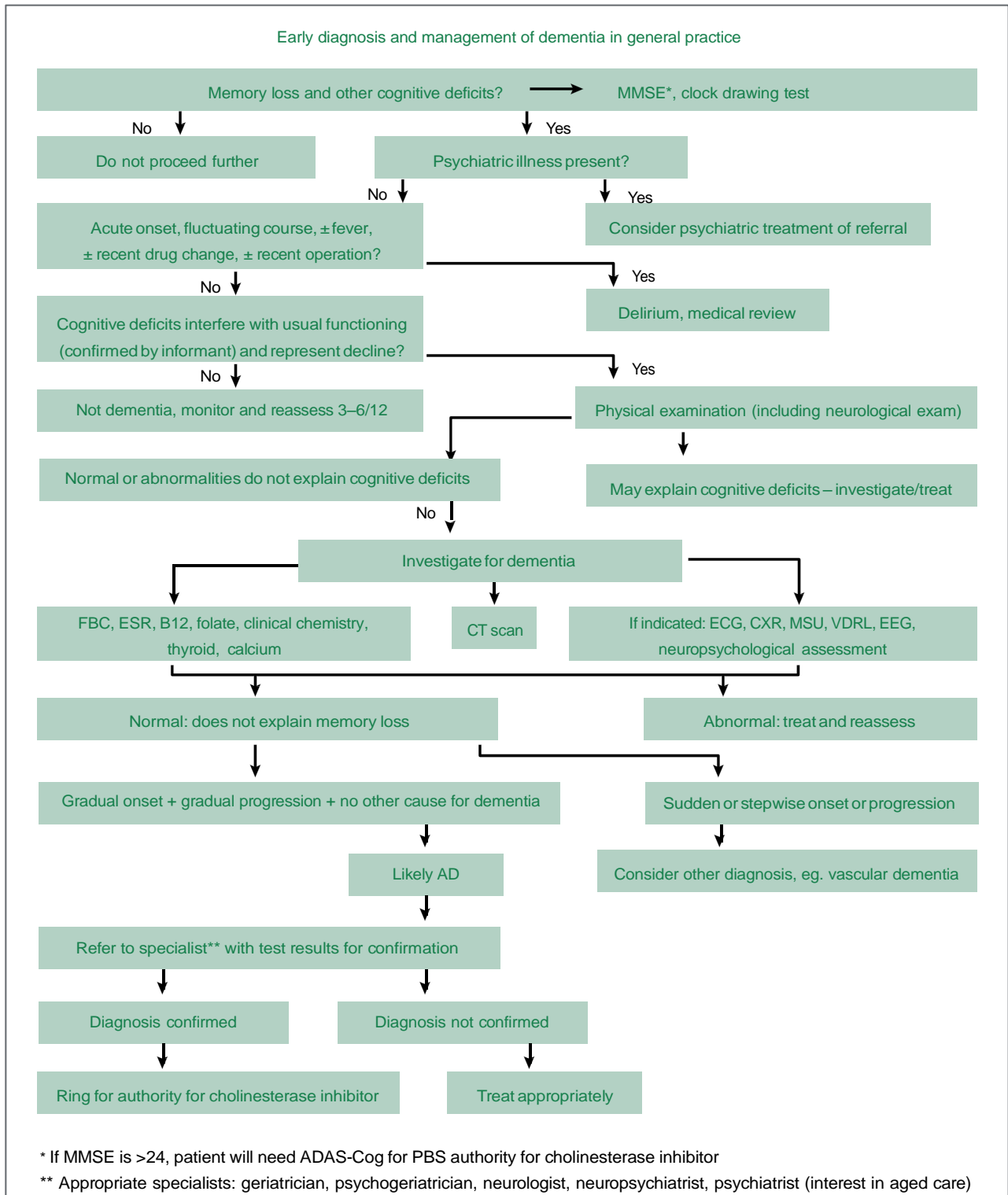❑ Entirely relevant

4. **Summative comments about this activity:**

_____

_____

_____

5. **Recommendations for improving this activity:**

_____

_____

_____

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ASSESSMENT TOOLS

Assessment algorithm and assessment form

This assessment algorithm summarises the assessment and diagnosis of dementia.

Early diagnosis and management of dementia in general practice

Memory loss and other cognitive deficits? → MMSE*, clock drawing test

No → Do not proceed further

Yes → Psychiatric illness present?

