



DEMENTIA TRAINING STUDY CENTRES

Advancing practice in the care of people with dementia

RESOURCE FOR AGED CARE ASSESSMENT CLINICIANS

DEMENTIA TRAINING STUDY CENTRES

Advancing practice in the care of people with dementia

RESOURCE FOR AGED CARE ASSESSMENT CLINICIANS

Authors

Ms Deb Ryan RN, Aged Care Assessment Team clinician/Aged Care Assessment Service Education Officer, Hume Regional Aged Care Assessment Service

Ms Debbie Senior RN, Master of Public Health, State Training Officer for the Aged Care Assessment Program, Victorian Department of Health

Dr Margaret Winbolt RN PhD, Director, Victoria and Tasmania Dementia Training Study Centre

Ms Deb Court Occupational Therapist, currently working as an Aged Care Assessment team clinician in a dementia liaison role, North-West Aged Care Assessment Service, Melbourne Health.

This resource is developed by the Dementia Training Study Centres (DTSC) program in collaboration with staff from the Aged Care Assessment Program (ACAP).

The ACAP is jointly funded by the Commonwealth and Victorian Governments
www.dtsc.com.au

© 2013 Dementia Training Study Centres

The Dementia Training Study Centres are supported by the Australian Government.

Contents

Introduction	4
1 Evident cognitive impairment but no formal diagnosis	5
2 Capacity	11
3 Behaviour or Psychological Symptoms of Dementia (BPSD)	15
4 Fitness to drive	10
5 Hoarding and squalor	23
6 Major neurocognitive disorder	26
7 Comparison of the Clinical Features of Delirium, Dementia, and Depression	27
8 Glossary	28

Introduction

Dementia is reported as the most common primary health condition of people presenting for an Aged Care Assessment Team (ACAT) assessment (more than twice as often as other conditions). The Aged Care Assessment Program (ACAP) National Training Resources state that ‘ACAT assessors must have a sound understanding of dementia, be skilled in its recognition and assist clients and carers to make informed decisions in order to plan for their deteriorating condition’.

This resource has been developed by the Dementia Training Study Centres (DTSC) program, in collaboration with staff from the ACAP to help clinicians to improve access to services for people with dementia who live in the community, and their carers. It complements existing dementia training such as the recommended online dementia training modules at www.dtsc.com.au.

As aged care assessment clinicians, it is very easy to feel overwhelmed by the amount of information collected when trying to reach a recommendation. At these times a focus on process can help clinicians identify and sort through the information relevant to particular aspects of a client’s assessment.

Problem solving is defined as ‘a process that uses the steps of data collection, problem identification, goal-setting, planning, implementation and evaluating care solutions’. This approach will be familiar to ACAT clinicians who are involved in problem solving on a day to day basis.

The key to effective problem solving is to ask the appropriate questions. These resources provide a set of questions with associated tips, alerts and resources, to support the assessment of people with dementia for:

- 1 Cognitive impairment (where no formal diagnosis)
- 2 Capacity
- 3 Behaviour and Psychological Symptoms of Dementia (BPSD)
- 4 Fitness to drive
- 5 Hoarding and squalor

Information about each of these topics is organised in relation to the following questions:

- ▶ What is the issue of concern for people contacting the program?
- ▶ Why and for whom are the issues of concern?
- ▶ What do we know about the issues of concern?
- ▶ What do we know about the people involved?
- ▶ What do those involved want to see occur?
- ▶ What are the options available for the issues identified?
- ▶ Who will do what?
- ▶ What follow-up is required?

These resources should be used in the context of the ACAP Guidelines 2014 and the ACAP National Training resources and are intended as a supplement to existing dementia training.

It is important to ask at each step during the assessment process:

What do those involved want to see happen?

The answers can alert clinicians to barriers to effective implementation of care-planning options; possible conflicts that may exist between the client and family members; unrealistic expectations of the ACAT clinician; and any other misperceptions people may have about the ACAP that may need to be addressed.

Case conferencing provides an ideal opportunity to monitor and reflect on the processes used to arrive at a recommendation and care plan. The ACAP National Training resources suggest using the SBAR (situation, background, assessment and recommendation) technique.

ISSUE 1

Evident cognitive impairment but no formal diagnosis

1.1 What do I need to know about the issue of concern?

Dementia is now called major neurocognitive disorder but the term dementia will continue to be used frequently.

The new terminology, and amended criteria, was introduced in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), published by the American Psychiatric Association in May 2013 (see page 32).

Major neurocognitive disorder includes Alzheimer's disease, cerebrovascular disease, frontotemporal dementia, Lewy Body disease, Huntington's disease, traumatic brain injury and other causes of significant cognitive impairment.

Major neurocognitive disorder now can be diagnosed in the absence of memory impairment if other areas of cognitive function are impaired. In addition there is a new diagnostic category, mild neurocognitive disorder, which was previously known as mild cognitive impairment.

The clinician needs to know:

- ▶ What the term cognitive impairment means
- ▶ What dementia is
- ▶ The symptoms of dementia
- ▶ How to differentiate between dementia, depression, and delirium
- ▶ What screening tools are available
- ▶ The importance of differentiating between the causes of major neurocognitive disorders (dementias):
 - Alzheimer's disease
 - Cerebrovascular disease
 - Mixed cerebrovascular disease-Alzheimer's disease
 - Frontotemporal Dementia
 - Lewy Body disease
 - Huntington's disease
 - Less common dementias
- ▶ The importance of identifying conditions that may result in a neurocognitive disorder being diagnosed
- ▶ How these conditions are diagnosed
- ▶ The clinician's role in this process:

ACAT clinicians do not make a formal diagnosis. The assessment process involves gathering information that will inform a diagnosis and lead to enhanced outcomes for clients and their carers/family.

The assessment clinician must understand what information needs to be gathered for the diagnostic process.

- ▶ Treatment and management options
- ▶ Pharmacological
- ▶ Rules governing prescribing and the Pharmaceutical Benefits Scheme (PBS)
- ▶ Non-pharmacological.

