

Cognitive Dementia and Memory Service Best Practice Guidelines

Service Guidelines for Victorian Cognitive Dementia and Memory
Services

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Abbreviations

AAV	Alzheimer's Australia Victoria
ACAS	Aged Care Assessment Service
ADL	Activities of Daily Living
APAT	Aged Psychiatry Assessment Team
APATT	Aged Psychiatry Assessment and Treatment Team
APS	Australian Psychological Society
ATSI	Aboriginal and/or Torres Strait Islander peoples, also refers to people who identify as Aboriginal
B12	Vitamin B12 levels
CALD	Culturally and Linguistically Diverse
CAMDEX	Cambridge Mental Disorders of the Elderly Examination
CAMDEX-DS	Cambridge Mental Disorders of the Elderly Examination – Down Syndrome
CDAMS	Cognitive, Dementia and Memory Service
CRC	Community Rehabilitation Centre
CRS Australia	Commonwealth Rehabilitation Service Australia
CT	Computed Tomography
DBMAS Vic	Dementia Behaviour Management Advisory Service Victoria
DVA	Department of Veteran Affairs
ECG	Electrocardiogram
EEG	Electroencephalogram
EPC	Enhanced Primary Care
ESR	Erythrocyte Sedimentation Rate
ETOH	Alcohol
FBE	Full Blood Examination
GDS	Geriatric Depression Scale
GLBTI	Gay, Lesbian, Bi-Sexual, Transgender and Intersex
GP	General Practitioner
HIP	Health Independence Program Guidelines
HIV	Human Immunodeficiency Virus
IQCODE	Informant Questionnaire on Cognitive Decline in the Elderly
LFTs	Liver Function Tests
MBS	Medicare Benefits Schedule
MRI	Magnetic Resonance Imaging
MMSE	Mini Mental State Examination
NAATI	National Accreditation Authority for Translators and Interpreters
NPI-Q	Neuropsychiatric Inventory – Short Form
OT	Occupational Therapist
PET	Positron Emission Tomography
RN	Registered Nurse
RUDAS	Rowland Universal Dementia Assessment Scale
SACS	Subacute Ambulatory Care Services
SMMSE	Standardised Mini Mental State Examination

SPECT	Single-Photon Emission Computed Tomography
ST	Speech Therapist
SW	Social Worker
TFTs	Thyroid Function Tests
TPD	Total and Permanent Disability
U&Es	Urea and Electrolytes
VDRL	Venereal Disease Research Laboratory
VINAH	Victorian Integrated Non-Admitted Health Minimum Dataset

Glossary

Term	Definition
Advance care planning	Advance care planning involves making decisions and arrangements about future medical care in the event that the person is unable to make these decisions. Advance care planning involves arranging a substitute decision maker for medical decisions, Enduring Power of Attorney (Medical Treatment), and discussing/documenting future wishes concerning medical treatment.
Capacity	A legal concept describing a person's ability to know what they are doing, be aware of and understand the consequences of their actions and make choices based on this knowledge and understanding ¹ .
Care Plan	A written document developed by the interdisciplinary team based on the assessments completed and the needs of the client and family/carer that includes a description of the client's diagnosis, prognosis and planned pharmacological and non-pharmacological management options, and plans to address the family/carer's needs. The VINAH care plan may differ from the CDAMS care plan (refer to the <i>Victorian Health Independence Program (HIP) Guidelines</i> ² section 1.1.5).
Carer	A person who provides care to the client. A carer may be a family member, friend, neighbour or paid carer.
Case Conference	An interdisciplinary meeting of the multidisciplinary team comprising CDAMS clinicians where the results of client assessments are discussed, and treatments are formulated and care plans are agreed upon.
CDAMS Clinicians	Medical, allied health, nursing and neuropsychology staff members.
Future care planning	Future care planning involves making decisions about future care arrangements should the person be unable to make decisions for themselves. Future care planning includes appointing substitute decision makers (Enduring Powers of Attorney), arranging or updating a will and discussing future care wishes.
Informant	A family member or carer provides information about the client.
Interdisciplinary team	A team comprising multiple disciplines who collectively share responsibility for the assessment and treatment of the client and develop a joint care plan.
Key worker	A CDAMS clinician who is assigned the role of being primary

¹ <http://www.publicadvocate.vic.gov.au/powers-of-attorney/511/>

² Can be viewed at: <http://health.vic.gov.au/subacute/hip-manual08.pdf>

	contact person for the client and their family/carer(s). The key worker is typically a nurse or allied health professional who completes the initial assessment, is involved in coordinating the development of the client's care plan, providing feedback and implementing the care plan.
Multidisciplinary team	A team comprising multiple disciplines where each discipline completes separate assessments and develop separate care plans and treatment goals.
Person centred care	Health care that focuses on understanding and addressing the client's needs and those of the care relationship.
Risk reduction	Risk reduction involves reducing the risk of dementia by engaging in a brain healthy lifestyle. For example, staying physically, mentally and socially active, maintaining a healthy diet and addressing cardiovascular risk factors.
Telehealth	The delivery of health services using information communication technology. E.g. using video conferencing.

EXECUTIVE SUMMARY

Cognitive Dementia and Memory Services (CDAMS) operate under Victorian Department of Health's suite of Health Independence Programs and are one of a suite of specialist clinics within subacute and ambulatory care service. CDAMS were first developed in the 1990s and since this time they have grown in number to cover all regions within the state of Victoria.

CDAMS' primary aim is to provide timely and expert multidisciplinary assessment, diagnosis, treatment, support, referral and information for people experiencing undiagnosed cognitive difficulties and dementia and their family/carers. To achieve this, CDAMS uses a person and family-centred process involving an interdisciplinary team of experienced and skilled clinicians, including specialist medical, neuropsychology, nursing and/or allied health professionals. Services may be delivered face to face, via telephone or using telehealth.

People presenting with concerns about their cognition or memory may self-refer or be referred by their family/carers, services, medical professionals and other advocates. During the in-take of referrals, information is collected about the person (known as the client) and their difficulties to identify their initial needs, determine their appropriateness for and prioritise CDAMS involvement. One CDAMS clinician will act as the client's primary contact throughout the CDAMS process, usually this is the nominated key worker. With the client's consent, CDAMS request their general practitioner (GP) forward details of their medical history and organise dementia screening tests.

The CDAMS key worker completes an initial assessment which may involve a home visit. During the initial assessment, more detailed information is collected from the client and their family/carer(s) to obtain a comprehensive understanding of the changes in the client's cognition and functioning. This includes assessment of the client's cognitive difficulties, medical and psychiatric histories, educational and employment histories, functioning, home environment, social situation, cultural background and language, supports, future care plan arrangements, and the needs of the family/carers.

The CDAMS medical assessment builds on the initial assessment and medical information and tests from the GP and includes physical and psychiatric examinations in addition to formal assessments of cognition, mood and behaviour. Additional pathology, imaging and other tests may be requested where necessary for diagnostic purposes. A neuropsychology assessment may be completed when a diagnosis cannot be made, is borderline or the client's presentation is unusual or complex.

Following completion of the assessments, an interdisciplinary case conference is held to discuss the findings and establish consensus regarding the client's diagnosis, prognosis, capabilities, pharmacological and non-pharmacological management options, preventative and care strategies, referrals and need for future CDAMS involvement. Feedback meetings are held with clients and their families/carers to discuss the diagnosis and care plan. The CDAMS key worker assists with implementation of the care plan by providing follow up contact and assistance with arranging services (where required) and

reviewing and adapting the care plan as needed. Where a diagnosis is unclear or prognosis uncertain, clients are offered a review assessment by CDAMS.

CDAMS is responsive to the issues, needs and identity of clients with identified diverse needs and endeavours to provide them with relevant, meaningful and easily accessible services. This includes people who are Gay, Lesbian, Bi-Sexual, Transgender and Intersex, people who identify as Aboriginal and/or Torres Strait Islanders, clients from culturally and linguistically diverse communities, clients with younger onset dementia, clients with intellectual disabilities suspected of having developed dementia and families/carers.

CDAMS actively coordinates and integrates with the client's existing services and engages additional services as needed to ensure continuity of care. The client's GP is engaged throughout the assessment process and provided with results of the CDAMS assessment and the care plan. The GP remains the client's primary care provider.

In addition to the diagnostic and treatment role, CDAMS provides consultancy through the dementia pathway, assists in building awareness of cognitive impairment and dementia, and provides information, advice and education. CDAMS also maintains strong links with community services.

Each CDAMS has a dedicated manager/coordinator/team leader who is responsible for ensuring provision of quality and evidence based services. CDAMS managers/coordinators/team leaders participate in regular state-wide coordinators meetings. New staff members receive a comprehensive orientation to CDAMS and are supported to acquire proficiency within the service. Quality activities are regularly completed to facilitate continuous improvement.

The CDAMS Best Practice Guidelines provide evidence based and best practice standards, criteria and guidelines for the operation and delivery of high quality CDAMS clinics. The guidelines may be used to assist in setting up new CDAMS clinics, evaluating practice standards in existing CDAMS and streamlining practices across clinics.

Section 1 INTRODUCTION

1.1 Background

Age is the single biggest risk factor for dementia, and the reality is that the Australian, and indeed Victorian populations, are ageing. Approximately 9% of Australians aged 65 or older have dementia, increasing to 30% of those aged 85 years or more³. Estimates suggest that between 2011 and 2020, the percentage of Victorians with dementia is expected to increase by 32%, from 75,000 to 100,200². In response to the increasing number of people with dementia, it was recognised as the ninth National Health Priority Area in 2012.

Dementia is characterised by progressive deterioration in cognition resulting in significant impairments in day to day functioning. There are over 100 different diseases and conditions which result in dementia, with Alzheimer's disease being the most common. Dementia affects each person differently and also has significant impacts on family and carers. It is the single greatest cause of disability burden in older Australia and was the third leading cause of death in 2010². It touches on every aspect of the care continuum from acute care, sub-acute care, community care, primary care through to residential care. People across the whole service system need knowledge of dementia and how to manage it.

Mild cognitive impairment (MCI) is a state between normal cognition and dementia. Some people with MCI remain this way for the rest of their lives, some improve, whilst some go on to develop Alzheimer's disease or other dementias. As awareness of dementia has grown amongst health professionals and the community, impairments in cognition are increasingly being diagnosed earlier, often at the MCI stage. Cognitive impairment is also being diagnosed in the pre-clinical stages with research suggesting that biomarkers associated with Alzheimer's disease are present many years before MCI arises⁴.

Accurate timely diagnosis of cognitive impairment and dementia has many benefits, including identification of potentially reversible or modifiable conditions. It also enables people affected and their families/carers to learn more about the condition, to understand the changes that are occurring and to plan for the future. The availability of medicines for the treatment of dementia and timely access to these also makes timely diagnosis important. Despite this, screening for cognitive impairment generally is not undertaken until families or carers become concerned about the persons functioning. As a result, on average there is a 3 year delay between initial symptoms of dementia being observed by families and a diagnosis being made⁵. This delay is far greater on average for those aged

³ Australian Institute of Health and Welfare AIHW (2012).

⁴ Sperling et al (2011).

⁵ van Vliet et al (2013).

under 65 who present with an early-onset dementia. Timely diagnosis is one of the focal areas of the *Living Longer Living Better*⁶ reforms.

The diagnostic process involved in the early identification of cognitive impairment and dementia is very complex, requiring comprehensive assessment which includes a combination of tests and investigations. Information from families and carers forms an essential part of the diagnostic process. It also assists with the identification of the needs of the person with cognitive impairment/dementia and their family or carers. The assessment process informs care plan development and helps to ensure a smoother course through the pathway of dementia.

Cognitive Dementia and Memory Services (CDAMS) were established across Victoria to provide initial diagnosis and treatment of cognitive impairment and dementia. This followed a Ministerial Task Force on Dementia Services in Victoria in 1997 which acknowledged the complex needs of people with dementia and their families/carers and in particular the importance of early diagnosis. In 2003, a review of CDAMS was funded by the Victorian Department of Human Services and conducted by Latrobe University Gerontology unit. A key recommendation was that the CDAMS role be endorsed and supported and that it remains one of assessment, diagnosis, initial care planning and referral. Furthermore, they recommended that consistency of service delivery be ensured across services through the development of practice guidelines. As a consequence, a working party was formed within the CDAMS State-wide coordinators group to review the available literature and current CDAMS practice across the state. CDAMS Practice Guidelines were subsequently developed in 2006.

Over the past 7 years, the number of CDAMS in Victoria has grown, and there have been further developments in the evidence and best practices for diagnosis and treatment of cognitive impairments and dementia. In light of these changes, the Department of Health funded a review of the 2006 guidelines. This CDAMS Best Practice Guidelines (June 2013) document is the result of this review and incorporates and reflects the current evidence and relevant State and Commonwealth policies.

1.2 Scope of these guidelines

These CDAMS Best Practice Guidelines provide the standards, criteria and guidelines for best practice assessment, diagnosis and treatment of people with dementia and their family/carers and the overall operation and management of the service. The purpose of these guidelines is to guide the CDAMS team in providing evidence based and best practice care to clients, their families and carers who present for diagnosis and treatment.

⁶ Can be viewed at:

<http://www.livinglongerlivingbetter.gov.au/internet/living/publishing.nsf/Content/tackling-dementia>

1.3 Policy Context

The following acts, policies, plans, initiatives and guidelines provide a context in which the CDAMS best practice guidelines have been developed and revised.

The *Victorian Public Health and Wellbeing Act 2008*⁷ provides a legislative framework for the promotion and protection of health in Victoria. As required by this Act, the *Victorian Public Health and Wellbeing Plan 2011-2015*⁸ was developed. This Plan aims to improve Victorian's health and wellbeing 'by engaging communities in prevention, and by strengthening systems for health protection, health promotion and preventative healthcare...' (p.1).

The *Improving care for older people: a policy for health services*⁹ focuses on improving the care provided by Victorian health services to older people. At the centre of this policy is: the adoption of a person-centred approach to care delivery; improved understanding of the health care needs of older people; and improved integration and coordination between the continuum of health care services.

The *Victorian Health Priorities Framework 2012-2022: Metropolitan Health Plan*¹⁰ and *Victorian Health Priorities Framework 2012-2022: Rural and Regional Health Plan*⁴ were released in 2011. These frameworks detail the long term planning and development priorities for Victorian healthcare. There are a number of target areas for improvement and these differ between metropolitan and regional and rural Victoria. Application of these frameworks aims to ensure services: are responsive to Victorian's needs; improve the health of Victorians; are equitable; are sustainable; are informed by current evidence and best practices; are accountable, productive and continuously improving; are building on existing health systems and building capacities of their workforce; are utilising information technology; are collaborating with other relevant services and between regional and rural services and metropolitan services.

The *Victorian Health Independence Program (HIP) Guidelines*¹¹ provide direction for aligning the Post Acute Care, Subacute and Ambulatory care Services (SACS) and Hospital Admission Risk Program. CDAMS is one of the SACS services. The HIP guidelines aim to achieve a better client journey across the care continuum through the implementation of 7 core principles: person and family-centred care; quality, evidence based and timely services; equity of access to services; coordination and integration; interdisciplinary approach; appropriate setting; promoting health independence.

⁷ A copy of the summary of this policy can be viewed at: <http://www.health.vic.gov.au/phwa/>

⁸ A copy of the summary of this policy can be viewed at: [http://docs.health.vic.gov.au/docs/doc/021BC69E18251D08CA25792F001458AF/\\$FILE/VPHWP%20Final%20A3%20fold%20summary_low%20res.pdf](http://docs.health.vic.gov.au/docs/doc/021BC69E18251D08CA25792F001458AF/$FILE/VPHWP%20Final%20A3%20fold%20summary_low%20res.pdf)

⁹ A copy of the summary of this policy can be viewed at: [http://docs.health.vic.gov.au/docs/doc/2E9A6C3C6CF7A06CCA25792B0077991B/\\$FILE/improvingcare-summary.pdf](http://docs.health.vic.gov.au/docs/doc/2E9A6C3C6CF7A06CCA25792B0077991B/$FILE/improvingcare-summary.pdf)

¹⁰ A copy of these plans can be viewed at: <http://www.health.vic.gov.au/healthplan2022/>

¹¹ Can be viewed at: <http://health.vic.gov.au/subacute/hip-manual08.pdf>

The *Subacute Ambulatory Care Services (SACS) specialist clinic: Clinic service capability framework and service model* (see Appendix 5.1) provides an overview of SACS programs and outlines the 5 levels of capability clinics are expected to operate under. The *Subacute Ambulatory Care Services: Cognitive Dementia and Memory Clinic (CDAMS) model* (see Appendix 5.2) provides a brief description of the aim and types of services provided by these clinics. The *Service capability framework for subacute and ambulatory care services Cognitive Dementia and Memory Services (CDAMS)* (Appendix 5.3) describes the roles of clinics operating at the different levels of capability. CDAMS operate as level 3 and 4 services.

The *Planning the future of Victoria's subacute service system: A capability and access planning framework February 2013*¹² outlines the role of subacute ambulatory care services specialist clinics, including CDAMS, which operate at some level 3 and all level 4 services.

Dementia is a key priority area in the *Living Longer Living Better*¹³ aged care reform package. This reform package will be focussing on a number of areas associated with the care of people with dementia including: timely diagnosis; service access and support for people with younger onset dementia, improving care across the health system.

The *National Framework for Action on Dementia 2013-2017 – Consultation Paper*¹⁴ continues on from the previous framework which was launched in 2006 and aims to improve the lives of people with dementia and their carers. This framework supports the action of all community and health groups to create and provide seamless and accessible dementia care services. The stages of care covered by this framework for action include: risk reduction, awareness and recognition; assessment, diagnosis and post diagnostic support; management, care, support and review; and palliative and end of life care.

The *Thinking Ahead: Report on the inquiry into dementia: early diagnosis and intervention*¹⁵ was released in June 2013 by the Commonwealth House of Representatives Standing Committee on Health and Ageing, following their Inquiry into Dementia: Early Diagnosis and Intervention. This report details 17 recommendation areas. The following recommendations are of most relevance to CDAMS: promoting awareness of symptoms of dementia and early diagnosis; providing access to early and timely dementia diagnostic services in regional, rural and remote Australia; streamlining

¹² Can be viewed at:

[http://docs.health.vic.gov.au/docs/doc/C9AD322DA3415050CA257B110009A9C0/\\$FILE/1206029_Planning%20the%20future_WEB.pdf](http://docs.health.vic.gov.au/docs/doc/C9AD322DA3415050CA257B110009A9C0/$FILE/1206029_Planning%20the%20future_WEB.pdf)

¹³ Can be viewed at:

<http://www.livinglongerlivingbetter.gov.au/internet/living/publishing.nsf/Content/tackling-dementia>

¹⁴ Can be viewed at: <http://www.health.gov.au/internet/main/publishing.nsf/content/dementia-nfad2013-2017>

¹⁵ Can be viewed at:

<http://www.aph.gov.au/Parliamentary%20Business/Committees/House%20of%20Representatives%20Committees?url=haa/dementia/report.htm>

referral pathways to access dementia diagnostic services; developing and evaluating a 'nation-wide multi-disciplinary approach to dementia diagnosis' (p.128); promoting brain health; and development of national guidelines for future care planning,

The *Pathways to the Future, 2006 and Beyond: Dementia Framework for Victoria*¹⁶ outlines areas for dementia risk reduction and provides strategies for improving the care and health of people with dementia throughout the dementia pathway. Strategies relevant to CDAMS include: pre-diagnosis of dementia - modifying lifestyle factors to try and delay deterioration; newly diagnosed: promoting positive ageing and social engagement, end of life planning, education and information and appropriate services and support for the person with dementia and their carer. Plans are underway to develop a dementia action plan for the state of Victoria.

The *National Indigenous reform agreement (Closing the Gap)*¹⁷ endorsed by the Council of Australian Governments (COAG), aims to reduce the disadvantage faced by ATSI peoples. This is a partnership agreement between all levels of government and commits all parties to work with Aboriginal communities to close the gap on Aboriginal disadvantage.

*Closing the Health Gap*¹⁸ is a Department of Health, Victoria, initiative that aims to improve the health and quality of the lives of ATSI peoples by focussing on improving their experience and access to health and improving the responsiveness of health services.

*Improving Care for Aboriginal and Torres Strait Islander Patients (ICAP)*¹⁹, also a Department of Health, Victoria initiative, continues to contribute to the increased identification of and support for ATSI peoples in Victorian Hospitals. This initiative funds Aboriginal Hospital Liaison Officers and has contributed to increased cultural awareness of health professionals, development of models of care for ATSI peoples and improved relationships between hospitals and Aboriginal organisations.

*The Well Proud: A guide to gay, lesbian, bisexual, transgender and intersex inclusive practice for health and human services*²⁰ is a Victorian Department of Health publication that provides information and recommendations for providing sensitive, inclusive and respectful care services to people who are gay, lesbian, bisexual, transgender and intersex.

¹⁶ Can be viewed at: http://www.health.vic.gov.au/agedcare/downloads/dementia_policyframework.pdf

¹⁷ Can be viewed at: http://www.federalfinancialrelations.gov.au/content/npa/health_indigenous/indigenous-reform/national-agreement_sept_12.pdf

¹⁸ Can be viewed at: <http://www.health.vic.gov.au/aboriginalhealth/victoria/index.htm>

¹⁹ Can be viewed at: http://www.health.vic.gov.au/aboriginalhealth/programs/improving_care.htm

²⁰ Can be viewed at: [http://docs.health.vic.gov.au/docs/doc/75618B0EE0847E0FCA257927000E6EED/\\$FILE/Well%20Proud%20Guidelines%20updated%202011.pdf](http://docs.health.vic.gov.au/docs/doc/75618B0EE0847E0FCA257927000E6EED/$FILE/Well%20Proud%20Guidelines%20updated%202011.pdf)

There are several pieces of legislation governing people's right to privacy and access to information kept about them. These include: the *Health Records Act (2001) Victoria*²¹; the *Commonwealth Privacy Act (1988)*²²; and the *Freedom of Information Act 1982*²³.

The *Victorian Charter of Human Rights and Responsibilities Act 2006, Act 43/2006*²⁴ provides legislation for the protection and promotion of human rights in Australia. The *Australian Charter of Health Care Rights in Victoria*²⁵ details the rights of people accessing and using these Victorian Health Services.

The *Disability Act 2008*²⁶ provides the legislative framework for the protection of the rights and responsibilities of people with a disability.

The *Carers Recognition Act 2012*²⁷ provides the legal framework for the recognition, promotion and valuing of 'the role of people in care relationships' (p.1).

The *National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse (CALD) Communities*²⁸ is part of the Living Longer Living Better aged care reforms. This strategy advocates that services include and empower people from CALD communities, provide them with equity in accessing the services, provide services of high quality which are evidence based and build capacities in CALD communities.

1.4 Intended Users

The CDAMS Best Practice Guidelines have been developed and revised for implementation by Victorian CDAMS.

1.5 Target Population

The CDAMS Best Practice Guidelines detail the practice standards, criteria and guidelines for delivery of best practice in the diagnosis, treatment and care of people with cognitive impairment or dementia and their carers.

²¹ Can be viewed at: www.health.vic.gov.au/healthrecords

²² Can be viewed at: <http://www.privacy.gov.au/law/act>

²³ Can be viewed at: <http://www.legislation.vic.gov.au>

²⁴ Can be viewed at: <http://www.legislation.vic.gov.au>

²⁵ Can be viewed at:

[http://docs.health.vic.gov.au/docs/doc/A828F4D7161E1D77CA2578AA007DDA38/\\$FILE/1105029_AC_HCR_A5_FA_web.pdf](http://docs.health.vic.gov.au/docs/doc/A828F4D7161E1D77CA2578AA007DDA38/$FILE/1105029_AC_HCR_A5_FA_web.pdf)

²⁶ Can be viewed at: <http://www.legislation.vic.gov.au>

²⁷ Can be viewed at: <http://www.legislation.vic.gov.au>. For information about implementing the Act see: <http://www.dhs.vic.gov.au/carersact>

²⁸ Can be viewed at:

[http://www.health.gov.au/internet/main/publishing.nsf/Content/2882705B40A380A1CA257AD80077A1B8/\\$File/D0982_CALD_WEB%20with%20p4%20corr.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/2882705B40A380A1CA257AD80077A1B8/$File/D0982_CALD_WEB%20with%20p4%20corr.pdf)

1.6 Methods used to review these guidelines

The CDAMS Best Practice Guidelines were developed in 2005 by a working party comprising Elizabeth Rand (Alfred Health CDAMS), Lyn Gray (Peninsula Health CDAMS), Michelle Mew (Sunshine Hospital CDAMS) and Helen Vasilopoulos (St Vincent's Hospital CDAMS). In 2013 the Department of Health, Victoria, funded the Academic Unit for Psychiatry of Old Age, The University of Melbourne to update the guidelines to reflect changes in best practice. The methods involved in updating these guidelines are outlined in Appendix 5.4.

