New England North West

Dementia Care Information

for Clinicians and Health Workers

NSW GOVERNMENT Health
Hunter New England
Local Health District

phn
HUNTER NEW ENGLAND
AND CENTRAL COAST
An Australian Government Initiative

HealthWISE
NEW ENGLAND NORTH WEST

ACKNOWLEDGEMENTS

The Dementia Partnership is a collaboration between HealthWISE New England North West (HealthWISE), Hunter New England Central Coast Primary Health Network (HNECC PHN) and Hunter New England Local Health District (HNELHD), which builds on a memory assessment and dementia care partnership dating back to 2003. The Dementia Partnership received seed funding from the Agency for Clinical Innovation (ACI) as part of the Building Partnerships program, which aims to improve care for older people with complex health needs. We would like to acknowledge the support that the ACI has provided to the Dementia Partnership, and the commitment of the Partnership organisations and their staff.

This booklet has been adapted from the Tweed Byron Dementia Care Information booklet. We would like to acknowledge the North Coast Primary Health Network and Northern NSW Local Health District, and thank them for allowing us to utilise the information, layout and graphics contained in their 2012 document.

The New England Dementia Partnership acknowledges the traditional custodians of the land on which we walk upon today as the First People of this Country. We pay respect to their continuing culture and the contribution they make to the life of our region.

This is the first edition of the New England North West Dementia Care Information booklet, printed in December 2016. The most recent version of the booklet is available in electronic format, complete with hyperlinks to recommended websites, on the **HealthWISE**, **HNECC PHN** and **HNELHD** websites. Feedback regarding the content and usability of the document is welcome through the **HNECC PHN** website.

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DEMENTIA IN AUSTRALIA

In 2015, it was estimated that 342,800 Australians were living with dementia, including one in ten Australians aged 65 or over, and three in ten of those aged 85 or over. By 2050 there will be four times the current number of people aged over 65 years, and by that time dementia will be their number one killer. Dementia will also be the number one cost to the health system by 2050, when compared to all other chronic diseases.

In our Aboriginal and Torres Strait communities, initial data suggests that dementia is around three to five times higher when compared with the total Australian population, equating to one in eight people over the age of 45-years living with dementia. An important consideration when assessing cognitive impairment in Aboriginal and Torres Strait Islander people is that dementia has not been traditionally recognised within the community and therefore not seen as a disease process. Community members also report a reluctance to seek diagnosis and support due to the fear that those with cognitive impairment will be removed to an aged care facility against the wishes of the family. **Alzheimer's Australia** have produced fact sheets, videos and linkages to other resources, to support Aboriginal and Torres Strait Islander communities and health professionals to assess and care for those with memory concerns and dementia.

When assessing and caring for those with cognitive impairment, it is important for clinicians to consider cultural backgrounds and cultural needs, especially when there are low literacy and health literacy levels, or when English is not the first language. In providing care and support to those from Culturally and Linguistically Diverse (CALD) backgrounds, ensuring clear communication may require a telephone interpreting service (phone: 131 450), and access to culturally and linguistically appropriate resources, which are also available on the **Alzheimer's Australia** website. The website also contains a resource kit to support health professionals and organisations to understand cultural barriers to accessing services, and how to develop services appropriate to the needs of CALD clients.

BENEFITS OF TIMELY DIAGNOSIS

One of the biggest issues facing those living with dementia, health professionals and carers, and our ability to implement appropriate management and care strategies, is that only fifty percent of all dementia cases in Australia are diagnosed. Of those that receive a diagnosis, the average delay between family members and close friends observing dementia symptoms and achieving a diagnosis is over three years.

Through early intervention, we can reduce the impact of dementia on our clients, their carers and families, and improve their quality of life. Early intervention requires the timely assessment of people with mild to moderate cognitive impairment and the diagnosis of a specific dementia subtype (i.e. differential diagnosis of dementia), so that appropriate management and support can be provided.

Timely diagnosis begins to enable a person living with dementia, their carers and family to:

- adjust to the diagnosis of dementia;
- prepare for the future;
- access appropriate medical intervention;
- manage other symptoms such as behaviour and mood changes; and
- review and manage current medications.

Symptoms similar to dementia can be caused by several different diseases and conditions, some of which are treatable and reversible, including infections, thyroid imbalances, depression, medication side-effects or nutritional deficiencies. A medical review of any symptoms and the identification of the cause of symptoms can bring relief. The quicker the review is conducted, the sooner appropriate management and treatment can begin.

The purpose of this document is to assist healthcare providers to recognise, assess, diagnose and manage dementia. As it is designed for the New England North West Region of NSW, it also provides specific information on the local dementia assessment and management services, as well as referral details.