The assessment clinician's first responsibility is to understand the cause of the impaired cognition. Where possible clients should be encouraged to include family and carers in the ACAT assessment.

1.2 Why is this of concern to me?

The clinician needs to consider the importance of:

- ▶ Client independence
- ▶ Person-centred approach
- ▶ Client safety
- ▶ Nutritional risk
- ▶ Access to treatment, support and education
- ▶ Client capacity and decision-making ability
- ▶ Obtaining accurate information that supports working with the client, carers and family regarding safety, support and future planning
- ▶ Identifying suitable supported accommodation options for the client or supporting the client and his/her carers to remain at home
- ▶ A diagnosis may be necessary for insurance purposes, medical expenses and driver licence authority.

1.3 For whom else might this be of concern?

Others who may be concerned:

- ▶ Client
- ▶ Family/carers
- ▶ Community agencies such as banks, shops, hairdressers.

1.4 What do I need to know about the client?

The clinician needs to know the following information about the client:

- ▶ The client's health status, history and capabilities
- ▶ Legal considerations, for example, the person's capacity to appoint an enduring power of attorney; and if there is a substitute decision maker, discuss advance care directives
- ▶ The history of cognitive decline. When did the symptoms begin?
- ▶ Onset. Was it slow and insidious or sudden?
- ▶ Presentation. Is there fluctuation, gradual decline or stepwise progression (sudden decline, with improvement)?
- ▶ Impact of the decline on the client and others.

1.5 What do those involved want to see occur (what are their expectations)?

What is the desired outcome?

Ask the client and those involved if they want further investigations in order to determine a diagnosis and possible treatment options and consider whether this will be possible.

- ▶ Clarifying expectations about diagnosis may be challenging due to: the impact of the disease process on the client resulting in changes to his/her insight and capacity
- ▶ The availability of several drugs available that can slow the disease progression in some people, (see 'Resources' on page 11 for further information)
- ▶ Carer stress levels
- ▶ Carer emotional status (feeling guilty, denial, length of time in the care role)
- ▶ Lack of available supports for the client
- ▶ Family dynamics/relationships
- ▶ Level of anxieties and fear for client with reduced capacities
- ▶ Limitations of a one off, comprehensive ACAT assessment.

1.6 What options are available to me?

The clinician needs to consider the following options:

- 1 A comprehensive assessment including medical history, physical status and history of the cognitive decline. Include information from the client, general practitioner (GP), and family
- 2 A cognitive screen using recognised screening tools, for example, Standardised Mini-Mental State Examination (SMMSE), Rowland Universal Dementia Assessment Scale (RUDAS), Geriatric Depression Scale (GDS), Informant Questionnaire on Cognitive Decline (IQCODE), and the clock drawing test
- 3 Use of culturally sensitive cognitive screening and assessment tools.
- 4 Referral to the client's GP for medical assessment or talk to the GP to confirm diagnosis
- 5 If the diagnosis proves complex, referral to a Geriatrician or specialist clinic/service:
 - Memory clinics or Cognitive, Dementia and Memory Service (CDAMS) in Victoria
 - Geriatrician/neurologist
 - Aged Psychiatry Services.

When presented with moderate to severe cognitive impairment it is often challenging to obtain a diagnosis and many clients never receive a formal diagnosis. (See Alzheimer's Australia (AA) help sheets for the stages of disease.)

Many clients will progress through their condition without seeking a formal diagnosis until later stages of the disease.

Some clients will not allow or tolerate an extended assessment and diagnostic process so it may be necessary to undertake a shorter assessment.

1.7 Who will do what?

Identify who will do what

Diagnosing the cause of cognitive impairment is a complex process and can involve many health professionals each of whom has a specific role. The process of diagnosis must involve the client's family and carers where possible.

The client's GP, for example:

- Is the source of the client's medical history
- Can initiate dementia screen (involves blood work up, relevant X-rays, CTs, medication review)
- Can provide referral to specialist services such as memory clinics, geriatrician, neurologist
- Can refer to the ACAT for further assessment and support.

Dementia screen

Dementia screen

A dementia screen (blood and urine tests) assists in identifying possible illnesses which could be responsible for the confusion. Examples of such illness are diabetes, hypothyroidism, infections, nutritional deficiencies, hormone imbalances, and reactions to medications.

Common blood tests include:

- Full Blood Examination (FBE)
- Random and/or Fasting blood sugar (R/FBS)
- Lipid studies
- Urea and Electrolyte levels (U & Es)
- Liver Function Test (LFT)
- Thyroid Function Test (TFT)
- Vitamin B12 and folate levels
- Homocysteine
- Serum calcium and phosphate
- Syphilis serology.

Potentially reversible causes of cognitive decline

Other specialised tests:

- ▶ Chest X-ray
- ▶ Electrocardiograph (ECG)
- ▶ Computerised Axial Tomography (CAT Scan).

Potentially reversible causes of cognitive decline:

- ▶ Normal pressure hydrocephalus
- ▶ Neoplasm (tumour)
- ▶ Vitamin deficiency
- ▶ Endocrine disorder
- ▶ Metabolic disorder
- ▶ Toxins
- ▶ Some infections
- ▶ Depression 'pseudo dementia'.

Irreversible causes of cognitive decline:

- ▶ Alzheimer's disease
- ▶ Lewy Body disease
- ▶ Pick's disease
- ▶ Parkinson's disease
- ▶ Progressive supra nuclear palsy
- ▶ Vascular dementia
- ▶ Head injury
- ▶ Dementia pugilistica
- ▶ Systemic lupus erythematosis
- ▶ Creutzfeld-Jacob Disease (CJD)
- ▶ Other less common dementias
- ▶ Huntington's Chorea.