No → Acute onset, fluctuating course, ± fever, ± recent drug change, ± recent operation?

Yes → Consider psychiatric treatment of referral

Yes → Delirium, medical review

No → Cognitive deficits interfere with usual functioning (confirmed by informant) and represent decline?

Yes → Physical examination (including neurological exam)

No → Not dementia, monitor and reassess 3–6/12

Normal or abnormalities do not explain cognitive deficits

May explain cognitive deficits – investigate/treat

No → Investigate for dementia

- FBC, ESR, B12, folate, clinical chemistry, thyroid, calcium
- CT scan
- If indicated: ECG, CXR, MSU, VDRL, EEG, neuropsychological assessment

Normal: does not explain memory loss

Abnormal: treat and reassess

Gradual onset + gradual progression + no other cause for dementia

Sudden or stepwise onset or progression

Likely AD

Consider other diagnosis, eg. vascular dementia

Refer to specialist** with test results for confirmation

Diagnosis confirmed

Diagnosis not confirmed

Ring for authority for cholinesterase inhibitor

Treat appropriately

* If MMSE is >24, patient will need ADAS-Cog for PBS authority for cholinesterase inhibitor

** Appropriate specialists: geriatrician, psychogeriatrician, neurologist, neuropsychiatrist, psychiatrist (interest in aged care)

Adapted with permission: South East Sydney Division of General Practice, 2009

This assessment form can be used to assess Behaviours of Concern in people with dementia.

People with dementia and Behaviours of Concern – assessment form

Patient's name:_____   Date of birth:_____

Presenting behaviour and characteristics (including duration, frequency, antecedents, consequences)

_____
_____
_____

Physical/psychological health status

Exclusion of delirium	Considered	Systems review	Reviewed
Infections		Eyes (spectacles, reduced acuity)	☐
Respiratory	☐	Ears (hearing aid, wax, audiology)	☐
Urinary	☐	Nutrition (vitamin deficiency	☐
Neurological	☐	dentition, oral hygene, swallowing,	
		appetite, hydration, diet, aspiration)	
Metabolic disorders		Continence (bladder distension,	☐
Electrolyte disturbance	☐	faecal impaction)	
Renal failure	☐	Mobility	☐
Hepatic failure	☐	Level of functioning	☐
Vascular disease		Pain	☐
Hypertensive encephalopathy	☐	Sleep patterns	☐
Shock	☐		

Hypoxia
Hypotension ☐
Cardiac failure ☐
Carbon monoxide poisoning ☐

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

Endocrine disorders
Hypo– or hyper– thyroidism ☐
Hypo– or hyper– adrenocorticism ☐
Diabetes ☐

_____
_____
_____
_____
_____
_____

Drugs
Alcohol ☐
Withdrawl ☐
Cholinergic drugs ☐
Psychotropics ☐
Cardiac drugs (beta blockers) ☐

Mental state

*Appear*ance (stance, facial expression, dishevelled)   _____

Toxins
Heavy metals ☐
Pesticides ☐

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

Trauma
Head trauma ☐
Subdual haematoma ☐
Heat stroke ☐
Postoperative ☐

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	**Carer assessment**
(support network, physiccal supports, financial support, lifestyle/cultural issues, social activities)	(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)	☐	---
Environmental stimulation (level of interest orienting, cues mouse level individual alternation)	☐	---

Screening tests for assessing cognitive impairment

Mini-Mental State Examination (MMSE)

The MMSE[1] is one of the most widely used clinical instruments for quickly detecting cognitive impairment and assessing its severity, as well as monitoring cognitive changes over time. A MMSE score is usually required to establish eligibility for access to subsidised acetylcholinesterase inhibitors through the Australian PBS.

 Advantages include:

- portable—requires only a pen and paper for administration

- provides a numerical score which is often used as a basis for classifying severity of cognitive impairment. The scoring system may also be helpful in following change over time

- does not require specific qualifications to administer and can therefore be used by a wide variety of personnel in various settings (with some training).

The MMSE can be influenced by pre-morbid intelligence, social class, physical disability, age, gender & education—dementia may be missed in some individuals & individuals without dementia may be misclassified. Another disadvantage is that it takes about 10–15 minutes to administer, and is therefore impractical for use within a standard GP consultation.

The MMSE cannot be reproduced here due to copyright. Official printed copies and information about the test are available from Psychological Assessment Resources (www.minimental.com).

The test includes questions about:

- orientation

- registration

- attention and calculation

- recall

- language.