STAGES OF DEMENTIA

There are three general stages of dementia, and depending on the subtype, can include the following features. It is important to remember that those living with dementia may not display all of the features listed below, that the symptoms may occur in varying patterns and at different stages, and that the rate of deterioration is variable – the table is meant as a general guide only. For further information, go to the **Alzheimer's Australia** website.

Early

- Increasing difficulties in cognition / thinking, such as memory loss, confusion and poor attention span, which start to impact on everyday function, such as work, social or domestic activities.
- Poor judgement and/or decision making.
- Difficulty in following conversations; tendency to repeat themselves.
- Difficulty in executing complex tasks, such as paying bills or balancing a cheque book; takes longer with routine chores.
- Loss of spontaneity, spark, or zest for life; loss of interest in activities; apathy; and/or depression may emerge.
- Loss of initiative; unwilling to start anything or try anything new; difficulty in adapting to change.
- Mood/personality changes; anxiousness and/or irritability about symptoms; keeps to oneself.
- Becomes less concerned about others.
- Depending on the sub-type, difficulties with reading, writing, and numbers may first occur in the early or moderate stage.

Moderate

- Increasing memory loss and confusion; shorter attention span.
- Confusion regarding time and place; may become lost if in unfamiliar surrounds.
- Difficulty recognising close friends and family.
- Difficulty organising thoughts or thinking logically, and bringing words to mind on the spot.
- Difficulty in attending to chores and self-care independently, such as bathing and cooking.
- Repetitive statements and/or movements.
- Loss of impulse control; inappropriate behaviour, such as dressing inappropriately.
- Display frustration, anger, irritability and become teary.
- Restlessness, especially in late afternoon or night (sun downing) – may wander the streets.
- Occasional muscle twitches or jerking.
- May have hallucinations.

Advanced

- Increasing memory loss and confusion; unable to recall something that occurred even a few minutes previously.
- Unable to recognise family, friends, or everyday objects.
- Loss of ability to communicate verbally.
- Loss of control of bladder and/or bowel.
- Little capacity for self-care, needing assistance with eating, showering, toileting, and dressing.
- Loses weight, even with proper diet.
- Restlessness, disturbed sleep, difficulty walking.
- May become aggressive.
- May have difficulty with seizures, swallowing, skin breakdown, and infections.
- Involuntary muscle movements and decreased mobility will continue to progress, leading to confinement in a wheelchair and/or bed.

RECOGNISING DEMENTIA

Dementia is a chronic, progressive and terminal condition. Early signs are subtle and may be hard to pick up on, even for those close to the person concerned. The person with dementia may also have trouble recognising any changes within themselves.

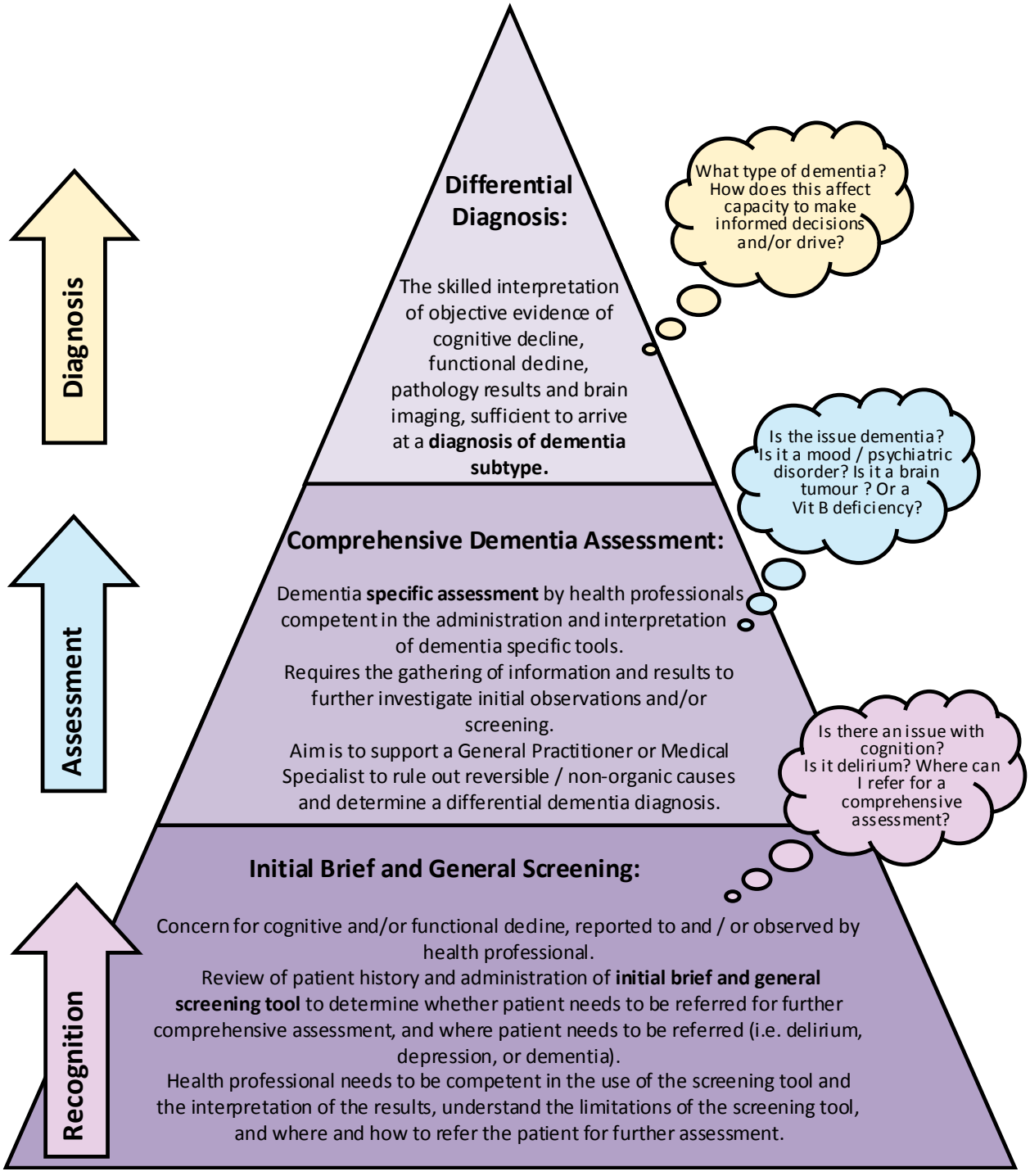
Early features vary a great deal, and depend on the underlying brain pathology. Importantly, while memory difficulties may be the first sign, impairment to language, behaviour or personality, and/or disruption to everyday tasks may also be an early sign.