Tips for clinicians

- ▶ Take a copy of the summary of delirium, dementia, depression symptoms to a home visit and use this to chart the history of the cognitive impairment, (see page 34 for the summary).
- ▶ Use the Alzheimer's Australia 'Help' sheets and send copies to carers and clients following the assessment. Select the most suitable sheets and print in an appropriate language if the client and carer do not read English.
- ▶ Consider a referral to the Alzheimer's Australia counsellor, if the family agrees. The counsellors can provide 'help' sheets and other appropriate supports including counselling.
- ▶ Good history taking is essential. For example, sourcing information from the family/carer: How long have they noticed changes? What can't the client do now that he/she could do one year ago? Was it a gradual onset over one to two years or a recent, sharp decline over a couple of months? Remember, it sometimes can be both.
- ▶ Ask questions such as 'how would you know that you could not continue the carer role?'
- ▶ Understanding carer issues and the impact on the sustainability of the care relationship is vital to maintain the client's independence.
- ▶ Clarifying the diagnosis can assist the carer into the future.
- ▶ In most cases, dementia, doesn't suddenly get worse, hence an understanding of delirium is required to support clients with dementia.
- ▶ Utilise other staff and, if you are unsure, seek help.
- ▶ A week after the home visit, phone the client or carer to check if they have any questions. This is another opportunity to provide support to the carer and client and check that the assessment outcomes align with the support required. This work can be included under care coordination.
- ▶ New staff should visit memory clinics as part of their orientation to the local services.
- ▶ A diagnosis of a form of dementia may entitle the client to extra funding if they are receiving services through a Home Care Package.

Resources

Resources

Alzheimer's Australia www.fightdementia.org.au

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders, (5th ed.)* (DSM-5). Arlington: American Psychiatric Association

Commonwealth of Australia, 2006, *Delirium in older people*, Dementia Training Study Centres online education modules www.dtsc.com.au

General Practitioner assessment of Cognition (GPCog) www.gpcog.com.au

Information on prescribing restrictions on anti-dementia drugs <http://www.pbs.gov.au/medicine/item/2479L-2532G-8495D-8496E>

Kimberley Indigenous Cognitive Assessment (KICA) www.wacha.org.au/docs/misc/KICA-Tool.pdf

National Centre for Classification in Health, Faculty of Health Sciences, University of Sydney (1998). *The international statistical classification of diseases and related health problems. 10th revision: Australian modification (ICD-10- AM)*

Pharmaceutical Benefits Scheme (PBS) www.pbs.gov.au

Rowland Universal Dementia Assessment Scale (RUDAS) <http://www.health.vic.gov.au/older/toolkit/06Cognition/01Delirium/docs/Rowland%20Universal%20Dementia%20Assessment%20Scale%20%28RUDAS%29.pdf>

ISSUE 2

Capacity

2.1 What do I need to know about the issue of concern?

The clinician needs to know:

- ▶ Difference between capacity and competency
- ▶ The key points about capacity
- ▶ How to assess capacity
- ▶ The clinician's role in assessing capacity
- ▶ What referral options are available.

Although often used interchangeably capacity and competency are in fact different:

- Capacity refers to a medical assessment about whether a person has the ability (that is, capacity) to understand and make a decision.
- Competency is a legal expression which means the person has been determined as competent to make a decision and his/her decision has legal standing.

It is therefore possible for clinicians to argue that a client has impaired capacity as a result of their dementia but it is the role of a court to determine if the person is competent to make a specific decision.

Key points:

- ▶ In law, competency is assumed. The onus is on clinicians or others to prove a person is not competent
- ▶ Capacity is decision specific
- ▶ Capacity can vary from person to person and situation to situation
- ▶ A person's capacity can fluctuate
- ▶ Broadly speaking, when a person has capacity to make a particular decision they are able to:
 - Understand the facts involved
 - Understand the main choices
 - Weigh up the consequences of the choices
 - Understand how the consequences affect them
 - Communicate their decision.

2.2 Why is this of concern to me?

The clinician needs to consider the importance of:

- ▶ The risks associated with issues such as financial management, driving, continuing to live at home, consent to medical treatment
- ▶ Poor decision making may impact on the safety of the client or others
- ▶ Duty of care concerns for the clinician
- ▶ The need to encourage future planning that will be most beneficial for the client and carers
- ▶ Requests from other service providers or family to assess and advise on capacity regarding a specific decision eg. continuing to live at home alone.

2.3 For whom else might it be of concern?

Others who may be concerned:

- ▶ Client
- ▶ Family/carers
- ▶ Other service providers
- ▶ Lawyers.

2.4 What do I need to know about the client?

2.5 What do those involved want to see occur? (what are their expectations)

2.6 What options are available to me?

2.7 Who will do what?

2.8 What follow-up is required?

The clinician needs to know the following information about the client:

- ▶ The client's medical status and history
- ▶ Social situation
- ▶ Cognitive status
- ▶ Factors that might be impacting on the client's capacity
- ▶ Cultural considerations
- ▶ Self-determination and human rights.

What is the desired outcome?

Ask the client, family, GP and other health service providers what specific outcomes they are seeking in regard to capacity. It may be to determine if the client has the capacity to appoint a substitute decision maker e.g. enduring power of attorney (financial, medical, guardianship). If the client does not have capacity, the family may need to apply to be appointed as administrators, or health professionals may need to apply to have a guardian appointed in certain situations, such as when there is a decision that needs to be made in relation to accommodation, (see 'tips for clinicians' on page 15).

The clinician needs to consider the following options:

- ▶ Assessment
- ▶ Referral
- ▶ GP
- ▶ Geriatrician
- ▶ Neuropsychology
- ▶ Victorian Civil and Administrative Tribunal (VCAT)/Local Guardianship Board
- ▶ GPs, Geriatricians and Neuropsychologists are all able to assess capacity. A GP may request a capacity assessment from a geriatrician as a component of a cognitive assessment.

Identify who will do what

The assessment clinician's role is to complete the assessment with awareness of the factors that impact on capacity: acute health issues; delirium; mental health conditions; medications; polypharmacy; chronic health or disability status (and precipitating stressors). This will enable the clinician to work with the client and/or people involved, to restore health and functioning before recommending the last resort of a substitute decision maker.