Section 2

CDAMS: DEFINITION OF SERVICE

The Cognitive, Dementia and Memory Service is an interdisciplinary, regional specialist service providing timely diagnosis, advice, support and referral for people with cognitive difficulties causing confusion, memory loss or thinking problems, and those who support them.

The Cognitive, Dementia and Memory Service provides:

- Timely assessment and expert clinical diagnosis for people experiencing cognitive difficulties.
- Information on appropriate treatments.
- Advice, initial support and referral.
- Consultancy, education, initial support and information to clients, family/carer(s) and professional service providers.
- Direction in planning for the future.
- Initial information on dealing with day to day issues.
- Linkages for clients and their family/carer(s) to other service providers or community supports.

Core Roles:

1. Diagnosis and Treatment

- i. To provide timely diagnosis and appropriate treatment advice including preventative.
- ii. To use a holistic person-centred approach which focuses on: addressing the client's needs; engaging them in decision making processes; assessing their remaining capabilities as well as their deficits; identifying strategies to strengthen their functioning and coping skills as well as those of their family/carer(s).
- iii. To provide short term assistance with care plan implementation, not case management.
- iv. To provide referral to any service appropriate to the needs of the individual with cognitive impairment and their family/carer(s).
- v. To address the particular needs of people with cognitive impairment/dementia and their family/carer(s) who have diverse needs including people who: are Gay, Lesbian, Bi-Sexual, Transgender or Intersex (GLBTI); identify as Aboriginal and/or Torres Strait Islanders (ATSI); are from culturally and

linguistically diverse (CALD) backgrounds; are younger; have an intellectual disability.

2. Consultancy
 - i. To be a publicly visible and accessible specialist consultancy for people with cognitive impairment and their families/carers.
 - ii. To offer clients who have been seen by CDAMS consultancy services throughout the pathway of dementia where appropriate and there is sufficient recent knowledge concerning the client.
3. Community Health Promotion, Engagement and Capacity Building²⁹
 - i. The CDAMS will offer general information, education and advice to any person or service in contact with a person with cognitive impairment.
 - ii. The CDAMS will have strong links to services relevant to the management of dementia. Eg APAT/APATT, ACAS, AAV, Carer Respite/Support Services etc.
 - iii. The CDAMS may undertake wider community awareness education.
 - iv. Increase expertise throughout the health and community service system and facilitate integration of services for people with cognitive impairment/dementia and their families/carers.

Core Principles of Practice:

These core principles of practice apply to the guidelines for each practice standard.

1. ***Person-centred care:*** CDAMS focuses on developing an understanding of the client and meeting their needs. A holistic assessment identifies the strengths and capacities of the client as well as deficits. Treatment and interventions recommended by CDAMS seek to build on the client's abilities, address their needs, minimise disability, and maximise quality of life, health and social connectedness.
2. ***Family/Carer-centred care:*** CDAMS works with families and carers to identify their needs, preferences and capacities. Where possible, CDAMS seeks to meet the needs and preferences of families and carers by building on their capacities, providing relevant resources and engaging and/or referring to services.
3. ***Consent:*** CDAMS actively seeks consent from clients for assessment, treatment and disclosure of information and communication with family, carers, GP and other relevant people/services.
4. ***Care continuity and integration:*** CDAMS provides dementia diagnostic and treatment services which are coordinated and integrated with the client's/family's/carers' existing services, engages services as needed to ensure continuity of care and take into account the care relationships.
5. ***Evidence based and quality services:*** CDAMS provides services which are based on current evidence, are best practice and meet quality standards.

²⁹ Capacity to provide these services may be reduced in Level 3 CDAMS.

Core Disciplines:

To be defined as a CDAMS the following core services must be provided from within the clinic budget.

Medical:

Either

- Consultant Geriatrician and/or Neurologist
 - with relevant experience in dementia and cognitive changes.
 - Registered Medical Practitioners with the Australian Health Practitioner Regulation Agency.
 - A Fellow of the Royal Australasian College of Physicians.

And/Or

- Psychiatrist and or Psychogeriatrician
 - with relevant experience in dementia and cognitive changes.
 - Registered Medical Practitioner with the Australian Health Practitioner Regulation Agency.
 - A Fellow of the Royal Australian & New Zealand College of Psychiatrists.

And may also include

- General Practitioner³⁰
 - with relevant experience in dementia and cognitive changes.
 - Registered Medical Practitioners with the Australian Health Practitioner Regulation Agency.

Nursing / Allied Health:

Must have clinical expertise, skills and experience in Geriatric or Psychogeriatric care and community based dementia care³¹.

Either

- Clinical Nurse Consultant, Nurse Practitioner or Registered Division 1 Nurse
 - registered with the Australian Health Practitioner Regulation Agency.

And/or

- Occupational Therapist
 - registered with the Australian Health Practitioner Regulation Agency.

And/or

- Social Worker
 - eligible to register with the Australian Association of Social Work.

And/or

- Speech Pathologist

³⁰ A Consultant Geriatrician, Neurologist, Psychiatrist or Psychogeriatrician must be available to provide specialist consultancy on initial prescriptions of cholinesterase inhibitors and memantine and for MRI referrals.

³¹ Regular internal or external supervision should be provided to Nursing/Allied Health staff who are less experienced in this area.

- eligible for membership of Speech Pathology Australia

Neuropsychology:

- Clinical neuropsychologists must be registered with the Australian Health Practitioner Regulation Agency and Psychology Board of Australia and endorsed as a clinical neuropsychologist or working towards endorsement as a clinical neuropsychologist.
- Clinical neuropsychologists should have a post-graduate degree in neuropsychology, and be eligible for membership of the College of Clinical Neuropsychologists,
- Clinical neuropsychologists are expected to adhere to the Australian Psychological Society (APS) Code of Ethics.
- Clinical neuropsychologists should possess relevant clinical experience in the neuropsychological differential diagnosis of dementia.

Management/Team Coordination:

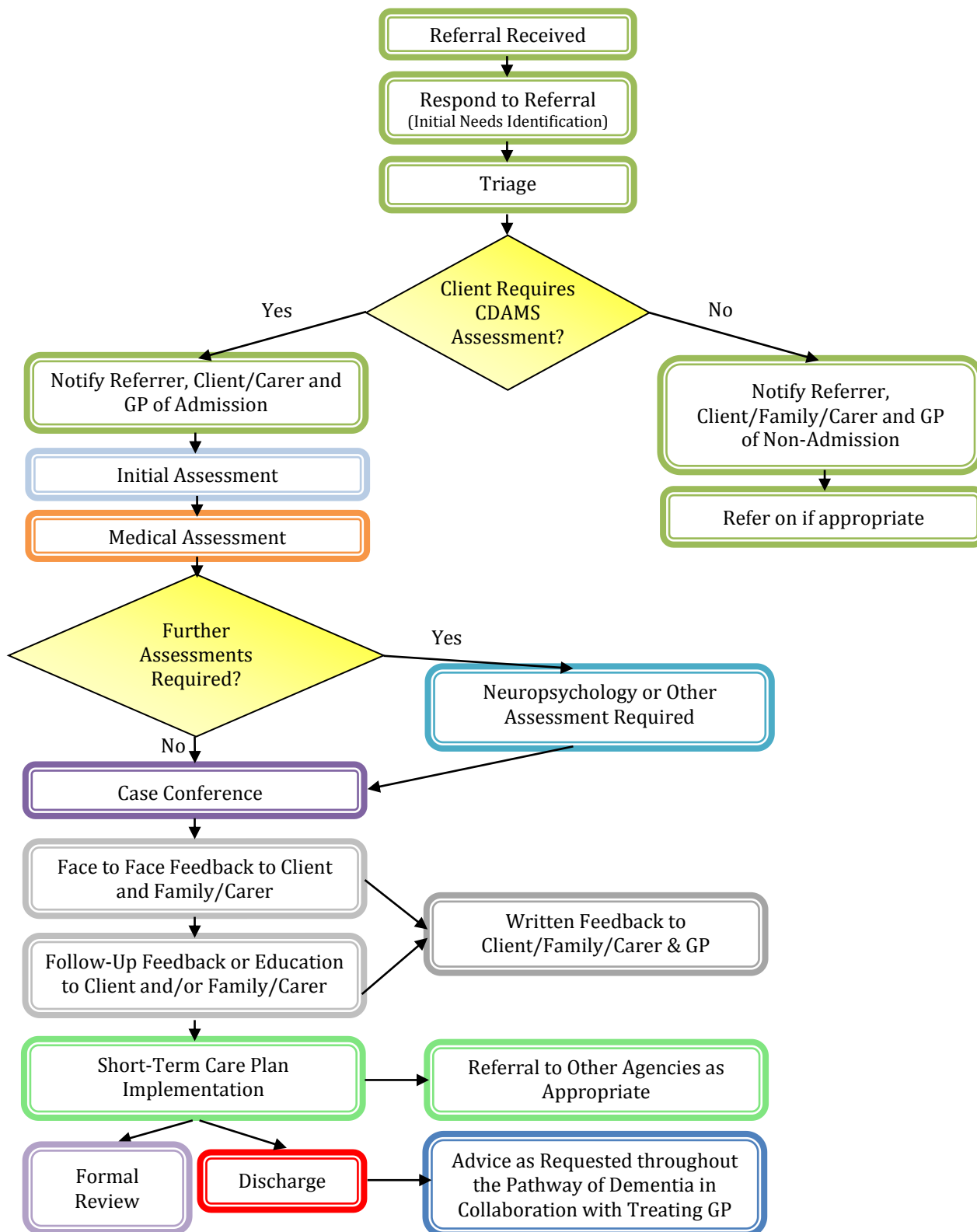
Each Cognitive and Dementia Memory Service should have a designated Coordinator or Team Leader who possesses relevant clinical and managerial experience.

Complementary Services:

The Cognitive Dementia and Memory Service must have access to a full range of interdisciplinary services either within or outside of their health service. Staff in this group would not necessarily be involved with every client, but would be expected to have some degree of expertise, experience and particular interest in dealing with clients with dementia and cognitive impairment.

- Speech Pathology
- Clinical Psychologist
- Physiotherapy
- Nutrition / dietetics
- Counsellors with expertise in behavioural management
- Recreation / Leisure consultancy
- Registered Nurse (Division 2)

Section 3: CDAMS SERVICE CHART



Section 4

STANDARDS, CRITERIA & GUIDELINES FOR BEST PRACTICE IN CDAMS

There are 20 practice standards, including 5 standards associated with identified groups with diverse needs. Underneath each standard are the associated criteria and guidelines. Each standard is contained within a box. Colour coded boxes have been used to indicate the relationship between the processes shown in the CDAMS Service Chart (refer to Section 3) and the Standards 1 and 3 to 9 which are detailed in the following pages.

Standard 1

PRE-ASSESSMENT AND INTAKE

Standard

All referrals require a process to identify the appropriateness of a CDAMS assessment to meet the client's needs.

The Health Independence Program Guidelines (2008) specify that each service must have a defined point of access, provide timely communication and identify the client's initial needs to determine service need, eligibility and prioritisation. Access to CDAMS must be based on clinical need and be equitable.

Criteria

- 1.1. Referrals to CDAMS may occur from any source, including the family/carer, GP, specialist, the client themselves or other advocates for the client. A GP referral is not essential for acceptance of a referral into CDAMS but involvement of GPs in this process should be encouraged.
- 1.2. The initial needs of a client for CDAMS are identified at intake.
- 1.3. Adequate information is obtained at intake to allow prioritisation and client's to be allocated to the most appropriate CDAMS clinicians.
- 1.4. If a referral to a CDAMS is clearly inappropriate information is provided on alternative services. Refer to Guidelines 1.2, 1.3 and 1.4 for further information on referrals that may be deemed to be inappropriate.
- 1.5. The intake worker (a health professional), or the CDAMS coordinator, allocates a CDAMS clinician who acts as the point of contact for the client/family/carer until a satisfactory outcome has been achieved.
- 1.6. CDAMS clinicians are matched with clients according to their needs and the circumstances of the referral³².
- 1.7. Timely response to referrals should occur within 3 working days of receipt – this may include immediate, written acknowledgement, of the receipt of the referral to the referrer. However, attempts should also be made to directly contact the referrer and client/carer/advocate by phone, or face to face as soon as possible.
- 1.8. The appointment process should have built in flexibility to enable appropriate responses to clients' needs and the ability to prioritise access for those with greatest need.

³² CDAMS operating as a Level 3 service may be restricted by the limited range of health professional disciplines within the team.

- 1.9. When a referral is considered appropriate for CDAMS, the GP (and referrer), client and relevant others should be notified of the acceptance of the referral, waiting times and details of the assessment process.

Guidelines³³

- 1.1. Any adult with undiagnosed cognitive problems which may be impacting on their functioning, including those with subjective memory complaints³⁴, regardless of age can be referred to CDAMS but the primary target is the diagnosis of dementia related illnesses.
- 1.2. Where the client is under 50 and there is no obvious evidence of risk factors for dementia (eg: family history of young onset dementia, stroke or central nervous system disorder) efforts should be made to pursue alternative more appropriate avenues of assessment as a first option.
- 1.3. Where cognitive or memory problems have been longstanding and there is no evidence of deterioration, or the decline is related to a known illness (eg: ABI, MS etc) then CDAMS assessment is usually not appropriate. Efforts should be made to establish the presenting issues and alternative avenues for addressing these.
- 1.4. To be appropriate for CDAMS, clients should require an interdisciplinary approach to assessment. CDAMS is not a neuropsychology service and referrals requiring neuropsychology only and not involvement by one or more other disciplines within the team, are generally not appropriate. Decisions concerning the outcome of these referrals should be made on a case by case basis, after consideration of the client's need.
- 1.5. The staff mix of a particular CDAMS may provide additional specialist assessment of specific client groups eg: intellectual disabilities³⁵.
- 1.6. For a referral to be accepted the client must agree to engage in the assessment process. If appropriate, efforts should be made to engage clients who are appropriate for CDAMS but reluctant, by working with their informal support network to assist and enable the client to partake with the process without breaching their privacy.
- 1.7. Adequate information at intake is required to determine a client's appropriateness for CDAMS. This should, where possible, include a medical, psychiatric and social profile, presenting complaints, any previous investigations and risks to the client and family/carer(s).
- 1.8. Intake information should be obtained from the client, family/carer(s), GP, specialists and other advocates involved.
- 1.9. Referrer, client and family/carer expectations of the service should also be identified at intake.

³³ Should be read in conjunction with the Core Principles of Practice on p19.

³⁴ Research indicates that subjective memory complaints is a predictor for MCI, dementia, depression, anxiety (Jessen et al, 2010; Jonker et al, 2000; Mitchell, 2008).

³⁵ This may be limited in CDAMS operating as a Level 3 Service.

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- 1.10. Written information about CDAMS should be provided to the client, family/carer(s) and referrer, where appropriate.
 - 1.11. Inappropriate referrals should be referred on to a more appropriate service and the referrer notified of any action taken together with the reasons for non-acceptance in CDAMS.
 - 1.12. CDAMS should provide training and information to intake workers to assist them with their role in assessing eligibility of referrals and obtaining relevant information about the referred client to assist with this decision process.
 - 1.13. In services that do not have central access units, CDAMS completes the intake and pre-assessment of referrals.
 - 1.14. CDAMS may be involved in triaging referrals.

Standard 2

ASSESSMENT PROCEDURES

Standard

Accurate assessment of new clients presenting with memory loss or cognitive difficulties requires, at minimum, first an assessment of their home situation and ability to function within the home by a suitably trained practitioner. Secondly a medical assessment, incorporating physical, cognitive and non-cognitive domains. Further assessment by a neuropsychologist or other relevant specialist may be provided if required. Where an informant is available a history should be obtained from them also.

Assessment procedures should be flexible so that the level of assessment is adjusted to the needs of the client. The client should be allocated a key worker (care coordinator) who provides a single point of contact and assists the client through the CDAMS process³⁶.

Criteria

- 2.1. CDAMS teams have a sound understanding of the clinical manifestations of dementia, behaviours, medico-legal implications of dementia and dementia management. Refer to Standard 14 for further details about team competency.
- 2.2. The CDAMS team should comprise of the core disciplines detailed in Section 2.
- 2.3. Effective assessment procedures: A person centred approach is used in engaging clients in the assessment process. Assessment procedures should support the quality of life, health, well-being and social connectedness of the client and their family/carer(s). Assessments are holistic, individualised and based on an assessment of a client's history and current abilities. Social support networks and family/carer needs are identified. Assessment is repeated as necessary until a consensus diagnosis is made or the client withdraws from the process.
- 2.4. Effective assessment procedures: The CDAMS assessment process generally involves an initial assessment which includes the client's home situation. This should preferably, but not exclusively, occur in the client's own home. This is usually followed by a medical assessment which may include a psychiatric assessment. Where a diagnosis cannot be made, is borderline or the presentation is unusual, clients may undergo neuropsychological or other relevant assessment, if appropriate. At the completion of the assessment process, feedback is provided to the client and with the client's agreement to the family/carer(s), GP and other advocates who are involved. Where a client has already received components of

³⁶ Health Independence Program Guidelines: <http://health.vic.gov.au/subacute/hip-manual08.pdf>

- the CDAMS assessment elsewhere, then the assessment process should be modified as appropriate to reduce duplication and stress to the client/carer/advocate.
- 2.5. Efficient assessment procedures: Assessments are conducted in a timely manner and clients/families/carers and significant others are involved and kept informed, where appropriate and in accordance with privacy and confidentiality hospital policies/procedures and relevant legislation (refer to Guideline 2.1.1 for more details).
 - 2.6. Obtaining information: Information required to make a fully informed assessment is obtained from a range of sources (eg family, carer(s), GP, medical/hospital record, advocates). This should include a collateral history. Refer to Guidelines under Standards 3 and 4 for information that should be collected as part of the assessment process.
 - 2.7. Providing information: Following feedback or completion of assessments, a written summary of the outcomes and recommendations for action, is to be provided within 5 working days to the client, and with the client's consent to their family/carer(s) and nominated GP. Refer to Standard 7 for more details on feedback. Provision of client information should be in accordance with privacy and confidentiality policies/procedures within the health service and relevant privacy legislation (refer to Guideline 2.1.1 for more details).
 - 2.8. Documentation: A system for documenting key assessment information is maintained and kept in the client's medical/hospital record (including electronic medical record).
 - 2.9. Clinicians: Medical, functional, psychological, cognitive, social and other relevant investigations are undertaken, as required, by professionals experienced in dementia. Refer to Standard 14 for details on team competency.

Guidelines³⁷

2.1. Obtaining information about the client and their needs.

- 2.1.1. Clients have the right to privacy and confidentiality. Use Privacy Principles when obtaining information. Refer to: the Health Records Act (2001) Victoria, at www.health.vic.gov.au/healthrecords; Commonwealth Privacy Act (1988), at <http://www.privacy.gov.au/law/act>; and the Victorian Charter of Human Rights and Responsibilities Act 2006, Act 43/2006, at <http://www.legislation.vic.gov.au>.
- 2.1.2. Interview clients in a manner, which ensures that their needs and wishes are identified independently of others.
- 2.1.3. Arrange an informant interview, if possible and client consents, to obtain information from family/carer(s) or other advocates or services involved.
- 2.1.4. Cross-check key information as necessary.
- 2.1.5. Use interaction, observation and measurement in the collection of information.

³⁷ Should be read in conjunction with the Core Principles of Practice on p19.

- 2.1.6. Identify risk factors, eg environment, nutrition, drugs.
- 2.1.7. Add new information to baseline information, as it becomes available.
- 2.1.8. Value and fully consider the opinions of families/carers. Allow adequate time when meeting with them so that their stories, needs and the approaches they have used to care for the client are acknowledged and understood.
- 2.1.9. Establish and maintain rapport in order to build a professional relationship with the client and family/carer(s).
- 2.1.10. Obtain consent to provide assessment information to others.

2.2. Obtaining clinical information

- 2.2.1. Obtain information from GPs and others.
- 2.2.2. Obtain information from direct assessment of the client.
- 2.2.3. Apply standardised screening tests as required.
- 2.2.4. Make referrals to appropriate specialists if further investigations are required.

2.3. Providing information

- 2.3.1. Discuss the use of obtained information with the client.
- 2.3.2. Keep clients/families/carers and significant others informed, where appropriate and in accordance with privacy and confidentiality hospital policies/procedures and relevant legislation (see Guideline 2.1.1 for more details).
- 2.3.3. With client permission, provide relevant assessment information to a client's GP or other referrer and to others who require assessment and management information.
- 2.3.4. CDAMS may make additional arrangements for the communication of information where there are multiple family members/carers. A key family member/carer may be identified and information disseminated through this person.
- 2.3.5. Provide clients/family/carers with information on medical conditions, treatment options, legal issues, aged care services, pensions/benefits, support strategies and related information. Where available, written information that has been translated into the client's/family's/carer's preferred language.
- 2.3.6. Provide written information about the outcome of an assessment and recommendations for treatment to a client. Where possible, have written information translated into the client's/family's/carer's preferred language.

2.4. Documentation

- 2.4.1. Maintain a chronological file of all assessments, investigations, meetings, decisions and communication including phone calls, e-mails and video-conferences related to the client. This may be in the form of a client record, medical record, hospital record or the electronic equivalent. The client's file

should be integrated into the relevant health service's records to provide a seamless approach across the services being utilised by the client.

- 2.4.2. Documentation including progress notes must be accurate and kept up to date.
- 2.4.3. Meet government documentation requirements. Refer to: Health Privacy Principles in the Health Records Act (2001) Victoria, at www.health.vic.gov.au/healthrecords; and relevant health service policies.

2.5. Clinicians

- 2.5.1. Where possible, a key worker should be allocated to each client.
- 2.5.2. Where possible and practical, clients and their family/carer(s) should be allocated to the most appropriate CDAMS clinician.
- 2.5.3. Consult and involve relevant professionals within and external to the service.

2.6. Efficient assessment procedures.

- 2.6.1. Ensure that best practice standards are met and an efficient service system maintained according to accepted management principles.
- 2.6.2. Ensure assessment tools and processes used are evidence based.
- 2.6.3. Address the needs of clients and their families/carers in a timely manner.
- 2.6.4. Provide clients with a single point of contact in the CDAMS, usually a key worker, and maintain continuity until the optimal outcome is achieved. The key worker is responsible for liaising and communicating with the client, family, carer(s) and other involved people/agencies, and coordinating the assessment process including, completing the initial assessment.
- 2.6.5. Where possible, there should be continuity of the medical specialist involved with the client. The main exception is for clients who receive medical assessments by more than one medical specialist. In these cases, continuity should be provided by the medical specialist whose skills best meet the client's needs.
- 2.6.6. Case conferences should be used to report on, cross check, obtain contributions from other disciplines on assessments completed and discuss care plans.
- 2.6.7. Document all case conferences.
- 2.6.8. Regularly review CDAMS procedures.