A total score of less than 24 out of the maximum total of 30 has a reasonable sensitivity (80-90%) and specificity (80%) for discriminating between dementia and normal controls.

[1]Folstein M., Folstein S, & McHugh P, 1975

Clock drawing test

The clock drawing test evaluates cognitive function. It was initially introduced as an indicator of constructional apraxia, and was later proposed as a screening test for dementia. It is an important component (subscale) in some other tests, such as the GPCOG.

Advantages include:

- provides a rapid screening method that respondents may find more interesting (& less insulting) than 'childish' items included in other tools

- may be more suitable for use with people from culturally and linguistically diverse backgrounds than verbally-based items in other tools

- may be useful as an adjunct to other assessment tools &/or as part of the diagnosis & care planning process.

Although the clock drawing test easily differentiates 'grossly abnormal' performance from 'normal' performance, gradations of abnormal performance are difficult and subjective to establish. Indeed, establishing a scoring system for distortions in clock drawing is complex, and many scoring systems have been proposed. The test is unsuitable for people with visual impairments or non-cognitive motor impairments, and may be affected by education or pre-morbid intelligence level. It is unlikely to be sufficient in isolation as a screen for dementia.[1]

The person undergoing testing is asked to:

- draw a clock (either on a blank sheet of paper or a piece of paper with a circle already drawn on it)

- put in all the numbers

- set the hands at a specific time (e.g. ten past eleven)

Scoring:

There are a number of scoring systems for this test. A simple system proposed by Shua-Haim[2] *et al.* awards one point for each of the following:

- approximate drawing of the clock face

- presence of numbers in sequence

- correct spatial arrangement of numbers

- presence of clock hands

- hands showing approximately correct time

- hands depicting the exact time.   .

[2]Shua-Haim J, Koppuzha G, Shua-Haim V, Gross J (1996)

General Practitioner Assessment of Cognition (GPCOG)

The GPCOG was developed for use as a brief screening tool in general practice in Australia[1]. It is recommended by the NSW Health care of patients with dementia in general practice guidelines.

Benefits include:

- assesses cognitive impairment and allows a brief assessment of functional status

- can be administered within a standard GP consultation (approximately 7 minutes to administer)

- includes a cognitive test and informant questionnaire – either can be used alone with only a slight loss in psychometric properties

- the informant section can be used alone if language problems preclude cognitive testing.

The GPCOG tool is not designed to monitor changes in cognitive function over time, and does not discriminate between people with low or very low function. Results of the test may be influenced by: impaired performance due to dysphasia, sight impairment, deafness, poor educational level, cultural factors and awareness of being tested or fear of testing; or factors that may overcome decreased cognition such as higher pre-morbid intelligence and education.[3]

The official GPCOG website[4] **www.gpcog.com.au** aims to support GPs in administering the GPCOG and to facilitate screening for dementia and cognitive impairment.

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[3]Brodaty H, Pond D, Kemp NM, et al. The GPCOG: a new screening test for dementia designed for general practice. *Journal of the American Geriatrics Society*, 2002; 50:530-534

[4]The University of New South Wales, Dementia Collaborative Research Centre – Assessment and Better Care (2009)

Administration

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)

	Correct	Incorrect
Time Orientation		
2. What is the date? (exact only)	☐	☐
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 Street	☐	☐
Kensington	☐	☐

___

Scoring guidelines

Clock drawing: For a correct response to question 3, the numbers 12, 3, 6, and 9 should be in the correct quadrant 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 5-10 years ago…*"

___

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

___

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:

- Consider that 3 or less = cognitively impaired.

___

[5]Brodaty H, Pond D, Kemp NM, et al. The GPCOG: a new screening test for dementia designed for general practice. *Journal of the American Geriatrics Society*, 2002; 50:530-534

The Rowland Universal Dementia Assessment Scale (RUDAS): A Multicultural Cognitive Assessment Scale

The RUDAS[6] was developed as a validated cognitive assessment tool for use with people across cultural and language groups. It is currently used clinically in New South Wales, South Australia, Victoria and New Zealand. Advantages include:

- tests multiple cognitive domains

- portable and easily administered by primary health care clinicians

- appears not to be affected by gender, years of education, differential performance factors, or preferred language

- easily administered in languages other than English and appears to be culturally fair, provided suitable interpreter services are available.