What follow-up is required?

- ▶ Client. Keep the client informed of the process and outcome of any hearings
- ▶ Family. Is there a legally appointed decision-maker, for example, a person given enduring powers of attorney (financial, medical, guardianship) by the client? It is helpful to have a letter from the client's doctor or geriatrician stating that enduring powers of attorney can be enacted.
- ▶ GP/Services. Need to be notified; who is responsible for decisions regarding the client's health and welfare, finances, and lifestyle.
- ▶ Legally appointed decision maker, for example State Trustees, need to be provided with financial information, as accurately as possible.
- ▶ GP/clinics/services/debtors. Need to be notified of the contact details for person given decision-making powers and responsible for the client's health and welfare.
- ▶ Advance care directives.

Tips for clinicians

As part of their orientation, new staff should attend a guardianship hearing.

- ▶ To apply for a guardian, the client needs to lack capacity about a specific decision e.g. moving to residential care or they would be otherwise at risk if they were to remain living in the community. Choices and decisions need to be considered in context, and the client may have the right to make the wrong decision. A guardian will only be appointed if there is a decision required e.g. moving to alternative accommodation like residential care.

A guardian is generally appointed only if:

- ▶ The client lacks capacity to make decisions regarding lifestyle and accommodation and a decision needs to be made;
- ▶ The client is not safe and is at risk of harm at home and residential care is a safer option;
- ▶ There is conflict e.g. the client or family member disagrees about the safest accommodation option.

VCAT or the relevant authority (Guardianship Board) will choose the least restrictive option for the client. For example, a guardian may trial increased services and support at home to reduce the risks before considering residential care.

Resources

Resources

Darzins, P., Molloy, D. W. & Strang, D. (2000). *Who Can Decide? The six step capacity assessment process*. Glenside; SA: Memory Australia Press

Dementia Training Study Centres, on-line education modules www.dtsc.com.au

New South Wales Government (2010) Capacity toolkit Section 5. Accessed January 2013 from http://www.diversityservices.lawlink.nsw.gov.au/divserv/ds_capacity_tool/ds_capa_life.html

Office of the Public Advocate Victoria www.publicadvocate.vic.gov.au/http://www.publicadvocate.vic.gov.au/administration-&-guardianship/167/

Department of Health, Victoria. Protocol between the Aged Care Assessment Service and the Office of the Public Advocate, 2011.

3.1 What do I need to know about the issue of concern?

The clinician needs to know:

- ▶ What is meant by the term 'behavioural and psychological symptoms of dementia (BPSD)'; the behaviours are usually an indicator of unmet need
- ▶ Causes (aetiology) of BPSD
- ▶ Impact of BPSD
- ▶ Types of BPSD
- ▶ Origin of BPSD
- ▶ Assessment of BPSD
- ▶ Prevention and management of BPSD - individual plans
- ▶ Non-pharmacological
- ▶ Pharmacological
- ▶ Referral options.

Defining BPSD

Behavioural and psychological symptoms of dementia are symptoms of disturbed perception, thought content, mood or behaviour that frequently occur in people with dementia.

Behavioural symptoms are usually identified on the basis of observation, for example, screaming, restlessness, wandering, agitation, hoarding, sexually inappropriate behaviours, shadowing, obsessive and/or repetitive behaviour, and physical (for example, disturbed sleep pattern, up and dressed at 3am) and verbal behaviours that are perceived by carer as aggressive.

Psychological symptoms are usually assessed based on an interview. The symptoms may be anxiety, depression, apathy, hallucinations and delusions.

Note: The term behavioural disturbance should be replaced by the term behavioural and psychological symptoms of dementia (BPSD) (International Psychogeriatric Association, 2010).

Non-pharmacological treatments

Non-pharmacological interventions are indicated as the first-line approach to all emotional and behavioural disturbances in people with dementia. Psychosocial interventions work best when they are tailored to people's backgrounds, interests, and capacity.

Pharmaceutical treatments

As a matter of principle, drug treatment for BPSD should be time-limited and with the exception of an antidepressant treatment for depression, should not exceed 12 weeks without a review.

When medication is discontinued, it is possible that some clients will experience recurrence of symptoms, meaning that medications may need to be recommenced.

The behaviour and psychological symptoms that may respond to pharmacological interventions are:

- ▶ Delusions
- ▶ Hallucinations
- ▶ Extreme anxiety and agitation
- ▶ Physical aggression.

3.2 Why is this of concern to me?

The clinician needs to consider the importance of the:

- ▶ Incidence of BPSD
- ▶ Studies suggest that behaviour and psychological symptoms are very common in any stage of dementia, and at certain stages nearly all people with dementia will exhibit some type of BPSD (Lyketsos et al, 2011)
- ▶ Studies have also shown that some BPSD are more persistent than others. For example, Drye et al (2012) stated that wandering and agitation are the most enduring behavioural symptoms in people with Alzheimer's disease.
 - Impact of BPSD. If not effectively treated, BPSDs can result in:
 - Considerable distress evident in the client
 - Potential risk to the carer, client or others
 - Significant financial cost
 - Impact on the quality of life for the client and the carer
 - Considerable carer stress and impact on health
 - Increased disability and reduction in function of the person with dementia
 - Premature admission to residential aged care.

3.3 For whom else might it be of concern?

Others who may be concerned:

- ▶ Person with dementia
- ▶ Family or carer
- ▶ Other service providers
- ▶ Community services.

3.4 What do I need to know about the client?

The clinician needs to know the following information about the client:

Every assessment completed with a client who has dementia needs to be viewed as an opportunity to screen for BPSD (ACAP National Training Resources).

Symptoms can be subtle and vary from person to person, yet contribute to significant carer burden. Often these symptoms are hidden by the client and/or their carer. Assessment clinicians need to be alert to the factors that may generate changes in health and function:

- ▶ Delirium, depression
- ▶ The client is not managing his/her health or treatment
- ▶ Medications and changes to medication regime (has there been any change or is the client managing their medications effectively and safely?)
- ▶ Other contributing factors impacting on functioning (stressors, changes in environment or carer circumstances, disease progression)
- ▶ Acute illness or exacerbation of chronic disease
- ▶ Carer stress levels that may be contributing to BPSD presentation and experience
- ▶ Changes in the person's usual routine, absence of usual carer.