2.7. Effective assessment procedures

- 2.7.1. Prior to commencing any assessment:
 - i. Establish the client's hearing status
 - ii. Language:
 - a. Obtain information about the client's/family's/carer's English proficiency at the referral stage.
 - b. Clarify the need for and advocate for an interpreter. An interpreter must be used where the client's/family's/carer's first language is not

- English. CDAMS do not use family/carers as interpreters wherever possible.
- c. Use level three (or above) NAATI accredited interpreters where available.
- 2.7.2. Take into account factors which may be influencing responses during the assessment, such as age, language proficiency, literacy, educational level and gender and sexual orientation. Avoid cultural, language, belief, gender, sexual and identity assumptions when undertaking assessment. Ensure these influences are accurately reflected in the assessment.
- 2.7.3. Consider all possible contributing factors in the assessment of communication difficulties including cultural context, educational and social history, language, hearing loss, visual impairment, dementia, dysphasia, mental state and related issues.
- 2.7.4. Adapt language and terminology used to maximise understanding and comfort of the client/family/carer(s).
- 2.7.5. Address client's needs where possible, allowing sufficient time even in the presence of communication difficulties.
- 2.7.6. Undertake assessment of the client's, family's and carer's needs within their social context, where possible.
- 2.7.7. Where the client consents and where possible, assess the family/carer's concerns without the client present.
- 2.7.8. Address the needs of family/carers that are consistent with supporting the client.
- 2.7.9. Actively advocate for the client and link family/carers to an advocacy service, where required.
- 2.7.10. All parts of the assessment process should be thoroughly completed to ensure the overall assessment is comprehensive.
- 2.7.11. Allocate adequate time to enable a comprehensive assessment to be undertaken. Additional time is often required for assessments of clients with complex presentations, intellectual disabilities, or where an interpreter is being used.
- 2.7.12. Make several contacts if the client's condition or behaviour is not representative of their normal behaviour or if a baseline level of functioning cannot be ascertained.
- 2.7.13. Meet with clients, their families, carers and clinicians to discuss all relevant issues.
- 2.7.14. Exercise sensitivity when interviewing the client and their family/carer(s) about behavioural issues.
- 2.7.15. Use case conferences to problem solve, reach consensus diagnosis and provide peer review.
- 2.7.16. Involve clients/carers in care plan decision making.
- 2.7.17. Care plans should address the needs of the client and family/carers, identified during the assessment process.
- 2.7.18. Provide short term assistance to implement the care plan.
- 2.7.19. Actively assist clients/family/carers to consider care and support options and provide them with information on these options.

- 2.7.20. Make referrals to appropriate service providers and/or provide clients, their families/carers with information so that they may self-refer. Where possible, provide short term follow up to check on the uptake of the referral by the client/family/carer(s).
- 2.7.21. Use resources and skills of other services and organisations to assist with the assessment process and address the needs of the client/family/carer(s) eg: ACAS, APAT/APATT, AAV, DBMAS Vic, CRCs etc.

Standard 3 INITIAL ASSESSMENT

Standard

Accurate assessment of new clients presenting with memory loss or cognitive difficulties requires, at minimum, an assessment of their home situation and ability to function within the home by a suitably trained clinician. Assessments are independent, comprehensive, sensitive, supportive and reassuring.

An initial assessment should build 'on the information collected through initial needs identification'³⁸ (p.21).

Criteria

- 3.1. An initial assessment should include as a minimum:
 - a. Collection of information such as the client's presenting complaint, medical and psychiatric history, medicines and family/social history. Information should be collected from the client and a reliable informant, often a family member or carer.
 - b. Collection of relevant information from the client's existing service providers such as their GP, ACAS, APAT/APATT etc.
 - c. An assessment of the client's functioning in their residential situation including their capacities within this environment. If there is no reliable informant to provide collateral history of the client's functioning, an observational assessment is indicated.
- 3.2. Identification of any risks and potential care/support needs.
- 3.3. Where a home assessment has been completed by an ACAS or APAT/APATT within the last three months and sufficient, current and relevant information has been provided to enable clinic assessments to commence, then an initial assessment of the home situation is optional. However in such cases a CDAMS key worker from within the team should still be assigned.
- 3.4. The method of assessing is professional, thorough and based on a systematic approach to obtaining information and identifying needs enabling development of rapport.
- 3.5. The home environment of the client/carers is respected and the assessment process is adapted to each set of circumstances.
- 3.6. If client/carers/advocate refuses assessment in the home a clinic based initial assessment should be considered.

³⁸ Health Independence Program Guidelines: <http://health.vic.gov.au/subacute/hip-manual08.pdf>

- 3.7. If the client is presenting for a review assessment in CDAMS, home visit may not be required, if this has been done during the previous assessment. However, a review of the home situation and care needs should still be considered, especially if there has been evidence or reports of functional decline.

Guidelines³⁹

- 3.1. Initial assessments are undertaken by the most appropriate clinician, usually the nominated key worker.
- 3.2. Discuss the assessment process with the client and family/carer prior to commencing the initial assessment. This includes the role of the CDAMS, who will be coming to the house/assessment and what will happen, promoting confidence in the process.
- 3.3. Prior to assessment offer the client the opportunity to have others present at the assessment, encouraging the presence of a reliable informant where possible.
- 3.4. Clarify need for and arrange an interpreter where needed. Refer to Guidelines under Standards 10.1. and 10.2.
- 3.5. Identify potential risks for clinicians/support workers prior to a home visit and implement an appropriate management plan to address these.
- 3.6. Where possible make the initial assessment appointment at a convenient time to the client/carer/advocate.
- 3.7. Identify client's/family's/carer's expectations of the service/assessment.
- 3.8. Reassure clients/families/carers that they retain control of decisions concerning their lives.
- 3.9. Clearly document the source information collected during the assessment, eg 'client reported', 'family/carer reported', 'observed' etc.
- 3.10. Use an empathic and supportive approach is used to engage the client, family and carer(s).
- 3.11. Use clinical screening tests that are psychometrically sound and administer them in a standardised manner, where applicable. Tools should be selected to screen for issues with cognition, functioning and behavioural and psychological symptoms. Refer to Appendix 5.5.
- 3.12. The initial assessment should involve assessment of the client's future care plans (including EPOAs and Advance Care Plans). Refer to Appendix 5.6.
- 3.13. Concerns about employment should be discussed where the client is employed.
- 3.14. Driving should be discussed and any concerns on the part of the client, family/carer(s) taken seriously. Refer to Appendix 5.7.
- 3.15. Hold separate discussions with the client and family/carer where practicable and desirable. These discussions may be in person, by phone, e-mail or video conference.
- 3.16. Value the opinions of both the client and family/carer/advocate.

³⁹ Should be read in conjunction with the Core Principles of Practice on p19.

- 3.17. Spend adequate time to obtain an understanding of the client's and family's/carer's needs.
- 3.18. Record cultural, linguistic, and educational differences and disabilities that may affect the assessment outcome.
- 3.19. Provide clients with the opportunity to disclose their gender and sexual orientation where relevant during the assessment. Exercise sensitivity and provide the client with reassurance and respect⁴⁰. Identify if the client has disclosed this information to family/carer(s) involved in the assessment process. If not, respect their rights to privacy and confidentiality. Seek the client's consent before documenting their gender and sexual orientation in their medical history.
- 3.20. Keep clients/family/carers/advocates well informed following an initial assessment.
- 3.21. Commence development of a care plan that identifies the needs of client's and family/carer(s) and proposed actions, including initiation of referrals and other actions as appropriate.
- 3.22. Suggested items for inclusion in an initial assessment, or if not possible at some stage in the assessment process, are shown in the box below.

Client details	Personal, domestic &	Social history
Presenting problems	community ADL functioning,	Family history
Medical problem list	including any assistance being	Employment
Relevant medical history	given	Educational history
Psychiatric history	Future care plans including	Home environment
Current medicines	Powers of Attorney, Will &	Living situation
Drug adverse events	Advance Care Plans	Drug use e.g. ETOH,
Investigation results	Activities/interests	smoking
Mobility and falls	Available supports (formal and	Cultural background &
Sleep pattern	informal) including services	language
Nutritional status	involved	Risks
Vision/Hearing	Mental State/Mood	Carer needs/issues
Driving	Behaviour	

⁴⁰ Refer to the Victorian Department of Health's publication 'Well Proud: A guide to gay, lesbian, bisexual, transgender and intersex inclusive practice for health and human services' for more information. May be accessed via:
[http://docs.health.vic.gov.au/docs/doc/75618B0EE0847E0FCA257927000E6EED/\\$FILE/Well%20Proud%20Guidelines%20updated%202011.pdf](http://docs.health.vic.gov.au/docs/doc/75618B0EE0847E0FCA257927000E6EED/$FILE/Well%20Proud%20Guidelines%20updated%202011.pdf)

Standard 4 MEDICAL ASSESSMENT

Standard

Accurate assessment of clients presenting with memory loss or cognitive difficulties ensuring that their medical abilities and disabilities have been accurately identified incorporating physical, cognitive and non-cognitive domains.

A medical assessment builds on the initial assessment and is necessary for the diagnosis and treatment of cognitive impairment or dementia⁴¹.

Criteria

- 4.1. CDAMS teams should include or have access to appropriate medical specialists i.e. Geriatrician, Psycho-geriatrician, Psychiatrist and/or Neurologist. Refer to medical core disciplines in Section 2.
- 4.2. Medical Specialists have a sound understanding of the physical and psychiatric disorders and the side effects of commonly used drugs that might contribute to cognitive impairment.
- 4.3. Medical specialist assessment ensures that the physical, medical, psychiatric and social needs of clients have been assessed.
- 4.4. Medical specialists have a sound understanding of the application, administration and interpretation of first line screening instruments for cognition assessment.
- 4.5. CDAMS medical specialists progressively expand their knowledge in the management of dementia conditions and are skilled in providing sound up to date advice to clients and carers on their management.
- 4.6. Sufficient time should be allowed for a comprehensive assessment to be completed.

Guidelines⁴²

CDAMS medical specialists:

- 4.1. Are capable of recognising the likelihood of cognitive impairment and dementia and ensuring that the client receives the type and level of medical and allied health services required. Other medical specialists and allied health services may be accessed within the CDAMS. Where these services are not available within the CDAMS, referral to other services may be required.

⁴¹ Health Independence Program Guidelines: <http://health.vic.gov.au/subacute/hip-manual08.pdf>

⁴² Should be read in conjunction with the Core Principles of Practice on p19.

- 4.2. Have the skills to recognise the need for detailed investigations leading to diagnosis.
- 4.3. Are experienced in the application of first line screening for conditions of dementia (cognitive impairment, functional impairment, depression, behavioural and psychological symptoms).
- 4.4. Are skilled in selecting, administering and interpreting formal assessment tools that: screen for a broad range of impairments in cognitive functions; and assess mood and behavioural and psychological symptoms. Tools selected should be validated for the client groups they are being used with and should be sensitive to the client's cultural background, educational background and intellectual functioning. Refer to Appendix 5.5.
- 4.5. Ensure relevant dementia screening investigations have been completed and are capable of interpreting the results.
- 4.6. Are capable of, or able to seek assistance with, interpreting results from neuroimaging, and communicating these results to the client, family/carer, GP and specialist.
- 4.7. Are skilled in considering differential diagnoses in their assessment of clients. Refer to Appendix 5.8 for diagnostic criteria for dementia types.
- 4.8. Follow the protocol for driving assessment. Refer to Appendix 5.7.
- 4.9. Are skilled in prescribing or recommending pharmacological treatment including medicines for dementia and behavioural and psychological symptoms.

Suggested items for inclusion in a medical assessment:

History:

Presenting problems
Past medical history
Past Psychiatric history
Medicines including side effects & any relevant past allergic reactions
Substance use & abuse, eg ETOH
Mobility and falls
Sleep pattern, eg RBD
Nutritional status
Continence
Family History

Physical examination:

Neurological examination
Cardiovascular examination
General Examination as appropriate

Formal assessment:

Cognition
Behavioural and psychological symptoms

Investigations

Imaging:

Non-contrast CT brain if not performed in last 12 months or since onset of memory problems
MRI, SPECT or PET if required for clarification
ECG

Pathology (dementia screen):

FBE, ESR, U&E's, LFT's, TFT's, B12, Calcium and Phosphate, Vitamin D, Glucose, urine analysis
Where indicated: VDRL, HIV, Red cell Folate

Other (where indicated):

Lumbar puncture
Genetic testing

Standard 5

NEUROPSYCHOLOGICAL ASSESSMENT

Standard

If appropriate, clients should have access to a comprehensive neuropsychological evaluation addressing cognitive, psychological, and behavioural issues.

Neuropsychological assessment provides more comprehensive assessment of the client's functioning, in particular their cognition, and assists with formulating a diagnosis.

Criteria

- 5.1. Neuropsychologists are expected to progressively expand their knowledge in the diagnosis and management of dementia conditions and are able to provide sound up to date advice to clients and carers.
- 5.2. Neuropsychologists require access to appropriate testing tools and testing environment.
- 5.3. Neuropsychologists undertake assessments and are involved in case conferences, and feedback sessions for each client, and in review assessments where appropriate.
- 5.4. Neuropsychologists should be of at least Grade 3 level of experience. If a Grade 2 appointment is made then internal or external supervision should be provided on at least a monthly (minimum 10 hours per year⁴³) or on an as needs basis by a Grade 3 clinical neuropsychologist, funded by CDAMS.
- 5.5. It is important that all neuropsychology assessment files, separate from the main medical file, be kept at least in adherence to APS guidelines.

Guidelines⁴⁴

It is imperative that sufficient time is allowed for the neuropsychologist to be involved in all of the following aspects of the CDAMS process:

5.1. Pre-assessment

- 5.1.1. Neuropsychologists should be available to: consult about clients who may require neuropsychological assessment; and prioritise clients requiring neuropsychological

⁴³ As per the Psychology Board of Australia's Guidelines for Continuous Professional Development.

⁴⁴ Should be read in conjunction with the Core Principles of Practice on p19.

assessment. A client may receive a neuropsychological assessment when a diagnosis cannot be made, is borderline or the presentation is unusual.

- 5.1.2. A neuropsychological assessment may be completed prior to the client receiving a medical assessment. This may occur when the client's presentation is complex or they are early in their symptom development, and the waiting time for a medical assessment is longer than that for a neuropsychological assessment
- 5.1.3. General background is gained from pre-assessment and intake information and initial assessment. All available medical and psychosocial information is reviewed.
- 5.1.4. An informant interview should be conducted where possible.
- 5.1.5. Previous neuropsychology results are reviewed.

5.2. *Assessment*

- 5.2.1. The clinical interview and testing is tailored to the individual client and carer concerns.
- 5.2.2. Assessment covers the general domains of intelligence level, pre-morbid level of function, orientation/attention, memory, executive function, praxis, visuo-spatial skills, and language, where possible. This includes scoring and interpretation of assessment findings.
- 5.2.3. Other information is gained from the assessment including mood, behaviour, general functioning, and insight.

5.3. *Report*

- 5.3.1 Neuropsychologists prepare an appropriate and comprehensive written report, which can include history, presentation, assessment tools used, assessment results, diagnostic formulation, and recommendations. Ideally, the neuropsychology report in its entirety should be sent to the referral source after feedback.

5.4. *Case Conference*

- 5.4.1 Neuropsychologists should attend case conference where intakes are discussed, diagnosis is established, and feedback and care planning are discussed, when possible.

5.5. *Feedback*

- 5.5.1. Neuropsychologists should be available for the family feedback meeting and care planning.
- 5.5.2. Neuropsychologists develop strategies specific to the client's cognitive profile and strengths that assist in maximising their functioning, and provide education to the client and family/carers on how these strategies may be implemented.

5.6. *Other*

5.6.1. Neuropsychologists conduct administrative duties as required.

5.6.2. Neuropsychologists contribute to education, counselling, and research activities as appropriate.

Standard 6

CASE CONFERENCING

Standard

An Inter-disciplinary case conference to discuss assessments is held for all clients.

*'When developing a care plan for clients with chronic and complex needs, case conferences...should be considered.'*⁴⁵

Criteria

- 6.1. On completion of all assessment procedures, an interdisciplinary case conference is recommended and should include all available team members involved in a particular assessment, including leave replacement staff.
- 6.2. All relevant disciplines within the CDAMS team should be available to share, with other team members, their assessment results and recommendations for each client.
- 6.3. Non-core service practitioners may be required to attend case conference if their opinions are sought.
- 6.4. As a result of the case conference, a care plan, inclusive of issues discussed and recommendations for action should be agreed upon for each client.
- 6.5. Considerations should be given to a client's capacity to appoint medical and/or financial decision makers. Determination of the client's legal and financial status and needs (including consideration of the need for powers of attorney/guardianship and concerns about abuse) is an essential part of the overall assessment of the client's social history and should be considered in terms of the client's future planning.
- 6.6. Consideration should be given to a client's driving capabilities and competencies. See Appendix 5.7.
- 6.7. Consideration should be given to the carer's needs and to social support needs.
- 6.8. The case conference and resulting care plan should be documented in the client's medical record.

Guidelines⁴⁶

- 6.1. CDAMS case conference should include all clinicians and substitutes involved in each client's assessment.

⁴⁵ p.25 Health Independence Program Guidelines: <http://health.vic.gov.au/subacute/hip-manual08.pdf>

⁴⁶ Should be read in conjunction with the Core Principles of Practice on p19.

- 6.2. A written record of those involved in the meeting and their roles must be maintained.
- 6.3. The findings of each clinician and the consensus regarding diagnosis, social and medical prognosis, capabilities, care strategies and future additional referrals must be documented in the client's medical record. Refer to Appendix 5.8 for guidance with dementia and MCI diagnostic criteria.
- 6.4. Preventative strategies should be identified, including early support, risk factor modification, education, information and counselling, and these should be documented in the client's medical record.
- 6.5. Specific consideration of the client's initial legal, financial, and driving capabilities and competencies should be documented in the client's medical record. Risk of abuse should also be considered. Where there are issues or actions need to be taken, these must be explicitly discussed and documented at case conference with a recommendation for action to be taken included in the clients care plan.
- 6.6. Case conference should occur once all relevant assessments are completed, but in addition, may also be conducted at any time interval along the assessment pathway.

Standard 7 FEEDBACK

Standard

On completion of a CDAMS assessment, feedback is provided to all clients and with the client's consent/agreement to their family/carer(s) as well.

Clients have the right to be informed about their diagnosis and treatment⁴⁷. They should be provided with opportunity to participate in development of and make choices associated with their care plan. Care plans developed from a 'consultative, collaborative approach...that actively involves the client, their family/carers and an interdisciplinary team ensures the best possible outcomes for the client.'⁴⁸

Criteria

- 7.1. On completion of all assessment procedures and the case conference it is essential to ensure that all clients, and with the client's permission their family/carer(s) also, receive feedback.
- 7.2. Feedback should include discussion of the assessment results, the likely diagnosis, prognosis and the suggested care plan with agreement reached on actions to be taken.
- 7.3. As a minimum, information and advice on Powers of Attorney, legal/financial issues, pensions/benefits, driving, services and care strategies (pharmacological and non-pharmacological) should be discussed.
- 7.4. With the consent of the client, the agreed care plan should be communicated with the client's GP and other relevant service providers.
- 7.5. Where an assessment is not completed or the client withdraws from the assessment process, attempts should be made to provide the client and with their permission their family/carer and GP, with results of the assessment to date as well as support/care options if identified.

⁴⁷ Australian Charter of Health Care Rights in Victoria:
[http://docs.health.vic.gov.au/docs/doc/A828F4D7161E1D77CA2578AA007DDA38/\\$FILE/1105029_AC_HCR_A5_FA_web.pdf](http://docs.health.vic.gov.au/docs/doc/A828F4D7161E1D77CA2578AA007DDA38/$FILE/1105029_AC_HCR_A5_FA_web.pdf)

⁴⁸ p.25 Health Independence Program Guidelines: <http://health.vic.gov.au/subacute/hip-manual08.pdf>

Guidelines⁴⁹

- 7.1. Following case conferencing, feedback meetings should be held with the client, and with their consent/agreement, with their family/carers, to ensure they are kept informed about the assessments completed, diagnosis made and treatments recommended by CDAMS.
- 7.2. During the feedback meeting, CDAMS should provide clients/families/carers with verbal and written information individualised to their level of understanding, needs and abilities. Information should be user-friendly and assist the client/carer to make informed decisions. Where possible written information should be provided to augment and reinforce verbal information. This information may include:
 - a. A written summary of the feedback session which includes the recommended actions and associated people/services responsible.
 - b. Information about their diagnosis and treatment. This may include information on management options that support the quality of life, health and well-being and social connectedness of the client and their family/carer.
 - c. Counselling and education services, in particular the Alzheimer's Australia and Carer Respite/support Services.
 - d. Home based and residential care, as required including information about the process of access to these for future use.
 - e. Legal issues including: Future care planning e.g. powers of Attorneys, advance care planning (refer to Appendix 5.6), pensions/benefits, driving and management strategies (refer to Appendix 5.7).
- 7.3. Where possible, the CDAMS clinicians who assessed the client and their family/carer(s) should be available to provide feedback on the results of the client's assessments.
- 7.4. CDAMS should involve and actively assist clients/carers in care plan decision making. This may include assisting clients and their families/carers to consider care and support options that are relevant to their needs and preferences at the time.
- 7.5. The duration of a feedback session should be flexible wherever possible. The CDAMS clinicians should consider the amount and type of information that is reasonable to expect a client/family/carer to comprehend in one session and accommodate their needs.
- 7.6. Where a client does not have existing arrangements for Enduring Powers of Attorney and is intent on appointing substitute decision makers, CDAMS should provide a judgement on capacity. Capacity should always be assumed unless there is evidence to indicate otherwise. If the client's capacity is unclear and they are intent on appointing Enduring Powers of Attorney, CDAMS may organise for a neuropsychological assessment specifically for a capacity assessment or may refer them elsewhere. If the client is diagnosed with dementia, has capacity, but chooses not to appoint Enduring Powers of Attorney, CDAMS should advise them to have their capacity assessed at the time that they wish to make these arrangements.
- 7.7. A summary of the feedback session and care plan should be:

⁴⁹ Should be read in conjunction with the Core Principles of Practice on p19.

- a. Documented in the client's medical record. This summary should include a list of the people present during the feedback session (including staff members, family/carers and others), items discussed and the care plan.
 - b. Sent to the client's GP.
- 7.8. Feedback should occur following completion of all assessments, but in addition, may be provided at any point throughout the assessment pathway.
- 7.9. Feedback may be provided over the phone or via video conferencing where this is preferred by the client/family/carer and is available, often where distance from the clinic is an issue.
- 7.10. With the client's consent:
 - a. The assessment results, diagnosis and agreed care plan should be communicated in writing to the client's GP and referrer (if different).
 - b. Participation of the client's GP should be encouraged through the provision of information and options for implementation of recommendations.
- 7.11. Where indicated, risk of suicidality or catastrophic reaction of the client should be assessed when a diagnosis of cognitive impairment or dementia is made.
- 7.12. A follow up feedback session, education session, phone call or home visit may be offered to: discuss issues not covered during the initial feedback session; provide opportunities for the client/family/carers to ask questions; provide education on strategies and treatments; reinforce information provided at the initial feedback meeting; and follow up on referrals that were made. Medical specialists should be skilled in prescribing or recommending pharmacological treatment for dementia and behavioural and psychological symptoms.
- 7.13. CDAMS clinicians should be skilled in disclosing a diagnosis of cognitive impairment or dementia to clients and families/carers in a sensitive and appropriate manner, explaining results of assessments completed.
- 7.14. The CDAMS clinicians should be skilled in recommending non-pharmacological management options that are appropriate to the diagnosis, needs and functional abilities of the client and the needs and abilities of the family/carer(s).

Suggested items to consider in the feedback and agreed care plan

- Diagnosis
- Prognosis
- Medicines
- Non-pharmacological management options: exercise, cognitive stimulation and strategies, risk reduction etc.
- Information/Education: Alzheimer's Australia, "Living with Memory Loss" program, memory strategies program (eg: LaTCH group or MaxCog).
- Services: APAT/APATT, ACAS, DBMAS Vic, CRC, planned activity groups, Home Help, respite, meals on wheels etc.
- Future legal and advance care planning (refer to Appendix 5.6): Enduring Powers of Attorney, Will etc.
- Future care plans
- Driving (refer to Appendix 5.7)
- Pensions/Benefits: Carer Allowance/Pension, Total and Permanent Disability
- Safety issues
- Carer support
- Counselling
- Medical referrals: genetic counselling, 2nd opinion, inpatient assessment
- Other: Brain bank, opportunities for involvement in research, suicidality risk

Standard 8

CARE PLAN IMPLEMENTATION

Standard

The CDAMS process continues until optimal outcomes are achieved.

Care plan implementation may involve commencing pharmacological and/or non-pharmacological treatment, linking the client and/or family/carer with services, and providing education and support.^{50 51} Care plans may need to be reviewed and must be based on evidence based care pathways⁵².

Criteria

- 8.1. At a minimum, CDAMS provide assistance to arrange the services required by a client and carer and remain available for support until services are in place within the short term, prior to discharge.
- 8.2. CDAMS is available to review and adapt the care plan as requested.
- 8.3. At any stage of the dementia pathway, difficulties may arise. In these situations advice may be sought from the CDAMS clinicians on the management of such difficulties. In consultation with the client's GP, CDAMS may provide advice and/or assistance with referral to other appropriate service providers such as ACAS or APAT.
- 8.4. The client's GP remains the client's primary care provider.