Administration

1. Memory: I want you to imagine that we are going shopping. Here is a list of grocery items. I would like you to remember the following items which we need to get from the shop. When we get to the shop in about 5 minutes time I will ask you what it is that we have to buy. You must remember the list for me:

- tea

- cooking oil

- eggs

- soap.

Please repeat this list for me (ask person to repeat the list 3 times. If person did not repeat all four words, repeat the list until the person has learned them and can repeat them, or, up to a maximum of five times).

Scoring: This is the learning part of the memory question. There are no points for this part of the question but the memory recall component later in the test has a maximum score of 8 points.

2. Body Orientation: I am going to ask you to identify/show me different parts of the body

- show me your right foot

- show me your left hand

- with your right hand touch your left shoulder

- with your left hand touch your right ear

- which is (point to/indicate) my left knee

- which is (point to/ indicate) my right elbow

- with your right hand point to/ indicate my left eye

- with your left hand point to/indicate my left foot

Scoring: Correct = 1, incorrect = 0. There are no half-marks for a partially correct response. Once the person correctly answers 5 parts of this question, do not continue as the maximum score is 5.

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[6]Storey et al. (2004). The Rowland Universal Dementia Assessment Scale (RUDAS): a multicultural cognitive assessment scale. *International Psychogeriatrics* (2004), 16:1, 13–31

3.Praxis (fist/palm): I am going to show you an action/exercise with my hands. I want you to watch me and copy what I do. Copy me when I do this… [demonstrate action – put one hand in a fist, and the other hand palm down on the table or your knees and then alternate simultaneously.] Now do it with me. I would like you to keep doing this action at this pace until I tell you to stop [approximately 10 seconds or 5 – 6 sequences, demonstrate at moderate walking pace.
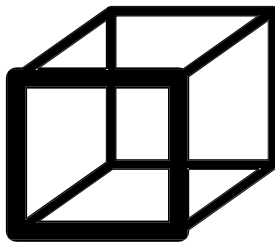
Scoring:
Normal [i.e. very few if any errors; self-corrected; progressively better; good maintenance; only very slight lack of synchrony between hands] = 2.
Partially Adequate [i.e. noticeable errors with some attempt to self-correct; some attempt at maintenance; poor synchrony] = 1.
Failed [cannot do the task; no maintenance; no attempt whatsoever] = 0

4. Drawing: Please draw this picture exactly as it looks to you (show cube on cue card or draw on unlined paper).

Scoring: Has test taker drawn a picture based on a square? (i.e.There is a square somewhere in the drawing) Yes = 1; No = 0.

Do all internal lines appear in test taker's drawing? Yes = 1; No = 0

Do all external lines appear in test taker's drawing? Yes = 1; No = 0

5.Judgement: You are standing on the side of a busy street. There is no pedestrian crossing and no traffic lights. Tell me what you would do to get across to the other side of the street safely (if person gives incomplete answer use prompt: "Is there anything else you would do?"). Record exactly what patient says and circle all parts of response which were prompted.

Scoring: Did person indicate that they would look for traffic? Yes = 2; Yes, prompted = 1; No = 0.
Did person make any additional safety proposals (e.g. be careful, ask for help, keep looking for traffic while crossing, walk quickly)? Yes = 2; Yes, prompted = 1; No = 0.

6.Memory recall: We have just arrived at the shop. Can you remember the list of groceries we need to buy?
(Prompt: If person cannot recall any of the list, say "The first one was 'tea'," and do not score for that item.
Only use the prompt 'tea' if no items are recalled; do not prompt if other items are mentioned.)

Scoring: 2 points each for any item recalled unprompted.

7.Language: I am going to time you for one minute. In that one minute, I would like you to tell me the names of as many different animals as you can. We'll see how many different animals you can name in one minute.
(Repeat instructions if necessary. Test administrator writes down names of animals listed.)

Scoring: One point for each different animal named (only score once per animal; no additional score if an animal is repeated). Maximum score for this item is 8. If person names 8 new animals in less than one minute there is no need to continue.

Total score
Add up the scores for each item to get a total score out of 30. Any score of 22 or less should be considered as possible cognitive impairment and referred on for further investigation by the relevant physician.

Caregiver assessment

This form can help to identify and monitor any changes in caregiver stress over time. This may be helpful when trying to access community services.

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	1	2	3	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.

Reproduced from American Family Physician 2002 VOLUME 65, NUMBER **11** / JUNE **1,** 2002   www.aafp.org/afp

Notes

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