Comprehensive information (history taking) regarding the BPSD of concern needs to be obtained to assist with appropriate management. Can use the CAUSED model – Communication, Activity, Unwell or Unmet need, Story, Environment, Dementia.

- ▶ Triggers
- ▶ Duration and onset, times. When did it start?
- ▶ Management strategies. What has/hasn't worked?
- ▶ Medications used for management, current and past
- ▶ Risks or options. Dementia Behaviour and Management Advisory Service (DBMAS education 2013).

3.5 What do those involved want to see occur? (what are their expectations)

3.6 What options are available to me?

3.7 Who will do what?

3.8 What follow-up is required?

What is the desired outcome?

- ▶ Ask the carer and client what would they like to see happen? For example, the carer may just want to sleep without disruption.
- ▶ What would assist the client (and carer) to remain living in the community?
- ▶ Does the client (and carer) want to continue to live in the community, prefer to move into residential care, or need a break (respite)?
- ▶ What are the expectations of the service providers?

The clinician needs to consider the following:

- ▶ Psychosocial interventions aimed at addressing the underlying need driving the behaviour
- ▶ Referral to specialist services, for example, DBMAS; Aged Psychiatry Services
- ▶ Changes to the environment: improve lighting, reduce background noises or provide appropriate assistive technology
- ▶ Referral to GP regarding controlled and hesitant pharmaceutical treatments
- ▶ Information for carers and families such as Alzheimer's Australia 'help' sheets, Alzheimer's Australia counsellor, support groups
- ▶ A diagnosis of a form of dementia may entitle extra funding if the client is receiving services through a Home Care Package
- ▶ In home respite and residential respite care.

The aim of an ACAT referral to mental health services is most often driven by the need for:

- ▶ Management of client extreme distress or emotional discomfort caused by the BPSD
- ▶ Management of any extreme risks that exist as a result of the BPSD.

The need to know the information that is required to refer to other services, for example, GP consent for referral to an Aged Psychiatry Service.

Identify who will do what

Family

- ▶ Take the client regularly to his/her GP, for example monthly at least; seek assessment from geriatrician or psychogeriatrician

GP

- ▶ Investigate the client's health status thoroughly, for example screen for delirium

Services/Carers

- ▶ Ensure paid carers are adequately trained to deal with the client's changed behaviours; and provide family with information on all respite options and assist family to explore if needed.

What follow-up is required?

Access to assessment and support services: DBMAS, Aged Psychiatry Services, community rehabilitation, planned activity groups, home care, respite, meals, carer respite, advance care planning, driving assessment.

Tips for clinicians

- ▶ Is the behaviour distressing for the client and/or carer? (A problem for one carer may not be a problem for another)
- ▶ If the client is distressed this is a trigger for management and treatment. A reminder is that behaviour is communication, it is telling us something. The onus is on the ACAT or carer to interpret the behaviour. The onus is on the carer to change or try to change his/her responses to the behaviour as the client is not able to change
- ▶ It is important for all involved to understand factors that may drive behavioural changes in a client with dementia, for example, depression, delirium, pain
- ▶ Be aware of the client's culture and personal history
- ▶ Consider the health and safety of the carer
- ▶ Support the carer in providing structured daytime activities so the person with BPSD is more likely to be tired and sleep at night eg., in-home respite or planned activity group
- ▶ What is the risk if the person is living alone? Risk of what? Is this risk acceptable? Will this risk impact on others?

Resources

Resources

Commonwealth Government Department of Health and Ageing, *Delirium Guidelines Australia* 2006 <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-publicat-dementia-delirium.htm>

Dementia Training Study Centres, on-line education modules www.dtsc.com.au

International Psycho Geriatric Association (1998) Behavioural and Psychological Symptoms of Dementia education pack www.ipa-online.net/pdfs/1BPSDfinal.pdf

NSW Government (2006), *Aged Care - Working with People with Challenging Behaviours in Residential Aged Care Facilities*.

http://www0.health.nsw.gov.au/policies/gl/2006/pdf/GL2006_014.pdf

ReBOC: Reducing behaviours of concern, hands on guide. DBMAS www.dbmas.org.au

10 helpful hints for dementia design at home: practical design solutions for carers living at home with someone who has dementia (2010)

<http://www.hammond.com.au/news/partnership-helps-make-homes-dementia-friendly>

Services

Services

Dementia Behaviour Management Advisory Service www.dbmas.org.au
24-hour help line: 1800 699 799

ISSUE 4

Fitness to drive

4.1 What do I need to know about the issue of concern?

'In all states and territories, legislation requires a driver to advise their driver licensing authority of any long-term or permanent injury or illness that may affect their safe driving ability'.

Assessing Fitness to Drive, Austroads

4.2 Why is this of concern to me?

4.3 For whom else might it be of concern?

The clinician needs to know:

- ▶ The impact of dementia on a client's ability to drive
- ▶ Warning signs/red flags
- ▶ How to access a driving assessment
- ▶ State legislation in relation to reporting driving issues; driving assessments and issuing and suspension of driving licences
- ▶ Roles and responsibilities in relation to driving issues
- ▶ Local alternative modes of transport and support, with consideration to reduced access to public transport in rural locations
- ▶ If the client had had a driving assessment, what was the outcome?
- ▶ Have restrictions been placed on the client's driving?
- ▶ Is the client abiding by the restrictions?
- ▶ Has the client been linked in for yearly driving assessments and by whom?