Guidelines⁵³

- 8.1. CDAMS links clients and their family/carer(s) to service providers identified and agreed to in the care plan and where possible, confirm that the service meets the client's needs. Where the client/family/carer(s) consent, the CDAMS key worker should refer them directly to these service providers. Where the client/family/carer(s) prefers, information for self-referral may be provided instead.

⁵⁰ Health Independence Program Guidelines: <http://health.vic.gov.au/subacute/hip-manual08.pdf>

⁵¹ National Framework for Action on Dementia 2013-2017 – Consultation Paper. Can be viewed at: <http://www.health.gov.au/internet/main/publishing.nsf/content/dementia-nfad2013-2017>

⁵² p.2 Improving Care for Older People: [http://docs.health.vic.gov.au/docs/doc/2E9A6C3C6CF7A06CCA25792B0077991B/\\$FILE/improvingcare-summary.pdf](http://docs.health.vic.gov.au/docs/doc/2E9A6C3C6CF7A06CCA25792B0077991B/$FILE/improvingcare-summary.pdf)

⁵³ Should be read in conjunction with the Core Principles of Practice on p19.

- 8.2. CDAMS identify potential future support and service requirements and provide verbal and written information on these as required.
- 8.3. CDAMS clinicians assure clients/families/carers that further advice and assistance is available including after discharge from the service and throughout the pathway of their dementia, where appropriate. This contact should be documented in the client's medical record. A new episode of care may be opened if the client's/family's/carer's need for advice/assistance is substantial and these needs are best met by CDAMS.
- 8.4. CDAMS provides advice and referral to other service providers such as ACAS, APAT, Alzheimer's Australia Victoria, Carer Respite/Support Services, driving assessors and others as requested by clients/families/carers or their GP, throughout the pathway of dementia, where appropriate.
- 8.5. Client's/Family's/Carers with identified diverse needs (ie. are GLBTI, identify as having an ATSI background, are from CALD communities, are younger or have an intellectual disability) may be referred to services which are specifically sensitive to their needs, where these services are appropriate and meet the client's needs and preferences.
- 8.6. CDAMS clinicians may offer follow up phone calls or home visits to assist with short term care plan implementation.
- 8.7. CDAMS may refer clients with more complex needs to HARP.
- 8.8. Discharge of clients from CDAMS may occur when:
 - a. The assessment and care planning processes have been completed.
 - b. The client/family/carer(s) declines to participate in the care planning process.
- 8.9. When discharged from CDAMS, the client's GP is responsible for coordinating and implementing the care plan.

Standard 9 CLIENT REVIEW

Standard

A client review is undertaken where it is identified to be an essential part of the care pathway.

The need for, and timing of, a review should be determined as part the care plan⁵⁴. Client reviews allow those previously assessed by CDAMS to access a timely diagnosis⁵⁵. They also allow the best possible delivery of care to people with complex needs.

Criteria

- 9.1. Where diagnosis is unclear or prognosis is uncertain, clients should be offered a review assessment at an interval identified by the CDAMS clinicians. This would also include clients with Mild Cognitive Impairment.
- 9.2. A review may be undertaken at the request of the client/family/carer(s) or their GP where the initial diagnosis is in question and where this is deemed appropriate by the CDAMS clinicians.
- 9.3. Clients with complex identified issues that require CDAMS expertise should be reviewed at an interval identified by CDAMS clinicians.

Guidelines⁵⁶

- 9.1. A review may include all or only parts of the CDAMS assessment process and team depending on the identified issues.
- 9.2. Development, agreement and implementation of a revised care plan may also be required. (Refer to Guidelines under Standards 7 and 8).
- 9.3. Feedback regarding the outcome of the review should be provided to the client and with their permission, to their family/carer(s) and their GP. (Refer to Guidelines under Standard 7).
- 9.4. Clients who were commenced on a cholinesterase inhibitor or memantine at CDAMS recommendation may be reassessed by the clinic within the first 6 months.

⁵⁴ Health Independence Program Guidelines: <http://health.vic.gov.au/subacute/hip-manual08.pdf>

⁵⁵ National Framework for Action on Dementia 2013-2017 – Consultation Paper. Can be viewed at: <http://www.health.gov.au/internet/main/publishing.nsf/content/dementia-nfad2013-2017>

⁵⁶ Should be read in conjunction with the Core Principles of Practice on p19.

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- 9.5. Generally, clients diagnosed with mild cognitive impairment should be reviewed on at least an annual basis, or more frequently if there are concerns.

Standard 10

WORKING WITH IDENTIFIED GROUPS WITH DIVERSE NEEDS

CDAMS works with a number of groups that have identified diverse needs. These diverse needs may influence the client's CDAMS assessment, in particular their cognitive assessment. The following standards, criteria and guidelines pertain specifically to working with these individuals:

- 10.1. *Aboriginal and/or Torres Strait Islander Peoples*
- 10.2. *People from Cultural and Linguistically Diverse Communities*
- 10.3. *People with Younger Onset Dementia*
- 10.4. *People with Intellectual Disability*
- 10.5. *Family & Carers*

These standards and guidelines should be read in conjunction with the Core Principles of Practice (refer to p19).

Please note: Standards 1-9 and 11-12 still apply to these groups.

Standard 10.1

ASSESSMENT OF ABORIGINAL AND/OR TORRES STRAIT ISLANDER PEOPLES

Standard

CDAMS are responsive to issues of culture, language, belief and identity in the provision of relevant, meaningful and easily accessed services to all Aboriginal and/or Torres Strait Islander peoples.

The prevalence of dementia in Aboriginal and Torres Strait Islander (ATSI) peoples⁵⁷ is estimated to be at least 3 times the national average and age of onset younger⁵⁸. Despite this, ATSI peoples face enormous challenges in addressing the needs of those with dementia, as the concept of dementia has not traditionally been part of their culture. Symptoms of dementia may not be identified and if they are, may not be attributed to a dementia syndrome, but rather part of ageing. When help is sought, there can be a reluctance to engage with mainstream health services. Difficulties include; wariness about services due to the cultural history with 'welfare type' services; cultural differences in non-verbal and verbal communication which can result in health professionals being perceived as 'unfriendly'; and under reporting of symptoms due to the family/carer not wanting to portray the person as impaired⁵⁹.

Services should engage with, be accessible, flexible and responsive to the needs of ATSI peoples.^{60 61}

Criteria

CDAMS clinicians:

- 10.1.1. Provide culturally sensitive and appropriate care to ATSI clients/families/carers/communities.
- 10.1.2. Are aware of issues that may arise related to ATSI culture and communication with people holding particular values and speaking particular languages.

⁵⁷ ATSI peoples also refers to people who identify as Aboriginal.

⁵⁸ Broe et al (2013); Smith et al (2010).

⁵⁹ Henderson and Broe (2010).

⁶⁰ Closing the Health Gap. Can be viewed at:

<http://www.health.vic.gov.au/aboriginalhealth/victoria/index.htm>

⁶¹ Closing the Health Gap Improving Care for Aboriginal and Torres Strait Islander Patients (ICAP).

Can be viewed at: http://www.health.vic.gov.au/aboriginalhealth/programs/improving_care.htm

Guidelines⁶²

- 10.1.1. Throughout the assessment consideration should be given to engagement and communication with ATSI peoples. CDAMS clinicians should have knowledge of the diverse ATSI culture and ways that ATSI peoples engage. They should also actively question these assumptions as there may be individual differences. Literature suggests that consideration should be given to the following:
- a. Less formal language may need to be used as part of developing and maintaining rapport. Non-verbal communication should be positive and a person centred and genuine approach used. The client/family/carer/community may decline services if any staff are perceived as being rude or abrupt.
 - b. The ATSI client, their family or carer(s) may not answer some questions because they are concerned about how the information may be used.
 - c. During the informant interview, an informal narrative is recommended.
 - d. Do not expect that the client/family/carer understands terms that may be used throughout the assessment process. Some concepts may be unfamiliar as they are not part of their culture.
 - e. Several appointments may need to be made before the client/family/carer(s) attends⁶³. Provide additional time throughout the assessment process, if needed.
- 10.1.2. Cognitive screening tools: The use of certain cognitive function screening tools may not be appropriate. Older ATSI peoples may have had poorer access to schooling and may have lower levels of literacy in English, yet be fluent in many Indigenous languages. Some concepts in the standard dementia screening tools may not apply within the ATSI culture. The KICA Cog Regional Urban⁶⁴ may be used where English is not the client's first language. The RUDAS may also be used⁶⁵.
- 10.1.3. Offer the client/family/carer the opportunity to have the Aboriginal Hospital Liaison Officer support them during the CDAMS process.
- 10.1.4. Treatment should include reduction of dementia risk factors and improving protective factors⁶⁶.
- 10.1.5. Where possible, ATSI clients/families/carers should be linked in with culturally specific services where these are available, appropriate and meet their needs. CDAMS may need to make more than one attempt to link ATSI clients/families/carers in with services.

⁶² Should be read in conjunction with the Core Principles of Practice on p19.

⁶³ Issues in the ATSI person's community often take precedence over health appointments.

⁶⁴ KICA Cog Regional Urban

http://www.mednwh.unimelb.edu.au/nari_tools/Files/KICA%20Regional%20Urban%20%28Cognitive%20section%20only%29.pdf

⁶⁵ Rowland et al (2006) & Storey et al (2004).

⁶⁶ Arkles et al (2010); Henderson and Broe (2010); Smith et al (2008); Smith et al (2010)

- 10.1.6. Maintain an awareness of, and access to relevant ATSI translated information.
- 10.1.7. Maintain an awareness of services and resources specifically available for ATSI clients/families/carers.
- 10.1.8. CDAMS clinicians should undertake ATSI cultural awareness training.
- 10.1.9. Where possible, CDAMS should build relationships with the Aboriginal Health Services in their area, provide them with information on CDAMS and offer consultancy.

Standard 10.2

ASSESSMENT OF PEOPLE FROM CULTURAL AND LINGUISTICALLY DIVERSE COMMUNITIES

Standard

CDAMS are responsive to issues of culture, language, belief and identity in the provision of relevant, meaningful and easily accessed services to all older people.

People from culturally and linguistically diverse (CALD) communities typically under-utilise services including those involved in the diagnosis and treatment of dementia. Reasons for under-utilisation may include: limited knowledge about dementia, lack of knowledge about available services, language barriers, social isolation and cultural issues. Consequently, people from CALD backgrounds tend to be diagnosed later in the dementia trajectory than the non-CALD community. In 2009, one in six Victorians with dementia did not speak English at home⁶⁷.

Health services should be accessible, responsive to and aware of the needs of people from CALD backgrounds.⁶⁸

Criteria

CDAMS clinicians:

- 10.2.1. Provide culturally sensitive and appropriate care to clients/families/carers from culturally and linguistically diverse communities.
- 10.2.2. Are aware of issues that may arise related to communication with clients/families/carers from culturally and linguistically diverse communities who may hold particular values and speak particular languages.

Guidelines⁶⁹

- 10.2.1. CDAMS should use face to face interpreting as a first preference in all assessments/reviews. However, if this is unavailable, phone interpreters could be considered where the assessment can be carried out effectively using this

⁶⁷ Access Economics (2009)

⁶⁸ National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse (CALD) communities. Can be viewed at:
[http://www.health.gov.au/internet/main/publishing.nsf/Content/2882705B40A380A1CA257AD80077A1B8/\\$File/D0982_CALD_WEB%20with%20p4%20corr.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/2882705B40A380A1CA257AD80077A1B8/$File/D0982_CALD_WEB%20with%20p4%20corr.pdf)

⁶⁹ Should be read in conjunction with the Core Principles of Practice on p19.

- medium. Phone interpreters should be used during the intake and pre-assessment period and when arranging appointments with clients/families/carers.
- 10.2.2. CDAMS maintain (or have access to) a list of skilled interpreters with experience in working with clients with cognitive impairment.
 - 10.2.3. CDAMS uses culturally appropriate and sensitive cognitive screening tools. The use of certain cognitive function screening tools may not be appropriate for certain cultural groups. Cognitive screening tools that are validated for the client's CALD background should be utilised where available. Refer to Appendix 5.5.
 - 10.2.4. Question in every case the assumption that a client/family/carer from a CALD background has certain service expectations. Research indicates that individual differences and preferences may be more important than assumed norms.
 - 10.2.5. Maintain an awareness of and access to relevant translated information.
 - 10.2.6. Refer to CALD services where these meet the needs of the client/family/carer(s).

Standard 10.3

ASSESSMENT OF PEOPLE WITH YOUNGER ONSET DEMENTIA

Standard

CDAMS are responsive to issues, needs and identity in the provision of relevant, meaningful and easily accessed services to people with younger onset dementia.

Younger onset dementias are defined as those in which the age of onset is under 65 years, or under 50 years for Aboriginal and Torres Strait Islanders. Access Economics projections for 2013 estimate that 5.7% of those diagnosed with dementia in Australia will be under 65 years of age⁷⁰. The pre-diagnosis period for this group is lengthy and typically very challenging for the person with dementia and their family/carers⁷¹. The time between symptom onset and diagnosis is longer for those with younger onset dementia compared with late onset dementia, an average of 4.4 years versus 2.8 years⁷². Behavioural symptoms are often the first to present but rarely attributed to a dementia syndrome⁷³. Frequently help is not sought until the behavioural, cognitive, personality and functional changes impact significantly on the person's family⁷⁴. Misdiagnoses are common and referrals for specialist assessment generally delayed⁷⁵. Issues with relationships, finances, employment, parenting and increasing dependency are commonly reported difficulties, and require additional attention by health professionals. Service access can also be challenging, as most of the services for dementia are aimed at meeting the needs of older people.

Criteria

10.3.1. CDAMS clinicians

- 10.3.1.1. Are skilled in engaging and developing therapeutic relationships with younger clients and their families in the CDAMS process.
- 10.3.1.2. Are aware of and sensitive to the additional concerns and problems that people with younger onset dementia and their family/carers may be facing including: changes in roles and relationships, financial concerns, employment, parenting responsibilities and dependence in ADLs.

⁷⁰ Deloitte Access Economics (2011)

⁷¹ Brown et al (2012); van Vliet et al (2011)

⁷² van Vliet et al (2013)

⁷³ van Vliet et al (2010); van Vliet et al (2011); van Vliet et al (2012)

⁷⁴ Luscombe et al (1998); van Vliet et al (2011)

⁷⁵ Mendez (2006), van Vliet et al (2012)

- 10.3.1.3. Are skilled in using a range of assessment approaches to diagnose cognitive impairment or younger onset dementia.
- 10.3.1.4. Are skilled in providing pharmacological and non-pharmacological treatment and recommendations that meet the needs of the client and their family/carer(s).

Guidelines⁷⁶

- 10.3.1. The assessment of younger clients presenting with possible younger onset dementia may be prioritised. Referrals for second opinions from private medical specialists should be accepted where possible.
- 10.3.2. CDAMS should be particularly attentive to repeatedly gaining consent throughout the CDAMS process and protecting the client's right to privacy.
- 10.3.3. CDAMS should collect information that is part of the usual initial assessment procedures (refer to Standard 3 for further details). In addition, particular attention should be given to assessing changes in the client's functioning in their: domestic and community activities of daily living, particularly financial tasks, driving and employment; daily life roles including their relationships including their parenting (where applicable); behaviour including conflict, interest, engagement and the presence of behavioural and psychological symptoms.
- 10.3.4. Family members may be provided with information on genetic testing and counselling where this is indicated.
- 10.3.5. Where the client is employed and wishes to continue employment but is having difficulties, CDAMS may either complete a workplace assessment or refer to CRS Australia⁷⁷, where the client consents.
- 10.3.6. Where indicated, the client and their family/carer(s) should be linked in with services. Referrals should be made to services specifically for people with younger onset dementia where this is available, indicated and the client consents. CDAMS should explore the client's and family's/carer's needs for counselling and refer accordingly.
- 10.3.7. CDAMS should provide information and where appropriate assistance with completing Total and Permanent Disability (TPD) insurance claims and Centerlink applications.
- 10.3.8. Any CDAMS may refer younger clients with an unclear diagnosis to the Royal Melbourne Hospital Neuropsychiatry Clinic for assessment.
- 10.3.9. CDAMS should offer clients diagnosed with younger onset dementia the option to be referred for a second opinion on their diagnosis.
- 10.3.10. Assisting clients with younger onset dementia and their family/carers through the CDAMS process can be stressful and emotional for clinicians. CDAMS clinicians should be provided with opportunities to debrief with their colleagues.

⁷⁶ Should be read in conjunction with the Core Principles of Practice on p19.

⁷⁷ Refer to: <http://www.crsaustalia.gov.au/>

Resources

Resources on Genetic Testing and Counselling

Alzheimer's Australia Tip Sheet on Dementia and Hereditary

<http://www.fightdementia.org.au/understanding-dementia/dementia--heredity.aspx>

Genetics Testing – Alzheimer's Disease and other Dementias

<http://www.genetics.edu.au/Information/Genetics-Fact-Sheets/FS45KBS.pdf>

Genetic Counselling Information Sheet

<http://www.genetics.edu.au/Information/Genetics-Fact-Sheets/FactSheet3.pdf>

Standard 10.4

ASSESSMENT OF PEOPLE WITH AN INTELLECTUAL DISABILITY

Standard

CDAMS are responsive to issues, needs and identity of people with an intellectual disability and dementia in the provision of relevant, meaningful and easily accessed services.

Adults with intellectual disabilities are living longer and experiencing many age related diseases, including dementia. Down syndrome is the most common cause of intellectual disability. It has the highest prevalence of early-onset Alzheimer's disease and this prevalence increases with age. Cognitive decline in those with Down syndrome can occur from 40 years of age, and in some cases even younger. The prevalence of dementia is higher in those with other intellectual disabilities (not Down syndrome). The annual incidence of dementia is up to 5 times higher⁷⁸ than the general older population.

It is well documented that diagnosing dementia in those with intellectual disabilities is challenging, particularly in the earlier stages. Adults with intellectual disabilities have lifelong lower baseline levels of functioning than the general population and this can range from mild to severe. This diversity in functional levels makes using standardised cognitive tests and applying diagnostic criteria difficult. Despite this, people with intellectual disabilities and dementia have the right to access 'appropriate diagnostic, assessment and intervention services and resources... [that] meet ...[their] individual needs and support ... healthy ageing'⁷⁹. Equality in accessing services is also reinforced in the HIP Guidelines⁸⁰. Furthermore, denying these individuals access to services contravenes Article 25 of the UN Convention on Rights of Persons with Disabilities⁸¹.

Criteria

10.4.1. CDAMS clinicians:

- 10.4.1.1. Are aware of issues related to engagement, communication with and assessment of clients who have an intellectual disability.
- 10.4.1.2. Are aware of how further declines in cognitive functioning may present in clients with intellectual disabilities.

⁷⁸ Strydom et al (2013)

⁷⁹ p280, Wilkinson & Janicki (2002).

⁸⁰ Health Independence Program Guidelines: <http://health.vic.gov.au/subacute/hip-manual08.pdf>

⁸¹ Can be viewed at: <http://www.un.org/disabilities/default.asp?id=285>

- 10.4.1.3. Are able to use a range of assessment approaches to assess for further cognitive decline in clients with intellectual disabilities.
- 10.4.1.4. Are aware that physical and sensory impairments, and medical and mental illnesses may present as functional decline.

Guidelines^{82 83}

The CDAMS process for diagnosing dementia in clients with intellectual disabilities follows the same pathway as outlined in the service chart in Section 3 of these guidelines. The standards 1-9 and 11-12 still apply. Additional care must be taken with several components of the process. These are outlined below.

- 10.4.1. Where possible, an initial assessment should be conducted at the client's home so that their behaviour, level of functioning and needs within a familiar environment may be assessed in addition to assessing the environment.
- 10.4.2. CDAMS clinicians should obtain information from family/carers who have known the client over time. This information should include:
 - a. The client's longitudinal baseline level of functioning⁸⁴. This should include information about their previous best level of functioning.
 - b. The changes they have observed in the client's functioning, behaviour and cognitive abilities, including:⁸⁵
 - i. What has changed? Refer to table 10.4.1 for common initial symptoms of change associated with dementia.
 - ii. Onset - When was the change noticed? What was the nature of the onset?
 - iii. Duration – How long did the change last for? Did the person subsequently improve or plateau in their functioning/cognition/behaviour? A rapid decline with a plateau may be due to another untreated condition.
 - iv. Temporal progression – Have the changes progressed?
 - v. Do functional changes correlate with the changes in cognitive domains?
 - vi. Are there other causes of the client's functional changes?
 - c. The client's routine and level of independence with ADLs. Executive dysfunction may be identified through careful questioning with regards to spontaneous initiation, sequencing, correcting and completing ADLs.
 - d. The presence of behavioural and psychological symptoms.
- 10.4.3. Where the client is able, a subjective history should be collected from them concerning their observations and perceptions of the issues.

⁸² Taken from Torr (2009)

⁸³ Should be read in conjunction with the Core Principles of Practice on p19.

⁸⁴ In clients with moderate to severe intellectual disability, declines in everyday functioning tends to be a better indicator of dementia than decline in memory function. Jamieson-Craig et al (2010).

⁸⁵ p4, Torr (2009)

- 10.4.4. Where the client resides in a group home, CDAMS should review the home's case notes on the client as part of the initial assessment. This can be used to confirm information collected on assessment.
- 10.4.5. Previously completed assessments of the client's functioning, cognition, speech and language should be obtained where available.
- 10.4.6. Clinicians should request examples of 'functional artefacts'⁸¹ made by the client. These may include: paintings, drawings or other works of art or craft, or video or audio recordings. If available, the clinician should assess for change in skills in completing these activities over time. This may include comparing recently completed art work or knitting or similar with that completed before the reported decline in functioning. The clinician may also ask the client to undertake these activities as part of their assessment.
- 10.4.7. Where possible, the client should be assessed doing a functional task which they have previously been able to complete.
- 10.4.8. Common objects such as a pen, scissors, cup, ball etc may be used to assess confrontational naming, object recognition, dyspraxias, and new learning and delayed recall by concealing objects in a bag, box, drawer, or around the room.
- 10.4.9. The Draw A Person Test, or other drawing test can be used as an analogous test to the Clock Drawing Test.
- 10.4.10. Formal assessment tools of cognition and functioning in those with intellectual disabilities may be used as part of the assessment. Formal cognitive tests may be used and may provide a baseline for comparing prospective tests. Tools that may be used include:
 - a. The Vineland Adaptive Behaviour Scale (Second edition)⁸⁶ assesses functioning and decline in communication, ADLS, socialization, motor skills and behaviour.
 - b. The Severe Impairment Battery (SIB)⁸⁷ assesses performance on a range of different tasks and can be used with clients who have severe intellectual disabilities.
 - c. The CAMDEX-DS⁸⁸ comprises an informant interview and neuropsychological battery. This tool assesses functioning, cognition, physical and mental health including changes in these domains.⁸⁹
 - d. The Broad Screen Checklist of Observed Changes⁹⁰ is a valid and reliable tool that may be used to assess for functional decline.
- 10.4.11. A thorough CDAMS medical specialist assessment should be completed. Refer to Standard 4. Particular attention should be given to assessing for physical medical and psychiatric causes for a client's decline in functioning and cognition, behaviour and/or mental state. Refer to Table 10.4.2 for further details concerning differential diagnoses and factors which may contribute to

⁸⁶ Sparrow et al (2007)

⁸⁷ Saxon et al (1993)

⁸⁸ Ball et al (2004)

⁸⁹ For further information on other cognitive tests refer to the British Psychological Society & Royal College of Psychiatrists, 2009 (<http://www.rcpsych.ac.uk/files/pdfversion/cr155.pdf>)

⁹⁰ Koenig (1996)

the client's decline. Where available, the cause of the intellectual disability should be identified. The presence of risk factors for dementia should also be investigated. Refer to Table 10.4.3 for further details of suggested areas that may be included in a CDAMS specialist medical assessment and Table 10.4.4 for risk factors for dementia. Imaging may be completed where the diagnosis remains unclear.

- 10.4.12. CDAMS may complete more detailed neuropsychological testing when indicated.
- 10.4.13. If medicines are prescribed, consideration should be given to whether the client will take them, who will dispense them and in which form they will be most readily accepted and tolerated (e.g. swallowing difficulties). Medicines should be commenced at sub-therapeutic levels and slowly titrated. The client should be regularly monitored for efficacy and tolerability. Anti-dementia drugs should be avoided in clients who have 'sick-sinus syndrome or other supraventricular conduction abnormalities of the heart, history of peptic ulcer disease, bronchial asthma or chronic obstructive airway disease, anaesthesia, hepatic and renal impairment, urinary retention, gastro-intestinal obstruction and history of seizures'⁹¹.
- 10.4.14. Where needed, the client should be referred to relevant aged care services.
- 10.4.15. For client's accommodated in group homes, it is preferable that they not be moved into aged residential care, unless their care needs cannot otherwise be managed.
- 10.4.16. Family/carers should be provided with education about diagnosis and strategies to assist in providing ongoing care. Follow up education may be provided to group home disability carers to assist them in adopting strategies to better support the ongoing care of the client.
- 10.4.17. Where a baseline level of functioning cannot be established, the client should be reviewed within 6 to 12 months to establish whether there is decline in functioning and cognition.

Table 10.4.1 Early signs of dementia in people with intellectual disabilities⁹²

<ul style="list-style-type: none">• Deterioration in activities of daily living that cannot be accounted for by changes in physical, medical or psychiatric status⁹³• Behavioural changes such as: increased apathy and inactivity, becoming lost, increased aggression, day-night confusion.• Changes in social functioning: Loss of amenability and sociability, or withdrawal of spontaneous communication.	<ul style="list-style-type: none">• Deterioration in cognitive and perceptual abilities including: decline in short term memory, increased problems with comprehension, decline in communication skills, changes in depth perception, disorientation and confusion.• Seizures and incontinence⁹⁴Changes in engagement: Loss of interest in favoured activities
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⁹¹ p.15, Prasher et al (2009)

⁹² From Kerr (2007), Strydom et al (2010) , The British Psychological Society and Royal College of Psychiatrists (2009)

⁹³ Decline in daily functioning has been found to be a more reliable indicator of dementia than decline in memory in those with moderate to severe intellectual disability. Jamieson-Craig et al (2010), Strydom et al (2007).

⁹⁴ Particularly in people with Down syndrome.

Table 10.4.2 Differential diagnoses and possible contributing factors to consider when assessing clients with intellectual disabilities for the presence of dementia⁹⁵:

1. **Physical problems.** Consider: hypothyroidism⁹⁶, anaemia, uncontrolled epilepsy, chronic infections, nutritional deficiencies (e.g. vitamin B-12, folic acid, niacin, hypercalcemia), cerebrovascular disease, cardiovascular disease, ischemic heart disease, hyperlipidaemia, diabetes, arthritis, pain, subdural haematoma, normal-pressure hydrocephalus, brain tumour, head injuries, HIV, neurodegenerative disorders such as neurosyphilis, Parkinson's disease and Huntington's disease.
2. **Sensory impairments.** Consider hearing and visual impairments including: cataracts, ear wax build up, other age related declines in hearing and vision.
3. **Mental health problems.** Consider: depressive illnesses⁹⁷, psychotic disorders, manic episodes, substance use/abuse
4. **Iatrogenic causes.** Consider medicine effects and side effects⁹⁸ including: polypharmacy, medicines with anticholinergic side effects, psychotropics/anti-epileptics.
5. **Impact of life events.** Consider changes in carers, loss of family, changes in accommodation arrangements, loss of day activities.
6. **Delirium.**
7. **Abuse.** Consider current or recent physical, emotional or sexual abuse.
8. **Impact of poor environment.** Consider the environment in terms of level of stimulation, level of support available, availability of meaningful and enjoyable activities and interactions and cues to aid orientation.

Table 10.4.3 Suggested items for inclusion in a medical assessment:

History:	Physical & Psychiatric examination:
Presenting problems, onset, duration, progression	Neurological examination e.g. frontal release signs, focal deficits, gait abnormalities, speech abnormalities
Medical history	Cardiovascular examination
Psychiatric history	General examination
Medicines including side effects & any relevant past allergic reactions	Mental state examination
Substance use & abuse, eg ETOH	Investigations
Mobility and falls	Imaging⁹⁹:
Sleep pattern, eg RBD	Non-contrast CT brain if not performed in last 12 months or since onset of memory problems
Nutritional status	MRI if required for clarification
Continence	Where indicated: ECG, EEG (if history of seizures)
Family History	Pathology (dementia screen):
Developmental history	FBE, ESR, U&E's, LFT's, TFT's, B12, Calcium and Phosphate, Vitamin D, Glucose, urine analysis
History of functional and communication abilities	Where indicated: VDRL, HIV, Red cell Folate, genetic testing, serum levels of anticonvulsants, lithium and other
Risk factors for dementia (Table 10.4.4).	
Formal assessment:	
Cognition	

⁹⁵ Primarily taken from the British Psychological Society and Royal College of Psychiatrists (2009) with additional information from Torr (2009).

⁹⁶ Hypothyroidism, depression and visual and/or hearing impairments are common co-morbidities in those with Down syndrome.

⁹⁷ Depression may be unrecognised and untreated for an extended period of time. Depression is very common in those with Down syndrome and dementia.

⁹⁸ Older people with intellectual disabilities often have 'impaired drug absorption...alterations in drug action, and...increased risk of drug interactions.' p.84 Prasher (2005).

⁹⁹ Neuroimaging may not be practical or useful for some clients. If neuroimaging is requested, information should be provided to the client about the test in language that they can understand.

Behavioural and psychological symptoms	medicines Where family history of intellectual impairment, major mental illness or neurological disorder: molecular karyotype or microarray, or referral to neurogenetics clinic
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Table 10.4.5 Risk factors for dementia¹⁰⁰

Age	Vascular risks: smoking, hypertension, hypotension, diabetes, hyperlipidaemia, vascular disease
Apo E 4	Lifestyle factors: sedentary lifestyle, social isolation, low educational level, low activity levels, low stimulus environment
Genetic disorders: Trisomy 21. Sanfillippo syndrome type B.	Trauma: head injury, seizures, falls, self-injurious head injury, boxing
Infective disorders: Congenital rubella syndrome	
Family history or neurodegenerative disorders or cerebrovascular or vascular disease.	
Epilepsy	
Alcohol/substance abuse/use	

Resources:

Down syndrome and Alzheimer's disease booklet

<http://www.cddh.monash.org/assets/dsad-booklet-final.pdf>

Working with people with intellectual disabilities in health care settings

<http://www.cddh.monash.org/assets/documents/working-with-people-with-intellectual-disabilities-in-health-care.pdf>

Dementia and people with learning disabilities: Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia.

[http://dcp.bps.org.uk/document-download-area/document-download\\$.cfm?file_uuid=264C29FC-D1BE-428A-4EA5-857A550796F7&ext=pdf](http://dcp.bps.org.uk/document-download-area/document-download$.cfm?file_uuid=264C29FC-D1BE-428A-4EA5-857A550796F7&ext=pdf)

¹⁰⁰ p.5, Torr (2009).

Standard 10.5

WORKING WITH FAMILY & CARERS

Standard

CDAMS recognises, respects and supports the contribution of family and carers in the assessment and care planning process (subject to the client's consent) and addresses their needs in addition to those of the client.

Family and carers are vital to delivery of person-centred care. They provide health services with valuable information about the client's current problems, functioning, medical history, behaviours and preferences. Family and carers should be included in the client's assessment and treatment (where consent is given). Caring has consequences. Health services need to be aware of stress and difficulties that carers experience. Health services must consider the needs of the family/carers.¹⁰¹

Criteria

- 10.5.1. CDAMS assessment process requires engaging (wherever possible) with family and other carers as a critical source of information.
- 10.5.2. The experience of family and carers should also be assessed, as degree of care-giver burden is a better predictor of service use. Family and carers may also have their own health issues.
- 10.5.3. CDAMS should ensure that the cultural and language needs and preferences of families and carers are considered.
- 10.5.4. Wherever possible, family and carers should be involved in the care planning process.
- 10.5.5. Families and carers should be provided with the opportunity for education and counselling regarding the illness, prognosis and available treatment.
- 10.5.6. Families and carers should be provided with information regarding future planning, including sources of care and support, financial and legal issues.
- 10.5.7. CDAMS should maintain strong links with carer education and support providers such as AAV and Commonwealth and state carer support programs (eg Commonwealth Carer Respite Services, and Carers Vic).

¹⁰¹ Improving care for older people. Can be viewed at:
[http://docs.health.vic.gov.au/docs/doc/2E9A6C3C6CF7A06CCA25792B0077991B/\\$FILE/improvingcare-summary.pdf](http://docs.health.vic.gov.au/docs/doc/2E9A6C3C6CF7A06CCA25792B0077991B/$FILE/improvingcare-summary.pdf)

Guidelines¹⁰²

- 10.5.1. Where possible, clients should be encouraged to include family and carers in the CDAMS process.
- 10.5.2. An informant report of function and change is very important in the assessment process. However, where there is discrepancy between family/carer and client reports of function, a more detailed assessment and direct observation are indicated.
- 10.5.3. CDAMS should recognise and respect the right of families and carers to choose the level of involvement they will have in the care process. This will vary between family members and carers and may change over time.
- 10.5.4. Family and carer needs and preferences should be identified and with their consent, referrals made for appropriate support services and information provided on how to access supports to meet future care and education needs.
- 10.5.5. Although family and carers are important in the assessment and care planning process, the client's wishes must have ascendancy should conflict arise. (This is clouded when issues of competency arise). When the client does not consent to the family/carer(s) being involved, the CDAMS team should ensure they operate within the bounds of privacy legislation. The Health Privacy Principles in the Health Records Act (2001) Victoria (p102-103) stipulates:

'A health service provider may disclose health information about an individual to an immediate family member of an individual if –

- a. Either –*
 - i. The disclosure is necessary to provide appropriate health services to or care of the individual; or*
 - ii. The disclosure is made for compassionate reasons; and*
- b. The disclosure is limited to the extent reasonable and necessary for the purposes mentioned in paragraph (a); and*
- c. The individual is incapable of giving consent to the disclosure within the meaning of section 85(3); and*
- d. The disclosure is not contrary to any wish –*
 - i. Expressed by the individual before the individual became incapable of giving consent and not changes or withdrawn by the individual before then; and*
 - ii. Of which the organisation is aware of could be made aware by taking reasonable steps...'*

¹⁰² Should be read in conjunction with the Core Principles of Practice on p19.

Standard 11

CO-ORDINATION WITH GENERAL PRACTITIONERS

Standard

CDAMS involve a client's general practitioner throughout the assessment process, provide the results of the assessment with recommendations for a care plan, subject to the clients consent.

*The HIP guidelines stipulate that GPs should be actively engaged throughout the CDAMS process to facilitate continuity of care. They 'remain responsible for the medical management of client while they are receiving services.'*¹⁰³

Criteria

- 11.1. A system for obtaining medical information and reports of screening investigations from the GP has been developed.
- 11.2. GPs are informed of the assessment outcome, including diagnosis and suggested care plan, subject to client's consent.
- 11.3. CDAMS provides ongoing expert advice to GPs on an "as needs" basis that is in response to their requests.
- 11.4. Links with GPs are maintained and communication encouraged.
- 11.5. Written information on CDAMS services and their contact details is provided and made accessible to GPs.
- 11.6. The client's GP remains their primary care provider.

Guidelines¹⁰⁴

- 11.1. The CDAMS has clear referral guidelines for GPs that outline the information that is required concerning the referred client (see box below). This may be communicated via letters, faxes, emails, phone calls or internet accessible information. GPs are encouraged to:
 - a. Provide medical information and investigation reports.
 - b. Facilitate dementia screening investigations prior to attendance at CDAMS.
- 11.2. Privacy legislation is adhered to. Refer to Guideline 2.1.1
- 11.3. CDAMS keeps GPs informed of matters affecting the care of their clients including decisions to refer their clients to other services and any changes in medicines.

¹⁰³ p.25 Health Independence Program Guidelines: <http://health.vic.gov.au/subacute/hip-manual08.pdf>

¹⁰⁴ Should be read in conjunction with the Core Principles of Practice on p19.

- 11.4. With client's consent, CDAMS provide GPs with a written compilation of the client's assessment results, their care plan, including diagnosis, and any subsequent actions taken.
- 11.5. CDAMS informs GPs of the option to participate in case conferences, care plan preparation and feedback meetings (either by phone or face to face) and to consider use of EPC Medicare and MBS items.
- 11.6. GPs are informed when referrals are not accepted and provided with rationale for this. Where possible, advice is provided to facilitate referral to more appropriate services.
- 11.7. CDAMS provides GPs with information concerning actions they need to take to facilitate continuation of dementia medicines (eg cholinesterase inhibitors).
- 11.8. On request, CDAMS provides GPs with advice concerning potential referrals and management of clients following their discharge from CDAMS.
- 11.9. Ensure that Medicare Locals and GP Victoria are kept informed of the role of CDAMS, and its contact details.
- 11.10. Where possible CDAMS participates in and encourages dementia education programs for GPs and Practice Nurses.

Suggested information GPs may provide and investigations that they may facilitate:

History:

Presenting problems
Past medical history
Past Psychiatric history
Medicines
Allergies including drug reactions
Substance use & abuse, eg ETOH
Mobility and falls

Physical examination:

Any General Examination results as appropriate

Screening assessment:

Cognition eg MMSE, GPCOG
Mood

Investigations

Imaging:

Non-contrast CT brain if not performed in last 12 months or since onset of memory problems
ECG

Pathology (dementia screen):

FBE, ESR, U&E's, LFT's, TFT's, B12, Calcium and Phosphate, Vitamin D, Glucose, urine analysis
Where indicated: VDRL, HIV, Red cell Folate

Standard 12 **TELEHEALTH**

Standard

Client assessment, case conferencing, feedback and review may be completed via telehealth.

Telehealth involves the delivery of health services using video-conferencing technology. In dementia care, telehealth is increasingly being used to facilitate diagnosis and treatment. Provision of such services has been demonstrated to provide accurate diagnosis, and be feasible and acceptable to health professionals, clients and their families/carers.

The Victorian Health Priorities Framework 2012-2022: Rural and Regional Health Plan¹⁰⁵ supports the use of telehealth to provide better service access to those in Rural and Regional Victoria.

Criteria

- 12.1. CDAMS may provide telehealth clinic services using videoconferencing where there is no practical alternative.
- 12.2. The availability of telehealth delivered CDAMS should not preclude a client and their family/carer from accessing face to face assessment where this is preferred.
- 12.3. Telehealth delivered CDAMS services are provided by health professionals skilled in the use of video conferenced assessment, diagnosis and treatment of people with cognitive changes, cognitive impairment and dementia and their families/carers.
- 12.4. Telehealth may be used to complete a medical assessment, limited cognitive assessment or allied health professional assessment.

Guidelines¹⁰⁶

- 12.1. CDAMS utilises secure video conferencing facilities in the provision of telehealth services¹⁰⁷. Facilities should utilise high speed internet connection and have high picture resolution.

¹⁰⁵ Can be viewed at: <http://www.health.vic.gov.au/healthplan2022/>

¹⁰⁶ Should be read in conjunction with the Core Principles of Practice on p19.

¹⁰⁷ The Australian Medical Association states that “It is mandatory that all medical practices integrating electronic communications to ensure they are compliant with appropriate standards around hardware and software, and secure transmission of data, including authentication.” AMA (2006).

- 12.2. All CDAMS clinicians involved in using telehealth are orientated to the equipment and processes used.
- 12.3. Information technology support should be available throughout the duration of the telehealth clinics to assist with addressing any issues that arise with the videoconferencing technology.
- 12.4. A skilled CDAMS clinician is located at the remote end of the telehealth service¹⁰⁸. Their role as the key worker is to:
 - a. Be the key CDAMS contact person for the client/family/carer.
 - b. Complete the initial assessment and any formal assessments requested by the medical specialist, neuropsychologist or allied health professional.
 - c. Obtain client consent to participate in telehealth.
 - d. Organise all documents and results required as part of the medical assessment e.g. dementia screen results, medical history etc, and ensure these are accessible by hub clinicians.
 - e. Organise the telehealth clinic appointments.
 - f. Ensure the set-up of the video conference facilities and check functioning e.g. sound and picture at the remote end. This role may be undertaken by information technology support personnel.
 - g. Provide the CDAMS medical specialist, neuropsychologist or allied health professional with a verbal summary of the client's needs, assessment results and any concerns.
 - h. Orientate the clients and their family/carer to the videoconference facilities and attend to any adjustments that need to be made, to accommodate for the client's/family's/carer's sensory losses, e.g. fine tuning sound.
 - i. Assist the CDAMS medical specialist, neuropsychologist or allied health professional at the hub end of the videoconference to administer all tests e.g. cognitive screening tests. The remote CDAMS clinician will also complete any assessment tasks which require physical contact with the client.
 - j. Complete all associated documentation
 - k. Complete all referrals and follow up.
- 12.5. Skilled CDAMS medical, neuropsychology and allied health staff are located at the hub end¹⁰⁹ of the videoconference. Their role is to:
 - a. Review all relevant client information and assessment results.
 - b. Develop rapport with the client and their family/carer(s).
 - c. Complete formal assessments by working with the remote clinicians to facilitate communication and testing.
 - d. Provide verbal feedback to the client and their family/carer concerning the results of the assessment and recommended treatment.

¹⁰⁸ The term 'remote CDAMS clinician' refers to a CDAMS clinician located in a regional or rural area of Victoria.

¹⁰⁹ The 'hub end' of the video conference may be a metropolitan, regional or rural CDAMS. The 'hub end' provides specialist assessment.

- e. Medical specialists should write a letter to the GP (and referrer) to inform them of the results of the assessment and treatment plan including any recommended medicines. The neuropsychologist and allied health professional are responsible for writing their own reports and sending these to the remote CDAMS.
- 12.6. At the beginning of each telehealth clinic, the CDAMS clinicians discuss the clients who will be attending.
- 12.7. The remote CDAMS clinician and hub CDAMS medical specialist, neuropsychologist and/or allied health professional engage in case conferences to discuss assessment results and treatments and to formulate an agreed care plan. This may be face to face, or via videoconference or teleconference.
- 12.8. Assessment tools that are valid for use with video conferencing should be used. At the time of approval for these guidelines (September 2013) the tools listed were validated for use with teleconferencing. Other assessment tools may become validated over time and clinicians should remain up to date with this research. These include:
 - a. Cognitive Screening/Assessment Tools: MMSE¹¹⁰, SMMSE¹¹¹, Boston Naming Test¹¹², letter fluency¹¹³, digit span recall¹¹³, Hopkins Verbal Learning Test – Revised total recall¹¹³, RUDAS¹¹⁴ and CAMDEX¹¹⁵.
 - b. Mood Assessment Tools: GDS¹¹⁶
 - c. Other Assessment Tools: The following tools have also been used in research on diagnostic accuracy of dementia using videoconferencing. The Katz assessment of ADLs, Instrumental ADL assessment and IQCODE¹¹⁷; and Short Blessed and three word recall¹¹³; letter and animal naming verbal fluency, Disability Assessment for Dementia and NPI-Q¹¹⁸. Results on the validity of the clock drawing test have been inconsistent^{113 115}.
- 12.9. Clients and families/carers should be given the opportunity to ask questions or provide feedback before the videoconference clinic appointment ends.

¹¹⁰ Anthony et al (1982); Cullum et al (2006); McEachern et al (2008)

¹¹¹ Loh et al (2004)

¹¹² Cullum et al (2006)

¹¹³ Shores et al (2004)

¹¹⁴ Wong et al (2012)

¹¹⁵ Ball et al (1998)

¹¹⁶ Loh et al (2004)

¹¹⁷ Loh et al (2005)

¹¹⁸ Martin-Khan et al (2012)

Standard 13

LEADERSHIP AND MANAGEMENT

Standard

The CDAMS are efficiently managed in accordance with their stated philosophy, to ensure quality of service.

CDAMS operate under the Health Independence Programs¹¹⁹ suite of services and within public health services that are accredited by the Australian Council on Health Care Standards¹²⁰. 'Effective clinical leadership is an important driver of quality and safety in health care.'¹²¹

Criteria

- 13.1. CDAMS have a dedicated management/coordinator/team leader position responsible for the service.
- 13.2. CDAMS managers/coordinators provide leadership and act in accordance with policies and delegated authority
- 13.3. CDAMS have systems and processes in place to ensure the program is appropriately managed.

Guidelines¹²²

13.1 Coordination, management and leadership

- 13.1.1. CDAMS has a dedicated coordinator/manager/team-leader, with the skills detailed in standard 14, who is responsible for:
 - a. Facilitating the flow of referrals through CDAMS to minimise waiting times where possible.
 - b. Ensuring that processes are followed to facilitate the client's/family's/carer's journey through CDAMS.
 - i. Facilitating allocation of key workers to individual clients.

¹¹⁹ Can be viewed at: <http://health.vic.gov.au/subacute/hip-manual08.pdf>

¹²⁰ For more information, refer to: <http://www.achs.org.au/>

¹²¹ p1. Victorian Quality Council. Can be viewed at: <http://www.health.vic.gov.au/qualitycouncil/downloads/clinical%20leadership%20web%20update%20Jan%202013.pdf>

¹²² Should be read in conjunction with the Core Principles of Practice on p19.

- ii. Overseeing/Coordinating the home visit and/or clinic appointments including initial, medical and neuropsychological assessments, and feedback and review meetings.
 - iii. Facilitating case conferences.
- c. Ensuring that data requirements such as service events and contact information for CDAMS clients are collected.
- d. Coordinating the CDAMS team and responding to their professional needs.
 - i. Providing leadership and representation for the team.
 - ii. Recruitment of suitably trained staff¹²³.
 - iii. Ensuring new staff are orientated to CDAMS.
 - iv. Ensuring less experienced staff are supported in developing further skills by providing learning opportunities, support, modelling and supervision.
 - v. Regular performance appraisals of staff¹²⁴.
 - vi. Organising and/or informing CDAMS staff of professional development opportunities.
 - vii. Coordinating and facilitating strategic planning on at least an annual basis¹²⁴.
 - viii. Advocating for the needs of the team including for increased EFT and regrading of positions as needed.
 - ix. Reporting issues to the SACs manager (or equivalent).
- e. Reviewing service outcomes.
- f. Facilitating quality improvement and research activities.
- g. Participating in quarterly state-wide coordinators meetings.
- h. Ensuring the CDAMS is operating in a manner consistent with best practice guidelines.

13.2 Cognitive Dementia and Memory Services have systems that encompass:

- 13.2.1. Strategic planning.
- 13.2.2. Policy development.
- 13.2.3. Procedures specifications.
- 13.2.4. Service delivery, performance and review.
- 13.2.5. Client/community liaison.
- 13.2.6. Service representation in internal and external forums.
- 13.2.7. Service complaints and compliments.
- 13.2.8. Financial accountability.
- 13.2.9. Administrative performance.
- 13.2.10. Staff selection/performance appraisal/development.
- 13.2.11. Ensuring implementation and ongoing review of Cognitive Dementia and Memory Service guidelines.
- 13.2.12. Ensuring implementation of the Department of Health program recommendations.

¹²³ May complete or assist with this role depending on level of management.

Standard 14 TEAM COMPETENCY

Standard

CDAMS team members have experience and demonstrate expertise across all key components of cognitive and aged care assessment, client/carer support, and the dementia and aged care service systems.

'The workforce needs to have the appropriate skills and levels of expertise to provide patients with the most clinically effective care'.¹²⁴

Criteria

14.1 CDAMS Coordinators/Managers/Team Leaders have:

- 14.1.1. Relevant clinical backgrounds, interest and demonstrated knowledge and skills in dementia care in a community setting.
- 14.1.2. Management experience and preferably qualifications
- 14.1.3. Well-developed interpersonal skills

14.2 CDAMS Clinicians:

- 14.2.1. Have relevant clinical qualifications, clinical knowledge, expertise, and skills in the assessment, diagnosis, treatment and management of people with dementia/cognitive impairment.
- 14.2.2. Have a specific interest in the area of dementia.
- 14.2.3. Have demonstrated clinical knowledge and skills in dementia care in a community based setting
- 14.2.4. Have a comprehensive understanding of dementia and the dementia pathway
- 14.2.5. Have well developed interpersonal skills
- 14.2.6. Are abreast of the latest research and developments in dementia including misinformation
- 14.2.7. Know how to involve carers/family and utilise their skills and knowledge, assess their capacity to care and include them as part of the care team.
- 14.2.8. Know and understand medico-legal issues as they pertain to dementia. E.g. Driving and Dementia; Enduring Powers of Attorney.