The clinician needs to consider the importance of:

- ▶ A history of car accidents reported by client or others
- ▶ Evidence of car accidents on inspection of the car, for example scrapes, dents, lapsed registration
- ▶ Clear evidence on assessment that the client has cognitive deficiency that may impact on driving capacity
- ▶ A formal diagnosis of dementia and its progression
- ▶ Reduced judgement and insight into the seriousness of cognitive changes and the impact of these on driving ability
- ▶ Duty of care concerns regarding risk to client and public
- ▶ Client's rights versus public safety
- ▶ The risk of a person with a form of dementia using farm equipment.

Others who may be concerned:

Client

May be dependent on driving due to increasing physical frailty; impacts on community access; care commitment to a dependent family member; may disregard risks to preserve independence. The client may have fears of driving an unfamiliar vehicle for the driving assessment or concerns about the cost of a driving assessment or failing a driving assessment.

Family

May be aware of safety risk but not sure who to contact, how to limit driving, fear of offending or angering the client; has been dependent on the client to drive.

GP

May be concerned that involvement in assessment of cognition and with the relevant authority could jeopardise relationship with the client.

4.4 What do I need to know about the client?

4.5 What do those involved want to see occur? (what are their expectations)

4.6 What options are available to me?

The clinician needs to know the following information about the client:

- ▶ The client's health status
- ▶ Cognitive status. Does the client have capacity to make the decision to drive?
- ▶ Driving history, accidents etc
- ▶ Carer's/family concerns. For example, do they feel safe in the car whilst the client is driving? What have they observed?
- ▶ Where, when and how the client wants to use the car.

What is the desired outcome?

The assessment clinician needs to understand the expectations of those involved, as this is a very sensitive area which often generates considerable anxiety and resistance from both the client and his/her carer or family.

Restricting driving may have a major impact on a client's or carer's independence and his/her ability to remain connected to the community. Appropriate transport options need to be identified.

Assessment clinicians also need to identify whether expectations are reasonable and deliverable within the context of their role. Asking questions, such as those suggested in this resource, will assist in the identification and navigation of people's concerns and help inform the best course of action.

The clinician needs to consider the following options:

- ▶ Assess risk
- ▶ Referral to:
 - GP for assessment of cognition and/or medical fitness to drive
 - A registered occupational therapist (OT) driving assessor.

Report to local driver licensing authority. The health professional should consider reporting directly to the driver licensing authority in a situation where the patient is either:

- Unable to appreciate the impact of his/her condition
- Unable to take notice of the health professional's recommendation due to cognitive impairment
- Continues driving, despite appropriate advice, and is likely to endanger the public.

In the Australian Capital Territory, New South Wales, Queensland, Tasmania, Victoria and Western Australia, health professionals who make such reports to driver licensing authorities, without the patient's consent but in good faith that a patient is unfit to drive, are protected from civil and criminal liability (Assessing fitness to drive, Austroads).

Before completing any formal report regarding a client's fitness to drive it is recommended the assessment clinician consider:

- ▶ The seriousness of the situation
- ▶ The risks associated with disclosure without consent versus the implications of non-disclosure
- ▶ The clinician's ethical and professional obligations
- ▶ Any circumstances indicative of serious and imminent threat to health, life or safety of any person.

Where the client is a risk to themselves or others, the assessment clinician must assume the responsibility to communicate the medical condition to the local driver licensing authority.

The authority will accept a letter or email from the clinician detailing the client's condition and the concerns held with regard to his/her fitness to drive and the clinician's involvement, up to the time of the report.

Any action taken in the interests of public safety should be taken with the consent of the patient wherever possible and should be undertaken with the patient's knowledge of the intended action.

Often older clients self-restrict their driving, that is, will not drive at night or restrictions may be imposed following a driving assessment, for example, they can only drive within a five kilometre radius of their home and cannot drive on freeways.

Post cancellation of driving licence

The assessment clinician or the ACAT program may be contacted by concerned family or others in the community regarding a client still driving his/her vehicle even though his/her licence has been cancelled. It is not within the role of ACATs to enforce, or have to deal with this issue directly.

Suggestions which assessment clinicians could put to the concerned parties include:

- ▶ Discuss strategies to remove or disable the car or remove the keys
- ▶ Speaking with the local police. The police are often not able to do anything unless the person is caught breaking the law but they may go and speak with the person involved
- ▶ Family members speaking with the client
- ▶ There may be a key person the client will listen to
- ▶ If there are substitute decision-maker arrangements in place, then this person may have to enact their responsibility, for example disable the car
- ▶ The family or concerned others may need to seek the appointment of a guardian to deal with this issue
- ▶ Advise the client and his/her family that the client may not be covered by their insurance company if they are involved in an accident and this could have financial and/or legal consequences
- ▶ Using public transport and taxis, if available, may be cheaper than maintaining a car.

4.7 Who will do what?

Identify who will do what:

Health professional:

- ▶ Advise the client and family that there are concerns about his/her fitness to drive
- ▶ Advise client or family of their obligation to report to state licensing authority
- ▶ Report issues relating to client's fitness to drive
- ▶ If appropriate, arrange a driving assessment by an occupational therapist (OT)
- ▶ Comply with local regulations in relation to reporting
- ▶ Offer and promote options and alternatives to driving.

Client

- ▶ Report issues relating to fitness to drive.

4.8 What follow-up is required?

Key points for clinicians

Family

If the client's licence is cancelled, or he/she fails a test

- ▶ Minimise temptation to drive by removing the car
- ▶ Contact the local council or private services to assess for eligibility for transport, shopping assistance, social outings and to assist with community access
- ▶ Before considering a powered scooter, the client should be assessed for suitability by an OT from their local community health centre
- ▶ GP – Assist with application for Multi Purpose Taxi Card.

- ▶ Do relatives get in the car with the client? Would you?
- ▶ Is the client:
 - Getting lost while driving?
 - Forgetting where he/she has parked?
 - Gaining demerit points for infringements?
 - Does the client have any major eye conditions or reduced vision?
 - It is always preferable to gain the client's consent if contacting the local driver licensing authority
 - Each client needs to be considered on a case by case basis, drawing on the expertise from the ACAT case conference.