¹²⁴ p32. Victorian Health Priorities Framework 2012-2022: Metropolitan Health Plan. Can be viewed at: <http://docs.health.vic.gov.au/docs/doc/Victorian-Health-Priorities-Framework-2012-2022:-Metropolitan-Health-Plan>

14.3 Administrative Staff¹²⁵:

- 14.3.1. Have an interest in dementia care
- 14.3.2. Have good interpersonal skills
- 14.3.3. Provide support to the service manager and clinicians.

Guidelines¹²⁶

14.1 CDAMS Teams exhibit:

- 14.1.1. A sound knowledge of relevant Federal and State Government policies and protocols as related to CDAMS, dementia and aged care.
- 14.1.2. Expertise in dementia and aged care.
- 14.1.3. Expertise within each team member's professional discipline.
- 14.1.4. Detailed knowledge of dementia and aged care services and facilities.
- 14.1.5. A willingness to maintain and improve their skills.
- 14.1.6. Engagement in regular in-service development and training in the assessment, diagnostic and support roles of CDAMS clinics.
- 14.1.7. An understanding of the skills and roles of each team member.
- 14.1.8. Seek and provide assistance to each other.
- 14.1.9. Effective informal and formal communication within the team.
- 14.1.10. Effective written and verbal communication skills.
- 14.1.11. A balance of professional skills.

14.2 CDAMS Coordinators/Managers/Team Leaders have:

- 14.2.1. A relevant clinical background and extensive knowledge and experience in aged and dementia care in a community based setting.
- 14.2.2. Management experience and appropriate qualifications.
- 14.2.3. Leadership skills.
- 14.2.4. Communications skills.
- 14.2.5. Organizational skills.
- 14.2.6. Management skills.

14.3 CDAMS Clinicians have:

Please note: These are in addition to the skills outlined in the Health Independence Guidelines¹²⁷.

- 14.3.1. Qualifications and relevant professional experience. Refer to Section 2.

¹²⁵ Not all clinicians will have all of these skills. Skills will depend on a clinician's qualification and experience.

¹²⁶ Should be read in conjunction with the Core Principles of Practice on p19.

¹²⁷ Can be viewed at: <http://health.vic.gov.au/subacute/hip-manual08.pdf>

- 14.3.2. Experience in working with people with cognitive impairment / aged care / older people, or are in the process of acquiring these under supervision of those who are experienced.
- 14.3.3. A comprehensive understanding of the characteristics of dementia, its management and the special needs of the person with dementia and their families/carers.
- 14.3.4. Strong knowledge base in cognitive, dementia and aged conditions.
- 14.3.5. Skills/expertise to identify risk factors for dementia, preventable dementias and those that are amenable to treatment.
- 14.3.6. Skills in engaging and developing therapeutic relationships with people with dementia, their family and carers.
- 14.3.7. Skills in sensitively disclosing and discussing diagnoses and assessment results with people with dementia and their families/carers.
- 14.3.8. Skills in recommending treatment options that are appropriate to the person's diagnosis, abilities, needs and the needs of the family/carer. This includes expertise in identifying strategies to strengthen coping skills of people with dementia and their families/carers.
- 14.3.9. Skills to adapt the complexity of communication to suit the abilities of people with dementia and their families/carers.
- 14.3.10. An understanding of behaviour management techniques and appropriate pharmacological and psychological management.
- 14.3.11. Knowledge about the health impacts of dementia, the consequences of treatment and care implications.
- 14.3.12. Knowledge about drug impacts on the person with dementia and effects on treatment.
- 14.3.13. An understanding of the legal basis of dementia / aged care.
- 14.3.14. A commitment to advocacy.
- 14.3.15. Knowledge of aged and dementia care services, facilities, supports and relevant policies.

14.4 Administrative staff have:

- 14.4.1. Clerical skills.
- 14.4.2. Relevant computer program skills.
- 14.4.3. Well-developed receptionist skills (including telephone skills).
- 14.4.4. Basic knowledge of dementia / aged care services and CDAMS functions.
- 14.4.5. Highly developed interpersonal skills.

Standard 15 INDUCTION TRAINING

Standard

New members of the CDAMS receive instruction and support to acquire the proficiency needed to provide a quality service to clients and their families/carers.

*'Staff participate in a comprehensive orientation program.'*¹²⁸

Criteria

- 15.1. Cognitive, Dementia and Memory Services have an induction training program
- 15.2. Cognitive, Dementia and Memory Service philosophy, policies and procedures are fully understood by new team members
- 15.3. New Cognitive, Dementia and Memory Service team members are made fully conversant with legal, policy and administrative obligations of their role.
- 15.4. Cognitive, Dementia and Memory Services provide peer support.

Guidelines¹²⁹

In addition to the health service's orientation, CDAMS should:

- 15.1. Introduce new team members to key managers and service providers both within the organisation and the community. This activity includes attendances at relevant meetings.
- 15.2. Orientate new team members to policies and procedures, including a detailed understanding of all guidelines contained in the CDAMS Best Practice document.
- 15.3. Provide new team members with a tour of the site, visits to related dementia / aged care services.
- 15.4. Provide new team members with an introduction to the role and functions of dementia, aged and disability services. Ensure meetings with relevant key organizations.
- 15.5. Provide new team members with lists of service providers and familiarise them with information resources available for clients/families/carers.
- 15.6. Introduce new team members to the process of the CDAMS assessment, including assessment techniques and tools, specific assessment issues and use of interpreters.

¹²⁸ p65. Health Independence Program Guidelines: <http://health.vic.gov.au/subacute/hip-manual08.pdf>

¹²⁹ Should be read in conjunction with the Core Principles of Practice on p19.

-
- 15.7. Conduct joint assessments with new team members, establish a timeframe for undertaking independent assessments, discuss and review practice.

Standard 16

CONTINUOUS QUALITY IMPROVEMENT

Standard

CDAMS operate within a formal continuous quality improvement framework.

*'Quality plans optimise client care by providing evidence of outcomes and identification of areas for enhancement.'*¹³⁰

Criteria

- 16.1. CDAMS develop and maintain a continuous quality improvement plan.
- 16.2. The Quality Improvement Plan includes domains for client feedback, team and staff competencies, assessment processes, service access, client outcomes, family/carer engagement and outcomes, service provider relationships, safety and information management.
- 16.3. CDAMS have dedicated time for Quality Improvement activities.

Guidelines¹³¹

16.1 A Quality Improvement Plan:

- 16.1.1. Is based on the Australian Council of Health Care Standards¹³² accreditation standards.
- 16.1.2. Is based on the need for corrective action
- 16.1.3. Is based on requirements of service agreements.
- 16.1.4. Identifies actions required
- 16.1.5. Identifies time frames for the actions.
- 16.1.6. Identifies who will be responsible for actioning various elements of the plan.

16.2 CDAMS should:

- 16.2.1. Consider review of 5-10% of clients to monitor diagnostic accuracy and client outcomes.
- 16.2.2. Benchmark to like services (CDAMS and memory clinics) to ensure best practice.

¹³⁰ p.71Health Independence Program Guidelines: <http://health.vic.gov.au/subacute/hip-manual08.pdf>

¹³¹ Should be read in conjunction with the Core Principles of Practice on p19.

¹³² For more information, refer to: <http://www.achs.org.au/>

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- 16.2.3. Share quality activity outcomes with other CDAMS to enable further development of best practice across services where appropriate.
 - 16.2.4. Carry out activities to assess service outcomes. See Appendix 5.9.

Section 5
APPENDICES

Appendix 5.1

SUBACUTE AMBULATORY CARE SERVICES (SACS) SPECIALIST CLINIC: CLINIC SERVICE CAPABILITY FRAMEWORK AND SERVICE MODEL

SACS Specialist clinics provide specialist assessment, diagnosis, intervention, management, education, advice and support to clients with specific conditions and are expected to operate at level 3 and level 4 services.

Clinics commonly provide time-limited, specialist diagnosis and intervention to the client and referral onto appropriate mainstream services for ongoing management if required. They also provide consultancy, education and support to carers, relatives and professional service providers. SACS Specialist clinics are delivered in a number of settings including a client's home and at a centre. Specialist clinics include: Continence, Falls and mobility, Chronic pain management, Cognitive dementia and memory services (CDAMS), Movement disorders, Polio Services Victoria, Chronic wound management and Transition of young adults with complex medical needs services.

Not all clients with conditions related to the above clinics require access to a specialist clinic. For example, many clients who have had a fall, have bladder issues or pain will be well managed by their general practitioner, nursing services, single discipline allied health intervention or in a community rehabilitation centre. Clients with complex, non-resolving and/or prolonged conditions may require access to specialist clinic consultation.

Documentation (comprising two parts) to support service consistency has been developed to outline the model of care and role of the clinics within the context of the subacute services planning framework. These documents have been developed in consultation with SACS Managers and the specialist clinic coordinators.

The following documents are attached:

1/ Specialist clinic service model

Outlines the model of care within each of the specialist clinics and includes:

- Aim of the clinic
- Clients seen
- Core clinical staff complement
- Clinic model/range of services: eg assessment, care planning, case conference, intervention, discharge etc (with a brief description of each)

2/ Service capability framework (SCF)

To quantify and describe the role of the clinics expected to operate at particular levels in line with the service capability framework (SCF) developed as part of the subacute services planning framework.

The SCF for subacute services uses a five-level classification where level 1 is the lowest and level 5 is the highest. The expected features of specific service levels are:

- Statewide (level 5)
- Regional (level 4)
- Sub-regional (level 3)
- Local (level 2)
- Local (level 1)

The work considers each of the seven service criteria within the SCF.

1. Service description and patient mix
2. Catchment
3. Clinical staff levels and involvement
4. Networking, integration and relationships
5. Quality standards and clinical guidelines
6. Infrastructure, equipment and supporting services
7. Teaching and research

These documents should be read in conjunction with the health independence program (HIP) guidelines (<http://health.vic.gov.au/subacute/hip-manual08.pdf>) and the Subacute Services Planning Framework (http://health.vic.gov.au/subacute/subacute_service_system_framework.pdf).

Appendix 5.2

SUBACUTE AMBULATORY CARE SERVICES

COGNITIVE DEMENTIA AND MEMORY SERVICES

(CDAMS) MODEL

Overall aim

The aim of Cognitive Dementia and Memory Services (CDAMS) is to provide early diagnosis, advice, support and referral for people with cognitive difficulties causing confusion, memory loss or thinking problems. CDAMS also aims to support family and carers of those with cognitive issues.

Clients

The primary target group for CDAMS is dementia related illness with a particular focus on clients with newly emerging cognitive issues.

Where the client is under 50 and there is no obvious evidence of risk factors for dementia, efforts should be made to pursue alternative more appropriate avenues of assessment as a first option. Where cognitive or memory problems have been longstanding and there is no evidence of deterioration, or the decline is related to a known illness (eg: ABI, MS etc) then CDAMS assessment may not be appropriate.

Core clinical staff complement

The range of clinicians comprising the inter-disciplinary team and the level of expertise and experience will be consistent with the level at which the service is expected to operate. At a minimum the service will comprise:

- a specialist medical practitioner;
- nursing/occupational therapist/social work; and
- a neuropsychologist or access to neuropsychology assessment if not on staffing

Range of services

The range of services to be provided in CDAMS will be consistent with the level at which the service is expected to be operating and comprises the following:

- Assessment;
- Case conference;
- Care planning;

CDAMS clinic service model August 2011

This document should be read in conjunction with the CDAMS clinic service capability framework. For further information on the Subacute Services Planning Framework refer to: http://health.vic.gov.au/subacute/subacute_service_system_framework.pdf

- Working with carers;
- Short term care plan implementation and referral to other service providers;
- Review and discharge; and
- Consultation-liaison and education

As a subacute ambulatory care services (SACS) CDAMS clinics are expected to deliver care in line with the Health Independence Programs (HIP) guidelines (<http://health.vic.gov.au/subacute/hip-manual08.pdf>).

Assessment

Assessments will be undertaken by the most appropriate team member and where possible at a time convenient to the client and carer/s. Assessments should occur in a setting that best addresses both client and clinical needs.

All clients should undergo an initial assessment by an appropriate team member that includes past history, assessment of their home situation and ability to function within the home. A standard assessment approach (possibly incorporating a standard form) should be used at the time of the initial assessment to help identify the need for referral to other health care professionals or service providers.

Family and carers provide an important source of information in the CDAMS assessment process. The experience of care-givers should be assessed, as degree of care-giver burden is a good predictor of service use. Where there is a discrepancy between care-giver and client reports of function then more detailed assessment and direct observation are indicated. Where possible, carers should have the opportunity for independent interview.

Following the initial assessment a medical assessment is undertaken, incorporating physical, cognitive and non-cognitive domains. Further assessment by a neuropsychologist or other relevant specialist may be provided if required. Where possible, the aim of the assessment is to develop a diagnosis.

Case conference

On completion of all assessment procedures an interdisciplinary case conference is held for all clients. All team members involved in a client's care should participate in the case conference.

CDAMS clinic service model August 2011

This document should be read in conjunction with the CDAMS clinic service capability framework. For further information on the Subacute Services Planning Framework refer to: http://health.vic.gov.au/subacute/subacute_service_system_framework.pdf

Care planning

As a result of the case conference, a care plan should be developed for each client including issues discussed and recommendations for action. Family and carers should be involved in the care planning process where possible. The care plan is developed to ensure all people involved in implementing the care plan are working towards the same goals. It should be goal-orientated, time-limited and based on the best available evidence. The care plan will evolve in response to changes in the client's circumstances, diagnosis or additional issues present.

For CDAMS, the care plan will involve developing a plan for treatment and/or management of the client's condition and referral to other service providers for ongoing or continuing management.

Working with carers

On completion of a CDAMS assessment, feedback should be provided to the client and their family and carers (with the client's consent). Feedback should include discussion of the assessment results, the likely diagnosis, prognosis and the suggested care plan with agreement reached on actions to be taken.

CDAMS should recognise and respect the right of families and carers to choose the level of involvement they will have in the care process. This will vary between carers and may change over time.

Families and carers should be provided with the opportunity for education and counselling regarding the illness, prognosis and available treatment. Families and carers should be provided with information regarding future planning including sources of care and support, financial and legal issues.

Family and carer needs should be identified and with their consent, referrals made for appropriate support services. Information on how to access supports to meet future care and education needs should also be provided.

Short term care plan implementation and referral to other service providers

Once a diagnosis has been established the focus of CDAMS is to ensure implementation of the short term care plan with referrals made to other service providers for ongoing client management.

Short term care plan implementation by CDAMS may include:

- Specific treatment for the client's condition including medication prescription;

- Provision of education and advice regarding the client's condition to the client and their family/carers;
- Linking clients to other service providers for ongoing management;
- Ensuring that referrals to agreed services are put in place;
- Remaining available for support until the agreed services are in place;
- Providing assistance to arrange services required by the clients family or carer; and
- Identifying potential future support and service requirements and providing verbal and written information to clients, carers and GP's/referrers on these as required.

CDAMS should remain available for support while referrals are being put in place. If future difficulties arise, advice may be sought from CDAMS on the management of such difficulties and referral to other appropriate service providers.

Review and discharge

The client's general practitioner should be informed when clients are discharged from the CDAMS service. Clients should be discharged when appropriate referrals have been made and clients are linked in with providers identified in the care plan.

In some cases client review may be undertaken where it is identified to be an essential part of the care pathway. Clients with complex identified issues that require CDAMS expertise should be reviewed at an interval identified by CDAMS clinicians.

A review may also be undertaken at the request of the client/carer or their general practitioner where the initial diagnosis is in question and where this is deemed appropriate by the CDAMS clinicians. This would also include clients with a diagnosis of Mild Cognitive Impairment.

Consultation-liaison and education

All level 4 CDAMS clinics are expected to provide a secondary consultation role to support level 3 services.

All CDAMS clinics (level 3 and 4) are expected to provide a secondary consultation role to support level 2 SACS services. CDAMS may be expected to provide a more general educational role within the health service regarding dementia and cognitive issues.

CDAMS clinic service model August 2011

This document should be read in conjunction with the CDAMS clinic service capability framework. For further information on the Subacute Services Planning Framework refer to: http://health.vic.gov.au/subacute/subacute_service_system_framework.pdf

Appendix 5.3

SERVICE CAPABILITY FRAMEWORK FOR SUBACUTE AMBULATORY CARE SERVICES COGNITIVE DEMENTIA AND MEMORY SERVICES (CDAMS)

Service Capability Framework for subacute ambulatory care services Cognitive Dementia and Memory Services (CDAMS)

*Expectation that SACS CDAMS clinics only operating at Level 3/4 services matching designated SACS service level

Service Criteria	Level 1	Level 2	Level 3*	Level 4*	Level 5
Service description & patient mix	Primary Care Services Clients with emerging cognitive issues.	Single disciplinary medical clinic OR Single discipline allied health or limited multidisciplinary allied health without medical input. Client profile includes clients with cognitive issues with a non-dementia related illness (MS, ABI) or with a known dementia related diagnosis. May also include screening for CDAMS.	Specialist clinic that is part of a network of ambulatory services linked with the community rehabilitation centre. Comprehensive multidisciplinary allied health AND Specialist medical input Model includes case conferencing with multidisciplinary team as required. Client profile includes clients with cognitive difficulties and dementia related illness requiring diagnosis.	Specialist clinic that is part of a network of ambulatory services linked with the community rehabilitation centre. Comprehensive multidisciplinary allied health AND Specialist medical input Model includes case conferencing with multidisciplinary team as required. Provision of regional or sub-regional consultancy services and have available consultation-liaison services in other disciplines. Client profile includes clients with cognitive difficulties and dementia related illness requiring diagnosis. May also include management of clients requiring particular expertise or working with specialised groups such as ATSI population or clients with intellectual disability.	N/A
Catchment	Local	Local	Sub-regional	Regional	Statewide

This document should be read in conjunction with the CDAMS clinic service model. For further information on the Subacute Services Planning Framework refer to:
http://health.vic.gov.au/subacute/subacute_service_system_framework.pdf
August 2011

Service Capability Framework for subacute ambulatory care services Cognitive Dementia and Memory Services (CDAMS)

*Expectation that SACS CDAMS clinics only operating at Level 3/4 services matching designated SACS service level

Service Criteria	Level 1	Level 2	Level 3	Level 4	Level 5
Clinical staff levels & involvement	GPs (general practice) and/or community based allied health & nursing practitioners	Medical-only clinics may comprise a range of specialists and/or GP with special interest relevant in cognitive impairment OR Allied health-only clinics may include a range of allied health disciplines and nursing support May include nursing or allied health within community rehabilitation centre.	Multidisciplinary team led by relevant medical specialist Medical involvement may comprise a range of specialists which may include geriatrician, psychiatrist, psychogeriatrician or neurologist AND Allied health involvement includes a range of allied health disciplines, nursing support and access to neuropsychology assessment. Multidisciplinary team approach to care including case conferencing.	Multidisciplinary team led by relevant medical specialist Medical involvement may comprise a range of specialists which may include geriatrician, psychiatrist, psychogeriatrician or neurologist AND Allied health involvement includes a range of allied health disciplines, nursing support and neuropsychology on staff Staff have extensive relevant experience and/or relevant postgraduate qualifications Multidisciplinary team approach to care including case conferencing	N/A
Networking & integration & relationships	May have informal relationships with specialist services in Level 2 and above	Established links with specialist services in Level 3 and above; established referral pathways from Level 1	Protocols established with Level 4 services which may include shared service model and/or specialist outreach from Level 4 service Established referral pathways from Levels 1 and 2 services	Established referral pathways from Levels 1, 2 and 3 services with outreach strategies supported by telehealth. Formal protocols to define shared service and outreach arrangements with Level 3 services Formal protocols specifying consultation-liaison input from/to relevant services	N/A

This document should be read in conjunction with the CDAMS clinic service model. For further information on the Subacute Services Planning Framework refer to: http://health.vic.gov.au/subacute/subacute_service_system_framework.pdf
August 2011

Service Capability Framework for subacute ambulatory care services Cognitive Dementia and Memory Services (CDAMS)

*Expectation that SACS CDAMS clinics only operating at Level 3/4 services matching designated SACS service level

Service Criteria	Level 1	Level 2	Level 3	Level 4	Level 5
Quality standards and clinical guidelines	Quality standards relevant to professional discipline	Adherence to specific clinical guidelines for relevant specialist clinic / specific client group Adherence to quality assurance activities specific to health service Clinical risk assessment	Adherence to specific clinical guidelines for relevant specialist clinic / specific client group Adherence to quality assurance activities specific to health service Integrated clinical governance and outcome measurement Use of clinical protocols based on best practice and current research and validated tools as available	Adherence to specific clinical guidelines for relevant specialist clinic / specific client group Adherence to quality assurance activities specific to health service Well-established clinical governance across all providers in the region/sub-region, active participation in benchmarking at regional and cross-regional level Use of clinical protocols based on best practice and current research and validated tools as available	N/A
Infrastructure, equipment & supporting services	Access to pharmacy, pathology, imaging as required	Access to clinical treatment/assessment rooms equipped with relevant aids and equipment	Access to clinical treatment/assessment rooms and facilities for case conferencing. Access to therapy areas equipped with aids and equipment including relevant cognitive assessment instruments/tools. Access to equipment /tools required for home-based visit/assessment	Access to clinical treatment/assessment rooms and facilities for case conferencing Access to therapy areas equipped with aids and equipment including relevant cognitive assessment instruments/tools Access to equipment/tools required for home-based visit/assessment	N/A
Teaching & research	GPs, nursing and allied health practitioners with high case load may participate in external education programs	Some members of clinical team have completed external education programs relevant to management of clients with cognitive issues	Majority of team members have completed external education programs relevant to diagnosis and management of clients with cognitive issues and have expertise in this area	May involve rotations by medical trainees in relevant area Accredited medical training site where relevant, with strong teaching focus, including offering education/training modules for staff in Level 1, 2 and 3 services and would have an active research program Team members have completed relevant post graduate training and/or have demonstrated relevant experience	N/A

This document should be read in conjunction with the CDAMS clinic service model. For further information on the Subacute Services Planning Framework refer to: http://health.vic.gov.au/subacute/subacute_service_system_framework.pdf

August 2011

Appendix 5.4

METHODS USED TO REVISE & UPDATE THE CDAMS BEST PRACTICE GUIDELINES

The methods used to revise and update the CDAMS best practice guidelines included:

1. Completion of a comprehensive literature review of national and international literature focussing on the following areas (see attachment 1):
 - a. Dementia diagnosis and treatment of Aboriginal and Torres Strait Islanders.
 - b. Dementia diagnosis and treatment of adults with intellectual disabilities.
 - c. Early-onset dementia diagnosis and treatment.
 - d. Assessment of dementia.
 - e. Pre-clinical and prodromal Alzheimer's disease and mild cognitive impairment: Assessment and follow up.
 - f. Treatment using anti-dementia medicines.
 - g. Uptake of recommendations and follow-up provided by specialist dementia assessment clinics.
 - h. Outcome measures
 - i. Driving and dementia.
 - j. Advance care and future care planning.
 - k. Telehealth.
2. Stakeholder consultations.
 - a. Victorian CDAMS. All CDAMS were invited to complete a structured survey and a semi-structured interview as part of the consultation process. These information collection methods were used to identify: current CDAMS practices; areas of practice that were not reflected in the 2006 guidelines; and new areas of practice. They were also invited to review a draft of the revised guidelines.