Resources

Resources

Dementia Training Study Centre online education modules www.dtsc.com.au

Assessing fitness to drive. National Transport Commission/Austrroads 2012 www.austrroads.com.au/images/stories/assessing_fitness_to_drive_2013.pdf

Assessing fitness to drive. Ballarat Health/DTSC www.dtsc.com.au

Transport Accident Commission Community Mobility for Older People (CMOP) Program www.tac.vic.gov.au/road-safety/safe-driving/older-drivers/community-mobility-for-older-people-cmop-program

Services

Services

Alzheimer's Australia www.fightdementia.org.au

Local driving license authority www.vicroads.vic.gov.au/Home/Licences/Medicalreview/Fitness+to+Drive+FAQs.htm

Transport Accident Commission www.tac.vic.gov.au

ISSUE 5

Hoarding and squalor

5.1 What do I need to know about the issue of concern?

Hoarding is recognised as a diagnosable, and treatable, behavioural mental health condition.

Squalor describes a living environment.

Prolonged or extreme hoarding may lead to squalor (Department of Health, Victoria 2012).

5.2 Why is this of concern to me?

Some clients may display hoarding behaviour and/or be living in a squalid environment.

The clinician needs to know

- ▶ The definition of hoarding
- ▶ The definition of squalor
- ▶ Where hoarding and squalor might intersect
- ▶ The difference between hoarding from household clutter, squalor or collecting
- ▶ The associated and contributing factors
- ▶ One-off clean ups are not effective and can cause great distress to the person with the hoarding behaviour.

The clinician needs to consider the importance of:

- ▶ The risks to the client or their dependents (for example, other adults, children or animals) identified by the referral source
- ▶ Hospitals being unable to discharge clients home due to the state of the home environment, so ACAT involvement maybe requested
- ▶ The impact the hoarding behaviour or the squalid living environment is having on the client resulting in safety concerns for the client, carers and or others (neighbours, paid care provider, animals or children)
- ▶ The impact of the hoarding behaviour or squalid living environment on the client's emotional and mental health
- ▶ The two complex living conditions – hoarding and squalor – could have progressed over many years and may now present considerable health risks and safety concerns, particularly with regard to the client's capacity to undertake daily living tasks using the rooms for their intended use (for example, bathroom, kitchen, bedroom, sitting room)
- ▶ Are there likely to be difficulties in getting services into the environment to support the client?
- ▶ The client may reject or not trust anyone approaching them at home
- ▶ Concerns regarding the client's cognitive capacity as the hoarding may be related to cognitive impairment or another psychiatric condition
- ▶ Concerns about the client's ability to make decisions, his/her degree of competence
- ▶ Concerns about the client's degree of insight with regard to the living environment and the impact of that environment on his/her health and safety, or the health and safety of any dependents
- ▶ Breakdowns in relationships/family support.

5.3 For whom else might it be of concern?

- ▶ Financial constraints from compulsive buying or acquiring possessions resulting in issues such as an inability to pay the mortgage or rent, utility maintenance or connections, food, clothing or health support needs like medicines, supplements, aids and equipment, and dental care.
- ▶ The client's inability to function fully due to environmental changes or safety challenges, access or egress from the building or the property
- ▶ Limitations regarding available resources to support the interventions required.

Others who may be concerned

Client

Risk of neglect due to inability to access appliances, taps, shower, stove and risk of falls and difficult access to the house; living a deliberately isolated lifestyle; does not readily accept support from services; needs a longer time to build rapport or trust.

Family

Concern re fire risk, house value (if property owned by client), risk of homelessness (if rental property), may equate the hoarding behaviour with a need for residential placement, may be unaware of severity of situation, may not know where to start to address the concern.

Neighbours

The client may have estranged neighbours who may have offered help in the past; neighbours may have reported concern to the local council about large amounts of clutter on the property, rodent infestation and/or unstable buildings impacting on their property, fire risk to their property.

Services

Unable to provide services that the client may benefit from, or need and agrees to receive, due to clutter inside and outside the home, or squalid conditions making access and entry to the environment unsafe.

Emergency services (regional or metropolitan)

Police, ambulance and fire services face unsafe conditions and fire risk. In Victoria, the Melbourne Metropolitan Fire Brigade maintains a list of high risk houses 'notifiable address' where hoarding is a contributing factor. The person living there needs to agree to their property being listed as a hoarding household.

5.4 What do I need to know about the client?

The clinician needs to know the following information about the client

- ▶ Has the client ever been assessed for hoarding behaviour, or if relevant, reasons for the squalid living environment?
- ▶ Is the client receiving any other type of support service?
- ▶ Has any other type of service been involved such as property manager, financial institution, mental health service, utility provider (gas, electricity, phone, water, sewerage)?
- ▶ Has the client recently seen a GP?
- ▶ Does the client connect with, or have visits from, any family members, friends or neighbours?
- ▶ Are any types of animals involved in large numbers?
- ▶ Are there concerns about the client's capacity or competence?

5.5 What do those involved want to see occur (what are their expectations)?

5.5 What do those involved want to see occur (what are their expectations)?

5.7 Who will do what?

5.8 What follow-up is required?

Resources

What is the desired outcome?

What do those involved want, and what is possible to manage the client's hoarding behaviour.

Much will depend on the client's degree of insight and ability to agree and be involved in proposed changes, for example, a process to slowly clean and organise aspects of the property; address health needs; ensure safe living conditions.

The clinician needs to consider the following options

Clinical assessment may require multiple specialists.

Use established hoarding and squalor tools to objectively rate degree of concern, refer to resources below to view the available tools.

Identify who will do what/who needs to be involved

- ▶ Geriatrician
- ▶ Mental health
- ▶ GP
- ▶ Case manager
- ▶ Home Nursing or Allied Health practitioner
- ▶ Property manager or Local Housing Service
- ▶ Financial institution
- ▶ Utility provider
- ▶ Legal services
- ▶ Animal services
- ▶ Cleaning Services
- ▶ Office of the Public Advocate (OPA) or Guardian application
- ▶ Home and Community Care (HACC) services
- ▶ Department of Veterans' Affairs (DVA).

What follow-up is required

- ▶ Contribute to a multi-agency action plan. Identify with other agencies who will take a service coordination role in the first instance, depending on the immediate need of the client.

Resources

Victorian Department of Health: <http://www.health.vic.gov.au/agedcare/publications/hoarding.htm>

Hoarding and squalor – A practical resource for service providers

Hoarding and squalor key messages statement

A new diagnostic criteria for dementia has been introduced to remove the stigma surrounding dementia and related conditions.

Dementia is now called major neurocognitive disorder but the term dementia will still be used frequently.

The new criteria was introduced in the fifth edition of the Diagnostic and Statistical Manual and Mental Disorders (DSM-5), published by the American Psychiatric Association in May, 2013.

The manual is both a classification system and a guide for all mental disorders affecting children and adults. It is used by clinicians to guide their diagnoses and is often referred to as the 'bible' in the fields of psychology and psychiatry.

The DSM-5 is the first significant update in 20 years and takes into account the latest research into causes and treatments of mental disorders including dementia.

The DSM-5 Task Force on neurocognitive disorder said the aim of removing the emphasis on the term dementia was an attempt to remove the stigma surrounding dementia and related conditions. The causes of major neurocognitive disorder include Alzheimer's disease, cerebrovascular disease, frontotemporal dementia, Lewy Body disease, Huntington's disease, traumatic brain injury and other causes of significant cognitive impairment.

In the DSM-5, the subcategories 'With Early Onset' (onset at age 65 years or younger) and 'With Late Onset' have been removed. The task force decided that there was no rationale for retaining the distinction between early and late onset, as the underlying pathology is the same, and the threshold of age 65 is arbitrary.

Another change is that memory impairment is not necessary for diagnosis. Now, major neurocognitive disorder can be diagnosed in the absence of memory impairment if other areas of cognitive function are impaired. This change better recognises the non-Alzheimer's types of dementia in which memory may remain intact. Instead, the disorder affects language, attention, spatial skills or judgement.

Comparison of the Clinical Features of Delirium, Dementia, and Depression

FEATURE	DELIRIUM	DEMENTIA	DEPRESSION
Onset	Acute, often at twilight; Chronic	Insidious	Can be acute or Chronic, may coincide with life changes
Course	Short, diurnal fluctuations in symptoms, worse at night, in the dark and on awakening	Long, no diurnal effects, symptoms progressive relatively stable over time	May have diurnal effects, (worse in the morning) situational fluctuations but less than with acute confusion
Duration	Hours - days/less than 1 month	Months to years	At least 2 weeks
Mood/Affect	Rapid swings	Depressed or disinterested	Extreme sadness, may have anxiety/irritability
Alertness	Fluctuates; lethargic or hyper-vigilant	Generally normal	Normal, may be reduced
Attention	Impaired, fluctuates	Generally normal	Minimal impairment but poorly motivated
Orientation	Fluctuates in severity	May be impaired	Selective disorientation
Memory	Recent and immediate impaired	Recent and remote impaired, may confabulate to cover-up deficits	Selective or patchy impairment – may complain about impairment
Thinking	Disorganized, distorted, fragmented, slow or accelerated; slurred, rambling, incoherent speech	Difficulty with abstraction, thoughts impoverished, judgment impaired, words difficult to find	Intact but with themes of hopelessness, helplessness, or self-deprecation. May have difficulty concentrating and be slow to speak
Hallucinations/ Delusions	Visual, auditory, tactile	May have delusions, usually no hallucinations	May have delusions (often paranoid)
Activity	Increased or decreased (fluctuate), tremors (poss.)	Normal, may be decreased in later stages	Variable, lethargic or agitation
Sleep Wake Cycle	Disturbed, cycle may be reversed	Fragmented	Disturbed, often early morning awakening
Triggers/ Etiology	Associated with physical or medication cause	Alzheimer's disease, Multi-infarct dementia, Alcoholism, Vitamin deficiencies, CVA, AIDS	Loss, genetic/familial
Mental Status Testing	Distracted from task	Failings highlighted by family, frequent "near miss" answers, struggles with test, great effort to find an appropriate reply	Failings highlighted by the patient, frequent "don't know" answers, little effort, frequently gives up, indifferent, does not care or attempt to find answer
Reversibility	Potential	Irreversible, often progressive	Potential

Adapted from: Edwards, N (2003) Differentiating the three D's: Delirium, dementia, and depression, MEDSURG Nursing, 12(6):347-357, and Foreman M, Zane D (1996) Nursing strategies for acute confusion in elders, American Journal of Nursing 96(4): 44-52.

AA	Alzheimer's Australia
ACAP	Aged Care Assessment Program
ACAT	Aged Care Assessment Team
APA	American Psychiatric Association
BPSD	Behavioural and Psychological Symptoms of Dementia
CAT	Scan Computerised Axial Tomography (CAT Scan)
CDAMS	Cognitive Dementia and Memory Service
CJD	Creutzfeld-Jacob disease
CMOP	Community Mobility for Older People
DBMAS	Dementia Behaviour Management Advisory Service
DSM-5	Diagnostic and Statistical Manual of Mental Disorders
DTSC	Dementia Training Study Centres
ECG	Electrocardiograph
FBE	Full blood examination
GDS	Geriatric Depression Scale
GP	General Practitioner
HACC	Home and Community Care
IQCODE	Informant Questionnaire on Cognitive Decline in the Elderly
LFT	Liver function test
OPA	Office of the Public Advocate
OT	Occupational therapist
PBS	Pharmaceutical Benefits Scheme
R/FBS	Random and/or fasting blood sugar
RUDAS	Rowland Universal Dementia Assessment Scale
SBAR	Situation, background, assessment and recommendation
SMMSE	Standardised Mini-Mental Status Examination
TFT	Thyroid function test
U & Es	Urea and electrolyte levels



**DEMENTIA
TRAINING**
STUDY CENTRES

VICTORIA & TASMANIA