The following CDAMS coordinators/clinicians participated in this consultation process:

Madeleine Adams	CDAMS Eastern Health
Joanne Bowman	CDAMS Northeast Health, Wangaratta
Kerry Devenish	CDAMS Northern Health
Cheryl Donohue	CDAMS Northern Health
Audra Fenton	CDAMS Central Gippsland Health Service
Vivien George	CDAMS Barwon Health
Lynn Gray	CDAMS Peninsula Health
Paula Jack and Fiona	CDAMS Austin Hospital
Gail Jenkins	CDAMS Goulburn Valley Health
Dr Dina LoGiudice	CDAMS Melbourne Health
Jennine Melville	CDAMS Monash Health

Michelle Mew	CDAMS Western Health
Elizabeth Rand	CDAMS Alfred Health
Anne Richards & Alison Dalziel	CDAMS Ballarat Health Service
Sarah Roach	CDAMS Albury Wodonga
Helen Vasilopoulos	CDAMS St Vincent's Hospital
Marie Wycisk	CDAMS Bendigo Healthcare Group

- b. Other Stakeholders/Experts. E-mail/phone/face to face consultations were conducted with a number of other identified experts or stakeholders. These included:

<i>Aboriginal and Torres Strait Islanders</i>	
Assoc Prof Dina LoGiudice	CDAMS Royal Park Campus, Royal Melbourne Hospital
Lorraine Parsons	Aboriginal Health Branch, Department of Health
John Price	Alzheimer's Australia Victoria
<i>Acute & Subacute Care</i>	
Andre Catrice	Ageing and Complex Care, Department of Health
Robyn Attoe	Peninsula Health
<i>Advance Care Planning</i>	
Bernadette Pound	Ageing and Complex Care, Department of Health
<i>Dementia and Carers</i>	
Di Calleja	Ageing and Aged Care Branch, Department of Health
<i>Dementia Diagnosis and Biomarkers</i>	
Prof David Ames	National Ageing Research Institute
<i>Hospital At Risk Program</i>	
Silvana Cavalli	Ageing and Complex Care, Department of Health
<i>Intellectual disability and dementia</i>	
Dr Jennifer Torr	Centre for Developmental Disability Health Victoria and St Vincent's Hospital CDAMS.
<i>Primary Care Physicians</i>	
Helen Threfall	General Practice Victoria
<i>Telehealth</i>	
Prof Leon Flicker	Western Australian Centre for Health Ageing

3. Planning and development meetings were held through the period during which the guidelines were revised and updated. These meetings were attended by:
 - a. Frits Kadijk, Senior Project Officer, Wellbeing, Integrated Care and Ageing, Department of Health, Victoria.
 - b. Elizabeth Rand, Manager, CDAMS, Caulfield Hospital, Alfred Health
 - c. Alissa Westphal, Lecturer in Dementia Care, The Academic Unit for Psychiatry of Old Age, Department of Psychiatry, The University of Melbourne.

Appendix 5.5

ASSESSMENT TOOLS

Cognitive Screening Tools

The spectrum of dementia related disorders affect a number of different domains. Cognitive tests rarely cover the full domain of functions that may be impaired and so more than one test is often required. The domains that should be assessed as part of a comprehensive assessment include:

- ‘Learning and memory’
- ‘Attention and concentration’
- ‘Speech and language abilities’
- ‘Executive functions’
- ‘General intellectual competence’
- ‘Visuo-spatial and visuo-constructional skills’
- ‘Sensory perceptual abilities’
- ‘Psychomotor speed’.

At a minimum the Dementia Outcome Measurement Suite recommend that the testing completed ‘should include attention, expressive and receptive language, memory, constructional ability and abstract reasoning’¹³³.

The Dementia Outcome Measurement Suite¹³⁴ recommends the following cognitive screening tools be used:

1. Modified Mini Mental Exam 3MS¹³⁵; May be used in place of the MMSE as it is freely available at no cost unlike the MMSE. The 3MS and MMSE do not assess frontal lobe function and so should only be used in addition to a second assessment tool which is sensitive to frontal lobe functioning. May be downloaded from: <http://www.dementia-assessment.com.au/cognitive/index.html>.
2. Alzheimer’s Disease Assessment Scale – Cognition ADAS-Cog¹³⁶: This test requires additional training to administer. It is often used to measure change in cognitive functioning. There is some normed data published for the ADAS-Cog¹³⁷.

¹³³ p109, Sansoni et al (2007).

¹³⁴ Sansoni et al (2007).

¹³⁵ McDowell (2006); Teng and Chui (1987).

¹³⁶ Rosen, Mohs, and Davis (1984).

¹³⁷ Graham et al (2004).

3. Rowland Universal Dementia Assessment Scale RUDAS¹³⁸: Better able to detect dementia in an Australian sample compared with MMSE and GPCOG. May be downloaded from: http://www.dementia-assessment.com.au/cognitive/RUDAS_scale.pdf.
4. Montreal Cognitive Assessment MOCA: designed to identify mild cognitive impairment. This test includes measures of frontal lobe functioning. May be downloaded from: <http://www.mocatest.org/>.
5. Addenbrookes' Cognitive Examination ACE-III¹³⁹ – The ACE-R¹⁴⁰ has been revised and replaced by the ACE-III. It is sensitive to early stages of dementia and is able to differentiate between Alzheimer's disease, FTD, progressive supranuclear palsy and other Parkinsonian syndromes. May be downloaded from: <http://neura.edu.au/sites/neura.edu.au/files/page-downloads/ACE-III%20Administration%20%28UK%29.pdf> and scoring guide http://neura.edu.au/sites/neura.edu.au/files/page-downloads/ACE-III%20Scoring%20%28UK%29_0.pdf
6. EXIT-25¹⁴¹ – Assesses executive functions. May be downloaded from: http://www.dementia-assessment.com.au/frontotemporal/EXIT25_Executive_Interview.pdf.
7. Frontal Assessment Battery FAB¹⁴² – Assesses executive functions. Can distinguish FTD from mild AD. http://www.dementia-assessment.com.au/frontotemporal/Frontal_FAB_Scale.pdf.

The table over page briefly shows the general cognitive areas tested by the various assessment and screening tools used by CDAMS in Victoria at the time of this review.

¹³⁸ Storey, Rowland, Basic, Conforti, and Dickson (2004).

¹³⁹ NeuRA (2012).

¹⁴⁰ Mioshi et al (2006).

¹⁴¹ Stokhold et al (2005).

¹⁴² Dubois et al (2000).

Test Battery ¹⁴³	Primary cognitive domains tested																									
	Attention					Memory					Language				Visuo-motor skills					Executive functions						
	Temporal orientation	Spatial orientation	Registration	Calculation	Visual attention	Visual memory	Immediate recall	Delayed recall	Cued recall	Semantic memory	Expressive language & Naming	Receptive language	Verbal fluency	Word finding/Naming	Visual perception	Visuo-spatial skills	V isuoconstructional skills	Ideational praxis	Ideomotor praxis	Abstract thinking	Problem solving	Planning	Task switching	Inhibition	Judgement/Decision making	Speed
ADAS-Cog	x	x	x			x	x	x	x		x	x		x	x	x	x				x	x			x	x
ACE-III	x	x	x	x			x	x	x	x	x	x	x	x	x	x	x			x		x				
BNT						x					x			x	x											
CANTAB			x		x	x	x	x	x		x			x	x	x					x	x	x	x	x	x
CAMDEX	x	x	x	x	x		x	x		x	x	x		x			x		x	x						
CERAD	x	x		x			x	x	x	x	x	x	x	x	x		x					x				x
CDT																x	x					x				
GF															x											x
GNT						x					x			x	x											
HDS	x	x	x	x	x	x	x	x		x	x	x		x	x	x	x	x	x	x		x				
KICA-Cog Regional Urban	x	x	x			x		x	x		x	x	x	x	x		x	x	x			x				
MMSE	x	x	x	x			x	x			x	x		x			x									
MoCA	x	x	x	x		x	x	x	x		x		x	x	x	x	x			x	x	x			x	x
NUCOG	x	x	x	x			x	x	x	x	x	x	x	x	x	x	x		x	x		x	x	x		
RUDAS			x		x		x	x					x			x	x		x			x	x	x		
Trails A&B					x																x	x	x		x	x
3 words, 3 phrases					x	x		x	x								x					x				

¹⁴³ Names of abbreviated tests are as follows: ADAS – Cog, Alzheimer’s Disease Assessment Scale – Cognition; ACE-III, Addenbrook’s Cognitive Examination – III; BNT, Boston Naming Test; CAMDEX, Cambridge Mental Disorders of the Elderly Examination; CERAD, Consortium to Establish a Registry for Alzheimer’s Disease; CDT, Clock Drawing Test; GF, Ghents Figures; GNT, Graded Naming Test; HDS, Hierarchical Dementia Scale; KICA, Kimberly Indigenous, Cognitive Assessment; MMSE, Mini-Mental State Examination; MoCA, Montreal Cognitive Assessment; NUCOG, Neuropsychiatry Unit Cognitive Assessment Tool; RUDAS, Rowland Universal Dementia Assessment Scale.

Culturally sensitive cognitive screening/assessment tools

Cognitive screening and assessment tools must be carefully selected and sensitively administered to clients from CALD or ATSI backgrounds to avoid or minimise cultural bias. Administering a translated version of a tool may not be adequate. Several of the tools recommended in the Dementia Outcome Measurement Suite¹⁴⁴ for use with clients from CALD and ATSI backgrounds are:

1. Alzheimer's Disease Assessment Scale – Cognition ADAS-Cog¹⁴⁵: Rated as a valid tool for people from CALD communities.
2. Rowland Universal Dementia Assessment Scale RUDAS¹⁴⁶: Rated as a valid tool for CALD communities and should be used with an interpreter where needed. Better able to detect dementia in an Australian sample compared with MMSE and GPCOG and was less influenced by CALD status¹⁴⁷. The single item testing judgement may not be suitable for use with ATSI peoples. May be downloaded from: http://www.dementia-assessment.com.au/cognitive/RUDAS_scale.pdf.
3. KICA Regional Urban: Cognitive Assessment¹⁴⁸: Developed for use with urban and regional ATSI peoples including Victorians aged 45+. May be downloaded from: <http://www.wacha.org.au/kica.html>.
4. Montreal Cognitive Assessment MOCA: Available in 37 languages. May be downloaded from: <http://www.mocatest.org/>.

A review of available translated cognitive assessment tools for older people from CALD backgrounds completed by Vrantsidis, LoGiudice, O'Connor, Dow, Runschl & Traynor can be found at:

http://www.dementia.unsw.edu.au/index.php?option=com_dcrc&view=dcrc&layout=project&Itemid=112&research_topic=15&researcher=0&research_type=0&year=0&population=0¢re=0&keywords=&searchtype=EXACT&pid=16&search=true

Informant Questionnaires:

A review by Cherbuin et al (2008) of self and informant rated dementia assessment tools recommended the following informant based screens for cognitive impairment, both of which were developed in Australia:

1. The Informant Questionnaire on Cognitive Decline in the Elderly IQCODE¹⁴⁹. The IQCODE is available in a number of different languages in short and long versions. May be downloaded from: <http://crahw.anu.edu.au/risk-assessment-tools/informant-questionnaire-cognitive-decline-elderly>.

¹⁴⁴ Sansoni et al (2007).

¹⁴⁵ Rosen, Mohs, and Davis (1984).

¹⁴⁶ Storey, Rowland, Basic, Conforti, and Dickson (2004).

¹⁴⁷ Basic et al (2009)

¹⁴⁸ Adapted from LoGiudice et al (2005).

¹⁴⁹ Jorm (2004).

2. The 31 item Concord Informant Dementia Scale CIDS¹⁵⁰ or 12 item shortened version (SCIDS). The shortened version takes 6-11 minutes to administer and can be obtained from Waite et al (1998) p202.

Functional Assessment Tools

Functional assessment tools used in a dementia assessment clinic context should cover personal and instrumental activities of daily living (ADLs). A dementia diagnosis requires a person's functioning to be significantly impacted. The tools recommended by the Dementia Outcome Measurement Suite¹⁵¹ include:

1. Alzheimer's Disease Cooperative Study – Activities of Daily Living Inventory¹⁵². This assessment covers a broad range of personal, domestic and community ADLs, as well as leisure engagement. It is administered to an informant who spends at least 2 days a week with the person. May be downloaded from: http://www.dementia-assessment.com.au/function/ADCS-ADL_Scale.pdf.
2. Disability Assessment for Dementia DAD¹⁵³ – The DAD assesses personal, domestic and community ADLs, as well as leisure engagement. May be downloaded from: <http://www.dementia-assessment.com.au/function/index.html>.
3. Cleveland Scale for Activities of Daily Living¹⁵⁴ – The CSADL assesses personal, domestic and community ADLs, as well as communication and social behaviour. May be downloaded from: <http://www.dementia-assessment.com.au/function/index.html>.

These tools take approximately 15 minutes to complete with an informant.

Assessments of Behavioural and Psychological Symptoms of Dementia

A wide variety of BPSD assessment tools exist, some of which are broad, whilst others are more symptom specific. Tools that assess a variety of symptoms are likely of more value within a dementia assessment clinic setting. The tools recommended by the Dementia Outcome Measurement Suite¹⁵² include:

1. The Neuropsychiatric Inventory NPI¹⁵⁵. The NPI assesses the presence and severity of the spectrum of BPSDs including those prominent in frontotemporal dementias. It also assesses the impact these symptoms have on the carer. May be downloaded from: <http://www.dementia-assessment.com.au/behavioural/NPI.pdf>.
2. Behavioural Pathology in Alzheimer's Disease BEHAVE-AD¹⁵⁶. The BEHAVE-AD was designed for use with people who have Alzheimer's disease, but has

¹⁵⁰ Waite et al (1998).

¹⁵¹ Sansoni et al (2007).

¹⁵² Galasko et al (1997).

¹⁵³ Gelinas et al (1999).

¹⁵⁴ Patterson & Mack (2008).

¹⁵⁵ Cummings (1994).

¹⁵⁶ Reisberg, Borenstein, et al (1987).

been used with people who have other dementias. It is not suitable for assessing symptoms that would be common in people with frontotemporal dementia. May be downloaded from: <http://www.dementia-assessment.com.au/behavioural/BEHAVE-AD.pdf>.

Dementia assessment clinics need to assess for the presence and severity of depressive symptoms which can impair cognition. Two tools recommended for assessment of depressive symptoms by the Dementia Outcome Measurement Suite¹⁵⁷ are:

1. The Cornell Scale for Depression in Dementia CSDD¹⁵⁸: The CSDD involves an interview with the person being assessed, as well as an interview with an informant. It takes approximately 20 minutes to administer. May be downloaded from: http://www.dementia-assessment.com.au/depression/Cornel_Scale_Guidelines.pdf.
2. Geriatric Depression Scale GDS¹⁵⁹: The GDS is a commonly used tool to assess for depression in the elderly. It has versions of different lengths 30, 15, 10 and 4 questions and takes between 5-10 minutes to administer. May be downloaded from: http://www.dementia-assessment.com.au/depression/geriatric_depression_scale_short.pdf. The GDS is available in several different languages and has been used in a number of different countries see: http://www.mednwh.unimelb.edu.au/nari_research/pdf_docs/6_GDS.PDF.

Global Impairment

The tools recommended by the Dementia Outcome Measurement Suite¹⁵⁸ for assessing the severity of dementia include:

1. Global Deterioration Scale GDS¹⁶⁰. Severity of dementia rated on seven levels of Alzheimer's Disease. Takes 5-10 minutes to administer. May be downloaded from: http://www.dementia-assessment.com.au/global/GDS_scale.pdf.
2. Clinical Dementia Rating CDR¹⁶¹. Gold standard scale for rating dementia severity. Takes 40-75 minutes to administer. Can be downloaded from: <http://www.dementia-assessment.com.au/global/index.html>
3. Dementia Severity Rating Scale DSRS¹⁶². Rates level of impairment across 12 domains of functioning. Takes 4-5 minutes to complete. Can be downloaded from: http://www.dementia-assessment.com.au/global/DSRS_Full.pdf.

¹⁵⁷ Sansoni et al (2007).

¹⁵⁸ Alexopoulos et al (1988).

¹⁵⁹ Sheikh & Yesavage (1986).

¹⁶⁰ Reisberg et al (1982).

¹⁶¹ Morris (1993).

¹⁶² Clarke & Ewbank (1996).

Appendix 5.6

FUTURE CARE PLANNING

Future care planning enables people to indicate their future care wishes and personal preferences should their health deteriorate and they no longer have the ability to make these decisions¹⁶³. Dementia is an illness that impacts on decision making capacity because it irreversibly and progressively impairs skills necessary to make and communicate decisions about care preferences. Having a future care plan in place ensures that the person's preferences for future care, including at end of life, are followed, even in the face of declining capacity. Whilst research suggests that a MMSE score of 18 to 20 is the threshold necessary for making informed decisions about future care plans¹⁶⁴, this is not widely accepted and capacity should be assumed unless there is evidence to suggest otherwise. However, the earlier in the disease trajectory future care plans are made, the more likely the person is able to meaningfully participate in the process¹⁶⁵.

Health professionals have a vital role in facilitating future care planning discussions with people with dementia and their families/carers¹⁶⁶. Assessment and diagnosis of dementia or mild cognitive impairment within a memory clinic has been highlighted as an opportune and important time for future care plans including advance care directives to be discussed, as with time, the person's abilities to make these decisions declines¹⁶⁶. Laakkonen et al (2008) reported that 59% of carers would have liked to have discussed advanced care planning at diagnosis but only 6% had the opportunity to do so. Inaction of health professionals has been identified as a barrier to advance care planning¹⁶⁷.

Future care planning in Victoria functions within the legal framework of the Medical Treatment Act (1988) and the Guardianship and Administration Act (1986) which provide the legal framework for the appointment of substitute decision making when people no longer have capacity to consent because they lack capacity and the Wills Act 1997 (Vic) which provides the legal framework for making and administering a will. Substitute decision making can involve the appointment of a substitute decision maker who endeavours to make the same decision the client would have in the current circumstances about continuing or ceasing treatment.

Future care planning involves the following:

1. *Appointing substitute decision makers including:*
 - a. *Enduring Power of Attorney (Financial)*
 - b. *Enduring Power of Attorney (Medical Treatment)*
 - c. *Enduring Power of Guardianship*

¹⁶³ Denning et al (2011), Department of Health, Victoria

¹⁶⁴ Fazel et al (1999); Gregory et al (2007).

¹⁶⁵ Denning et al (2011).

¹⁶⁶ Hamann et al (2011); Okonkwo et al (2008); Wain et al (2009); Wald et al (2003).

¹⁶⁷ Cavalieri et al (2002); Rurup et al (2006).

2. *Discussing future care wishes and preferably documenting these*
3. *Arranging/updating a will*

Future care planning is an ongoing process of working with the client to plan future care through developing, enacting and reviewing advance care plans. It is a personal experience at a time when the client may feel vulnerable due to a new diagnosis. Effective discussions require a skilled and empathetic approach.

As part of providing the Best Care for Older People Everywhere¹⁶⁸, health professionals should ask clients if they have future care plans.

Role of CDAMS in Future Care Planning

The CDAMS process may be the first time a client is introduced to the future care planning process. Some clients may be prepared to document their preferences immediately. Whilst for other clients it may be the first time they have considered future care planning. The approach considered for future care planning should include:

1. Identify Future Care Plan arrangements

As part of the initial assessment, CDAMS should check whether the client has one or more of the following future care plans:

- a. Enduring Power of Attorney (Financial)
- b. Enduring Power of Attorney (Medical Treatment)
- c. Enduring Power of Guardianship
- d. Refusal of Treatment certificate
- e. Statement of Choices
- f. Will
- g. Other written and signed document stating their future health and care wishes.

2. Provide direction and assistance

- a. Provide the client and their family/carer(s) with information and education on future care planning e.g. Office of the Public Advocate's 'Take Control' booklet and video 'You decide who decides'
- b. Advise the client that whilst they have capacity they should develop a future care plan.
- c. Liaise with the client's GP and other health providers (as relevant) in relation to future care plans and/or the client's/family's/carer's attitude toward future care planning.
- d. Where the client is interested and the service available, CDAMS may refer them to the advance care planning program within the health service.
- e. CDAMS should advise clients diagnosed with dementia that do not intend to make a future care plan but may do so in the future, to have their capacity assessed when they wish to make these arrangements.

¹⁶⁸ Victorian implementation of the Council of Australian Governments Long Stay Older People initiative
<http://www.health.vic.gov.au/older/toolkit/>

- f. When a client wishes to make future care arrangements but concerns about their capacity¹⁶⁹ are identified during the assessment process, CDAMS may complete a capacity assessment or refer them on for assessment.
- g. Where a client does not have capacity, CDAMS should advise the client, their family/carers and GP, that should the client require financial, medical or lifestyle decisions to be made, an Administrator and/or Guardian may need to be appointed to make these. Where there are financial, medical or lifestyle decisions that need to be made at the time of assessment, and the client does not have capacity, CDAMS may refer the client to the Victorian Civil and Administrative Tribunal for appointment of an Administrator and/or Guardian. The family/carers should be provided within information about Administration and Guardianship¹⁷⁰ and the process involved, including what to expect.

Resources:

Department of Health, Victoria

Information about advance care planning, contact details for advance care planning services, publications and relevant links.

<http://www.health.vic.gov.au/acp/index.htm>

Office of the Public Advocate

Information about arranging powers of attorney, guardians and administrators. Downloadable 'Take control' booklet that may be provided to clients/families/carers and short online video 'You decide who decides'.

<http://www.publicadvocate.vic.gov.au/publications/121/>

Respecting Patient Choices

Information booklets, forms for advance care planning including appointing an Enduring Power of Attorney (Medical).

<http://www.respectingpatientchoices.org.au/>

Best Care for Older People Toolkit

<http://www.health.vic.gov.au/older/toolkit/>

¹⁶⁹ A person is assumed to have capacity unless proven otherwise.

¹⁷⁰ Guardianship Facts Sheet:

<http://www.publicadvocate.vic.gov.au/file/file/Publications/Updated%20factsheets%202012/Guardianship%20FACT%202012.pdf>

Appendix 5.7 DRIVING

Protocol for CDAMS Driving Assessment

Legal Framework:

In Victoria, people diagnosed with dementia are legally obligated to advise VicRoads. Where assessed as fit to continue drive, VicRoads issues the person a conditional licence.

THE FOLLOWING FOUR STAGES ARE RECOMMENDED WHEN APPROACHING THE NEED FOR DRIVING ASSESSMENT.

Stage 1 – Identification of need for driving assessment by CDAMS Clinicians.

Obtain a history from the client, family/carer and significant others regarding any recent concerns including changes in confidence, judgement, reaction times, disorientation whilst driving, accidents (including cause/fault), general safety, increased hostility from other drivers, unexplained dents, changes to driving patterns. Consider social issues including: who currently drives; do family/grandchildren drive with client; when was their driving last observed etc. Be mindful that the history provided may be unreliable due to the client/family/carer being fearful of action being taken. Family/carers who rely on the client driving, may not disclose concerns as this may result in them becoming geographically isolated.

- a. Assess clients' insight into changes/concerns regarding driving
- b. Consider results of medical, neuropsychological and other CDAMS assessments (Refer to Attachment A for possible indicators pertaining to Neuropsychological assessment).
- c. Where there is a diagnosis of dementia
 - i. Very Early / Mild – Memory & Language problems but no evidence of visuoperceptual or frontal problems and no concerns raised on history. – If a diagnosis of dementia is made the client has a responsibility to notify VicRoads & their insurer. A VicRoads Medical Report¹⁷¹ is required, with recommendation for regular review. Advise the client that VicRoads may request an OT driving assessment. If the client agrees, a VicRoads medical report should be forwarded to VicRoads. If client disagrees, notify client of their responsibility in writing and document this in their medical records.

¹⁷¹ May be downloaded from: http://www.vicroads.vic.gov.au/NR/rdonlyres/7878F7E8-1076-4675-974F-8AD99A98AF17/0/MedicalReport_1212_WEB.pdf

VicRoads does not expect health professionals to notify them of potential/future problems only existing problems (ie: those that present a risk now).

- ii. Where there is evidence of visuo-perceptual and frontal problems &/or concerns on history – The recommendation should be made that either they clearly shouldn't drive or an OT driving assessment is recommended if they wish to continue to drive. A medical report should be submitted to VicRoads and this may be indicated even if the client does not agree (see stage 2).
- d. Diagnosis of mild cognitive impairment - may still need assessment depending on history as above and/or outcome of formal cognitive assessment.
- e. Discuss potential risk factors regarding driving with the CDAMS team during the next case conferencing or other opportunity, depending on urgency.
- f. Document specific concerns and plan of action.

Stage 2 – Advising client of need for driving assessment.

- a. *Determine clients' response to undertaking driving assessment in a setting conducive to discussing sensitive matters. It is recommended this occur separately to the feedback session, where possible.*
- b. Attempt to engage client in the process by explaining the need to ensure both their own and others safety and to alleviate family/carer concern if appropriate. Inform client that assessment provides them with the **opportunity to prove their ability to drive safely and protects them legally.**
- c. Inform client and family of their duty of disclosure to VicRoads and Insurer, and document this discussion.
- d. Determine which service the client will be most amenable to discussing the need for assessment with, including GP/Referrer/CDAMS/other. This discussion can disrupt the relationship the client/family/carer has with these services. Where this is likely, strong consideration should be given to preserving their relationship with their GP who will be providing care in an ongoing nature. In this case, CDAMS should take responsibility for having this discussion with the client and family/carer.
- e. Ensure the client and family/carer understand that the process of assessment includes both on road and off-road components.
- f. Discuss cost of assessment and possible outcomes. (No change, restricted license or license cancellation.)

IT IS ALWAYS PREFERABLE TO GAIN THE CLIENTS CONSENT

- a. **If the client voluntarily agrees to assessment:** Complete VicRoads medical assessment form ticking box to indicate that an "Occupational Therapy driving assessment is required" if appropriate and send to Vic Roads for approval. Ensure that your medical specialty is clearly indicated on form and that all co-morbidities are also indicated not just the cognitive difficulties. NB: VicRoads may also request that the clients GP complete a medical form if consideration of the clients' whole current

medical history is not evident. *Advise client that VicRoads make the decision as to whether an OT driving assessment is appropriate and that they will advise the client when this has been approved. Only then can a driving assessment be arranged with an OT driving assessor.*

- b. If the client does not agree to assessment (or in the case where they are clearly unfit to drive):** Discuss options with family to discourage driving (eg disable car, hide keys, use community transport etc). Discuss advantages of not driving such as: legal liability if they have an accident when driving; saving costs associated with running a vehicle; and inform the client of the potential loss of insurance cover if they continue to drive with a known medical condition. *Following discussion with client and family the CDAMS team inform client they are either medically unfit or that their fitness to drive is unclear and that VicRoads will be informed resulting in either suspension of their license until they undertake assessment or cancellation of their licence if VicRoads determines them to be medically unfit.*
- c. Advise the client to cease driving until the outcome of the assessment is known.**
- d.** Document the following in the client's medical record and in writing to the client/family/carer: discussion with client and family/carer; advice provided to the client; action that the client will take and action CDAMS will be taking eg client ceasing driving, medical report to VicRoads, referral to Occupational Therapist Driving Assessor.

Stage 3 – Identification of driving assessment service (once approved by Vic Roads)

- a. Determine which service should undertake driving assessment considering the following:**
 - i. Availability/waiting list/urgency
 - ii. Cost (private services can be utilised but usually at an increased cost).
 - iii. Veterans Affairs recipients may have their OT driving assessment funded by DVA if the need for assessment is related to their war caused injury (It's worthwhile just checking).
- (NB: assessment must be carried out by a qualified OT driving assessor - VicRoads and RACV assessments are not suitable for clients with complex cognitive difficulties).
- b.** Contact OT Advisors PH: 03 92846331/6870 for further enquiries.
 - c.** Make the referral including completion of medical form and other information as requested e.g. neurological and neuropsychological assessments.

Stage 4 – Identification of follow-up services.

- a. Ensure outcome of assessment is communicated to referring agent/CDAMS**
- b.** Determine if alternative modes of transport are required i.e. Multipurpose Taxi Card, Council/Voluntary transport to groups etc and organise as required. This may be completed by the client's GP.

- c. CDAMS should provide information to client and family/carers e.g. Alzheimer's Australia information sheets.
- d. Advise client/carer to carry details of own address/address of others for easy reference. Advise client/carer that they can apply to get another form of identification such as a proof of age card if their licence is cancelled or surrendered. It can be applied for through the Victorian Commission for Gambling and Liquor Regulation.
- e. Determine need for counselling of client/carer in situations where the license is cancelled or restrictions are imposed.

THE ABOVE INFORMATION PROVIDES GUIDELINES ONLY. EACH CLIENT'S CASE MUST BE CONSIDERED INDIVIDUALLY FOLLOWING CASE CONFERENCE (OR OTHER) DISCUSSION WITH THE CDAMS TEAM.

Resources

- 1. Alzheimer's Australia including Alzheimer's Australia Victoria
 - i. Driving information help sheets.
<http://www.fightdementia.org.au/driving-and-dementia.aspx>
 - ii. Dementia and Driving in Victoria.
<http://www.fightdementia.org.au/victoria/publications-from-alzheimers-australia-vic.aspx>
- 2. CDAMS driving brochures for clients and families.
- 3. VicRoads
 - i. The Victorian Older Drivers Handbook.
<http://www.vicroads.vic.gov.au/Home/Licences/Handbooks/Older+drivers.htm>
 - iii. VicRoads Medical Review Information Sheet
<http://www.vicroads.vic.gov.au/NR/rdonlyres/B23411F3-657B-40FA-9E9D-AE2E68386E8E/0/VicRoadsMedicalReview.pdf>
 - iv. Dementia and Driving.
<http://www.vicroads.vic.gov.au/Home/Licences/Medicalreview/Dementia+and+driving.htm>
- 4. Austroads
 - i. Assessing Fitness to Drive.
<http://www.austroads.com.au/assessing-fitness-to-drive/>
- 5. RACV
 - i. Guide to Dementia, Driving and Mobility.
<http://www.racv.com.au/wps/wcm/connect/f9981e804edf0306a6f6fe568bfb9e53/Dementia+PDF.pdf?MOD=AJPERES>
- 6. Other Resources
 - i. Driving and Dementia Toolkit for Health Professionals (3rd Edition) – Canadian publication.
<http://www.rgpeo.com/media/30695/dementia%20toolkit.pdf>

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- ii. Victorian Commission for Gambling and Liquor Regulation.
<http://www.vcglr.vic.gov.au/> phone: 1300 182 457
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CDAMS Driving Assessment

Attachment A

Neuropsychological Assessment Outcomes that raise concern regarding a client's driving ability.

- a. Lack of insight and awareness of cognitive deficit - clients fails to see the need to make adjustments and adaptations in light of their brain impairment.
- b. Specific deficits in visuo-spatial (eg: unilateral spatial neglect), visuo-constructional, visuo-perceptual skills (eg: visual closure, figure group perception, visual spatial relations) on testing.
- c. Reduced rate of information processing and psychomotor response speed on timed neuropsychological tasks.
- d. Attentional deficits on formal testing, signs of reduced 'mental effort' as the assessment progresses.
- e. Executive or 'frontal' deficits, including
 - i. poor planning and organisational skills that may impede judgement and decision making in complex traffic situations;
 - ii. dissociation between 'knowing' and 'doing' - that is the client may describe an appropriate plan of action, but is unable to carry out the plan due to executive deficits. This may be detected on the initial or medical assessment.
 - iii. lack of initiation, client requires prompting and structure to complete tasks;
 - iv. difficulties comprehending 'cause and effect' relationships (eg: if I do not adjust my speed during a heavy rain storm I may have an accident).
 - v. Impulsivity, perseveration, cognitive impersistence, and cognitive inhibition.
- f. Behavioural difficulties including reduced frustration tolerance, rigidity, poor impulse control and self-monitoring; poor anger management; egocentric behaviour.
- g. Moderate to significant recent or short-term memory deficits, where there is evidence of disorientation to person, place and time, geographical disorientation and/or frequently losing personal items.

Appendix 5.8

DIAGNOSTIC CRITERIA

*'The application of diagnostic guidelines which accompany classificatory systems has consequences for the diagnosis, treatment and care of individuals...Improving the quality and consistency of dementia [diagnoses]...must therefore begin with the use of agreed definitions and classifications.'*¹⁷²

The World Health Organisation's International Statistical Classification of Diseases Related Health Problems 10 Revision (ICD-10¹⁷³), including the Australian Modification (ICD-10-AM¹⁷⁴), and the American Psychiatric Association's Diagnostic and Statistical Manual for Mental Disorders, 4th (DSM-IV¹⁷⁵), now 5th revisions (DSM-5), are the primary manuals used for diagnosing and classifying dementia. There are some differences in terminology and diagnostic criteria between these two classification systems. A review of the ICD-10/ICD-10-AM, DSM-IV and other dementia diagnostic criteria/classification systems can be found in Sansoni et al (2007) and the Australian Institute of Health and Welfare (AIHW, 2007).

The AIHW (2007) and Dementia Outcome Measurement Suite (Sansoni et al, 2007) recommends the World Health Organisation's ICD-10 or ICD-10-AM are used for dementia diagnosis and classification, and the resulting impairments in the person's functioning be classified according to the International Classification of Functioning, Disability and Health (ICF¹⁷⁶). Additional dementia diagnostic criteria may be used to assist in the differential diagnosis of some dementia types.

- **Lewy bodies dementia** – Refer to: McKeith et al (2005).
- **Fronto-temporal dementia** –
 - Consensus criteria for frontotemporal lobar degeneration refer to: Neary et al (1998).
 - International consensus criteria for behavioural variant of frontotemporal dementia refer to: Rascovsky et al (2011).
 - Consensus classification system for primary progressive aphasia and its variants, refer to: Gorno-Tempini et al (2011).
- **Prodromal Alzheimer's disease or mild cognitive impairment due to Alzheimer's disease** – The National Institute on Ageing and Alzheimer's Association developed clinical and research criteria for prodromal Alzheimer's disease, refer to: Albert et al (2011).

¹⁷² p.5 Australian Institute of Health and Welfare (2007).

¹⁷³ World Health Organisation (1992). Can be viewed at: <http://www.who.int/classifications/icd/en/>

¹⁷⁴ National Centre for Classification in Health (2002).

¹⁷⁵ American Psychiatric Association (1994).

¹⁷⁶ Can be viewed at: <http://www.who.int/classifications/icf/en/>

- **Pre-clinical Alzheimer's disease** – The National Institute on Ageing and Alzheimer's Association developed research criteria for prodromal Alzheimer's disease, refer to: Sperling et al (2011).
- **Alzheimer's disease** – The National Institute on Ageing and Alzheimer's Association developed research criteria for prodromal Alzheimer's disease, refer to: McKhann et al (2011).
- **Vascular dementia** – Diagnostic criteria for vascular dementia is problematic. There are a number of different types of vascular dementias, several sets of diagnostic criteria, with variable levels of sensitivity and poor agreement between these. Imaging should be used as part of diagnosing a vascular dementia.
 - Differential diagnosis of vascular dementia from Alzheimer's disease – Refer to: the Neuroepidemiology Branch of the National Institute of Neurological Disorders and Stroke and Association Internationale pour la Recherche et l'Enseignement en Neurosciences (NINDCS-AIREN) International consensus diagnostic criteria (Román et al, 1993); or Alzheimer's Disease Diagnostic and Treatment Centres ADDTC criteria (Chui et al, 1992). These diagnostic criterion are the least sensitive but most specific in diagnosing vascular dementia
 - Differential diagnosis of subcortical ischemic vascular dementia from multiple or critical-infarct dementia, refer to: Erkinjuntti et al (2000). Use in conjunction with ADDTC or NINDCS-AIREN.

Appendix 5.9

ASSESSING CDAMS OUTCOMES TO IMPROVE QUALITY

Outcomes are broadly defined as that which results from the provision of a service or intervention, in this case the provision of CDAMS. Outcomes vary depending on the perspective examined. These include:

- i. Outcomes related to the process and service delivered by CDAMS e.g. diagnoses made, accuracy of diagnoses, number of referrals, number of education sessions provided, documentation compliance etc.
- ii. Outcomes for clients, family and carers. These include health outcomes for the client. Perceptions of outcomes often differ depending on the person's perspectives and as a result, collecting outcomes from the client as well as their family/carers is essential.
- iii. CDAMS team satisfaction and development.

Outcomes for CDAMS may be collected or assessed using the following approaches:

- i. File audits.
- ii. Prospective data collection using formal and informal assessment tools.
- iii. Retrospective auditing of VINAH data – VINAH may be used to evaluate and benchmark services.
- iv. Surveys or feedback from CDAMS staff.
- v. Surveys or feedback from other services.
- vi. Surveys or feedback from GPs.
- vii. Surveys of focus groups with clients, families and carers.

CDAMS may use VINAH to benchmark against other services or assess their performance against the practice standards.

The following table provides some suggested areas that CDAMS outcomes may be assessed for each of the standards of practice. The results of these activities may be used to identify quality improvement opportunities.

Practice Standard	Outcomes that may be assessed
<i>Standard 1:</i> Pre-Assessment & Intake	<ul style="list-style-type: none"> • Response time to referrals • Adequacy of information collected at intake and pre-assessment to allow for referrals to be triaged accurately. • Number of referrals that are not accepted and reasons for this. • Frequency that the client, family/carer and GP are notified of referral acceptance and provided with relevant information.

	<ul style="list-style-type: none"> • Frequency of triage CDAMS is required to do, where there is a central access unit. • Survey or focus group: Clients who self-referred family/carers who referred concerning the accessibility of the service.
Standard 2: Assessment Procedures	<ul style="list-style-type: none"> • Frequency that information is collected from a range of sources including frequency in which an informant history is collected. • Frequency and timeframe in which written feedback is provided to the client and their family/carer and GP • Frequency in which the CDAMS assessment processes are followed i.e. initial assessment, medical assessment and neuropsychological assessment (where indicated) • File audit: Frequency of and reasons for documentation in medical records. • Survey or focus group: Client/family/carer knowledge about how to contact the key worker or equivalent. • Number of different disciplines of CDAMS clinicians.
Standard 3: Initial Assessment	<ul style="list-style-type: none"> • Waiting time until initial assessment. • Number of sources information is collected from. • Number of home visits. • Survey or focus group: Client/Family/Carers experience and satisfaction with the service provided during an initial assessment. • Frequency of clients declining any further involvement with CDAMS at initial assessment. • File audit: Audit of documentation to measure comprehensiveness of information collected at initial assessment.
Standard 4: Medical Assessment	<ul style="list-style-type: none"> • File audit: Comprehensiveness of medical assessment and types of cognitive assessment and other assessment tools used. • File audit: Number, type and accuracy of cognitive impairment/dementia diagnoses made. • Frequency of clients declining any further involvement with CDAMS at initial assessment. • File audit: Communication with GPs: Frequency of letters being sent to GPs concerning assessments completed. • GP survey: GP feedback on usefulness of information containing in letters from medical specialists. • Client focus group or survey: Client satisfaction with and experience of the medical assessment.
Standard 5: Neuropsychological Assessment	<ul style="list-style-type: none"> • Timeframes for accessing neuropsychological assessment. • File audit: Number, type and accuracy of cognitive impairment/dementia diagnoses made. • File audit: Reasons for referral.

	<ul style="list-style-type: none"> • Client focus group or survey: Client satisfaction with and experience of the neuropsychological assessment. • Number of follow-up education sessions provided to clients/families.
Standard 6: Case Conferencing	<ul style="list-style-type: none"> • File audits or case conference diary: Frequency and attendance at case conferences • File audit: Documentation of case conferences • Amount of time spent discussing clients during case conferences. • CDAMS Team survey: Satisfaction with case conferences.
Standard 7: Feedback	<ul style="list-style-type: none"> • File audit: Frequency, attendance at, areas discussed and documentation of feedback sessions. Frequency in which information is provided on Powers of Attorney, legal/financial issues, pensions/benefits, driving, services and care strategies and treatments. Frequency in which client consent is obtained to involve family/carer and share information with the GP. Frequency of feedback summaries are provided to the client/family/carer. Accuracy of diagnoses and effectiveness of treatment. • Survey or focus group: Client/Family/Carers experience and satisfaction with the feedback session. This should include a measure concerning the ease of understanding and usefulness of the information provided during the session. • Timeframe between initial assessment and feedback.
Standard 8: Care Plan Implementation	<ul style="list-style-type: none"> • File audit: Frequency and types of referrals made to other services. Number of recommendations suggested in the care plan. • Survey or focus group: Client/Family/Carers experience and satisfaction with care plan implementation including uptake of recommendations and referrals. Changes in their quality of life. • Survey of services referred to: Assessing appropriateness of referral and identifying any indicators which may result in a client/family/carer not accepting a service they were referred to. • VINAH: Length of time CDAMS remains involved. Number of follow up contacts.
Standard 9: Client Review	<ul style="list-style-type: none"> • VINAH or file audit: Number of clients reviewed. Accuracy of diagnoses and effectiveness of treatment as assessed on review. Diagnostic groups being reviewed. Outcomes of recommendations made at the client's previous feedback including uptake of referrals and lifestyle changes to reduce risk factors. • Survey or focus group: Client/Family/Carers experience and

	satisfaction with reviews.
Standard 10.1: Assessment of People from an ATSI background	<ul style="list-style-type: none"> • VINAH: Frequency of referral of ATSI people. Number of ATSI people who complete the entire CDAMS process. Number of contacts over which the service is provided. • VINAH and file audit: frequency in which an interpreter is arranged when needed for the client and family/carer. • CDAMS team survey: Number of staff who have completed cultural awareness training. Confidence in providing culturally appropriate care to ATSI people. Knowledge about ATSI cultural issues which may impact on assessment and treatment of dementia. • File audit: number of times RUDAS or KICA Regional Urban or equivalent is used. Frequency in which language, culture and identity of the ATSI client is reflected in their documentation. • Survey or focus group: ATSI Client/Family/Carers experience and satisfaction with the service. • Survey of Aboriginal Health Services: knowledge about and use of CDAMS. • Diary audit: Number of contacts with ATSI services and groups specifically for engagement and information sharing.
Standard 10.2: Assessment of People from Culturally and Linguistically Diverse Communities	<ul style="list-style-type: none"> • VINAH: Frequency of referral of CALD people. Number of CALD people who complete the entire CDAMS process. Number of contacts over which the service is provided. • VINAH and file audit: frequency in which an interpreter is arranged when needed for the client and family/carer. • CDAMS team survey: Confidence in providing culturally appropriate care to CALD people. Knowledge about CALD issues which may impact on the assessment and treatment of dementia. • File audit: Number of times RUDAS or other cognitive screens validated for the client's CALD group are used. Frequency in which language, culture and identity of the CALD client is reflected in their documentation. • Survey or focus group: CALD Client/Family/Carers experience and satisfaction with the service. • Survey of CALD specific services: knowledge about and use of CDAMS. • Diary audit: Number of contacts with CALD services and groups for provision of information and education.
Standard 10.3: Assessment of People with Younger Onset	<ul style="list-style-type: none"> • VINAH: Frequency and acceptance of referrals for clients under the age of 65 years old. Frequency of diagnoses of younger onset dementia. Frequency of referrals for neuropsychological assessment. Number of contacts over

Dementia	<p>which the service is provided. Number of CDAMS clinicians involved in service delivery to the client/family/carer. Frequency of client referred for a second opinion to CDAMS from a medical specialist.</p> <ul style="list-style-type: none"> • File audits: Accuracy of diagnoses. Number of recommendations suggested in the care plan. Frequency in which the client is referred for a second opinion and consistency of this with the medical specialist/neuropsychologists diagnosis. • Survey or focus group: Client/Family/Carers experience and satisfaction with the service.
Standard 10.4: Assessment of People with an Intellectual Disability	<ul style="list-style-type: none"> • File audits: Frequency of referrals accepted for clients with intellectual disabilities. Frequency of diagnoses of dementia. Number of contacts over which the service is provided. Frequency of client referred for a second opinion to CDAMS from a medical specialist or to another CDAMS and consistency of this with the medical specialist/neuropsychologists diagnosis. Number of recommendations suggested in the care plan. Uptake of recommendations made in the care plan. Number of referrals to aged and disability services. • Survey or focus group: Family/Carers experience and satisfaction with the service.
Standard 10.5: Working with Family & Carers	<ul style="list-style-type: none"> • Survey or focus group: Family/Carers experience and satisfaction with the service. Change in ratings of care related burden over duration of CDAMS involvement. Uptake of recommendations and outcomes of these. • File audit: Number of contacts with family/carer. Number of follow up education/information/feedback sessions. • Diary audit: Number of education/information sessions provided to carer education and support services. • File audit: Number of referral to services specifically to improve support of family/carers. Frequency of attendance of families/carers at a client's CDAMS appointments.
Standard 11: Coordination with GPs	<ul style="list-style-type: none"> • VINAH: Number of referrals from GPs. Number of referrals from GPs not accepted. Number of contacts with GPs. • File audits: Number of letters to GPs and frequency of these. Frequency of other written information on management of aspects of dementia sent to GPs e.g. assessment and ongoing prescription of cholinesterase inhibitors or memantine. • Diary audit: Number of education or information sessions provided to GPs. • GP survey: GPs perception of accessibility and usefulness of CDAMS including usefulness of information provided.

	<ul style="list-style-type: none"> • Survey: Family/carers on follow through of medical recommendations that were suggested to the GP by CDAMS. • Updated contact information accessible on the internet.
Standard 12: Telehealth	<ul style="list-style-type: none"> • Diary audit: Number of telehealth sessions provided. • VINAH and file audit: Number of clients who complete the entire CDAMS process. • Survey or focus group: Client/Family/Carers experience and satisfaction with a telehealth delivered CDAMS. Uptake of recommendations provided via telehealth and outcomes of these. • CDAMS clinician survey or feedback: Usefulness of this technology in the diagnosis and management of dementia and cognitive impairment.
Standard 13: Leadership and Management	<ul style="list-style-type: none"> • Presence of a dedicated CDAMS coordinator/manager/team leader for the majority of the year. • VINAH: Number of appointments that were available but not filled. • CDAMS team survey: Feedback on staff's perception of the responsiveness of the CDAMS coordinator to their and the team's needs. • Clinic diary: Attendance at state-wide coordinators meetings. Performance appraisals completed on time. Staff leave cover arranged where possible. Occurrence of at least one CDAMS planning meeting annually. Frequency of opportunities provided to more junior or less experienced staff to develop skills through on the job training. Number of professional development opportunities organised for the team. Prompt recruitment of new staff (subject to the health services authorisation). • E-mail audit: Number of professional development opportunities disseminated to CDAMS clinicians.
Standard 14: Team Competency	<ul style="list-style-type: none"> • CDAMS team survey: Knowledge in all aspects of dementia diagnosis and treatment. • Client/Family/Carer survey or focus groups: Confidence with the skills of the CDAMS team during the assessment and treatment processes. • VINAH: Number of clients who complete the CDAMS process. • Other: Staff are credentialed and maintain their relevant registrations. • CDAMS team survey: Confidence in the knowledge and skills of peers.
Standard 15: Induction Training	<ul style="list-style-type: none"> • Clinic diary or e-mail audit: All new staff attend the induction program. All new staff are orientated to the CDAMS process,

	<p>and their role. All elements of orientation and induction are completed by each new staff member.</p> <ul style="list-style-type: none"> • Audit of induction folder use: All new staff have read through the CDAMS induction which includes the best practice guidelines. • Clinic diary: Number of joint assessments with new team members.
Standard 16: Continuous Quality Improvement	<ul style="list-style-type: none"> • Number of quality improvement activities being completed by CDAMS or CDAMS is participating in. • Outcomes of aspects of the service are being collected.

Please note: Prospective data collection may be used in place of file audits.

Assessing client satisfaction with services:

Measuring the satisfaction and collecting feedback from the person receiving the service including their family members/carers is vital to evaluating service outcome. Providing person and family centred care is key principle to the HIP model of care¹⁷⁷. Sansoni et al (2007) cite 7 key constructs developed by Hawthorne (2006) that a measure of client satisfaction should include (p.309):

- *'Health services access, environment and care coordination*
- *Provision of health information which helps to set patient expectations*
- *The relationship between the patient and health care staff, specifically empathy with the patient*
- *Participation in making choices regarding health treatment, including the associated fears and loss*
- *Satisfaction with the treatment provided...*
- *The effectiveness of treatment...*
- *A general satisfaction with the experience of health care'.*

The Dementia Outcome Measurement Suite suggest having one overall rating of client satisfaction, for example (from p.314)¹⁷⁸:

How satisfied are you with your health care?

- *Very satisfied*
- *Satisfied*
- *Not sure*
- *Dissatisfied*
- *Very dissatisfied*

¹⁷⁷ Victorian Government Department of Human Services (2008).

¹⁷⁸ Sansoni et al (2007).

The Short Assessment of Patient Satisfaction (SAPS)¹⁷⁹ is not a dementia specific tool but may be used to collect information on many aspects related to the person's experience.

The CDAMS Satisfaction Questionnaire¹⁸⁰ may also be used to measure family/carers satisfaction.

¹⁷⁹ Hawthorne et al (2006). Tool can be viewed at:

<http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-continence-patient-satisfaction-tools-instructions-report.htm~ageing-continence-patient-satisfaction-tools-revised-SAPS.htm>

¹⁸⁰ p.130-139 Review of CDAMS (2003). Tool can be viewed at:

<http://www.health.vic.gov.au/subacute/cdamsrpt2003.pdf>

Section 6

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