Recognising whether there is a need for further assessment begins with listening to the concerns of those experiencing the symptoms, and their carers and/or family, and understanding the importance of timely diagnosis.

Suspect dementia when any of the following are present:

- **Cognitive symptoms, such as:**
  - forgetfulness;
  - repetitive questions;
  - difficulty recalling names and other words;
  - not knowing common facts;
  - communication problems;
  - disorientation; and/or
  - marked change in behaviour/personality.
- **Neurological symptoms, such as:**
  - gait disturbances; and/or
  - apraxia (characterised by the loss of ability to execute or carry out learned purposeful movements).
- **Functional symptoms affecting daily living, such as:**
  - getting lost;
  - medication mismanagement;
  - neglecting household chores;
  - trouble shopping;
  - difficulty handling money;
  - loss of driving skills;
  - neglecting personal hygiene; and
  - making mistakes at work.

STAGES OF ASSESSMENT



ASSESSMENT **PROCESS**

The key components required for comprehensive dementia assessment include:

- reports of decline in cognition and function over time; **and**
- evidence of impaired cognition (cognitive assessment); **and**
- evidence of impaired everyday function (reports, assessment tools, and observation); **and**
- ruling out of reversible and/or nonorganic causes (pathology, imaging and assessment).

Medical and Social History

A complete medical, family and background history is required, along with details of current problems and the timeframe. Questions should be asked about forgetfulness; orientation; problem solving; coping with everyday life; changes to personality or behaviour; longstanding or recent issues with mood; alcohol consumption; presence of pain; and medication/drug use. Descriptions of the person's difficulties from family members, obtained with consent, are vital in the diagnostic process.

Polypharmacy is common in older adults, and can have cumulative negative side effects that can impact cognition. Failure to identify side-effects (e.g. anti-cholinergic drugs) may lead to further complications, such as delirium, which can present as dementia, but can be treatable.

The health professional and treating team need to establish when the change in function was first noticed, whether the change was sudden (e.g. days or hours) or gradual (e.g. over months or years) and whether the person's difficulties are getting worse (or improving). Determining the onset and progression of symptoms can contribute to identifying the subtype of dementia, assist in ruling out other treatable or reversible disorders (such as depression, psychosis, and delirium), and identify comorbid conditions (such as Parkinson's disease, stroke, syphilis and other medical conditions).

Psychological Evaluation

The symptoms of depression and anxiety can impact cognition and may be mistaken for dementia. Consequently, screening for issues concerned with mood, anxiety and psychological wellbeing are commonly included in the diagnostic process for dementia. This may involve interviews with the person and their carer / family, or self-report questionnaires designed to identify the presence of symptoms of depression, anxiety, and other psychological disorders.

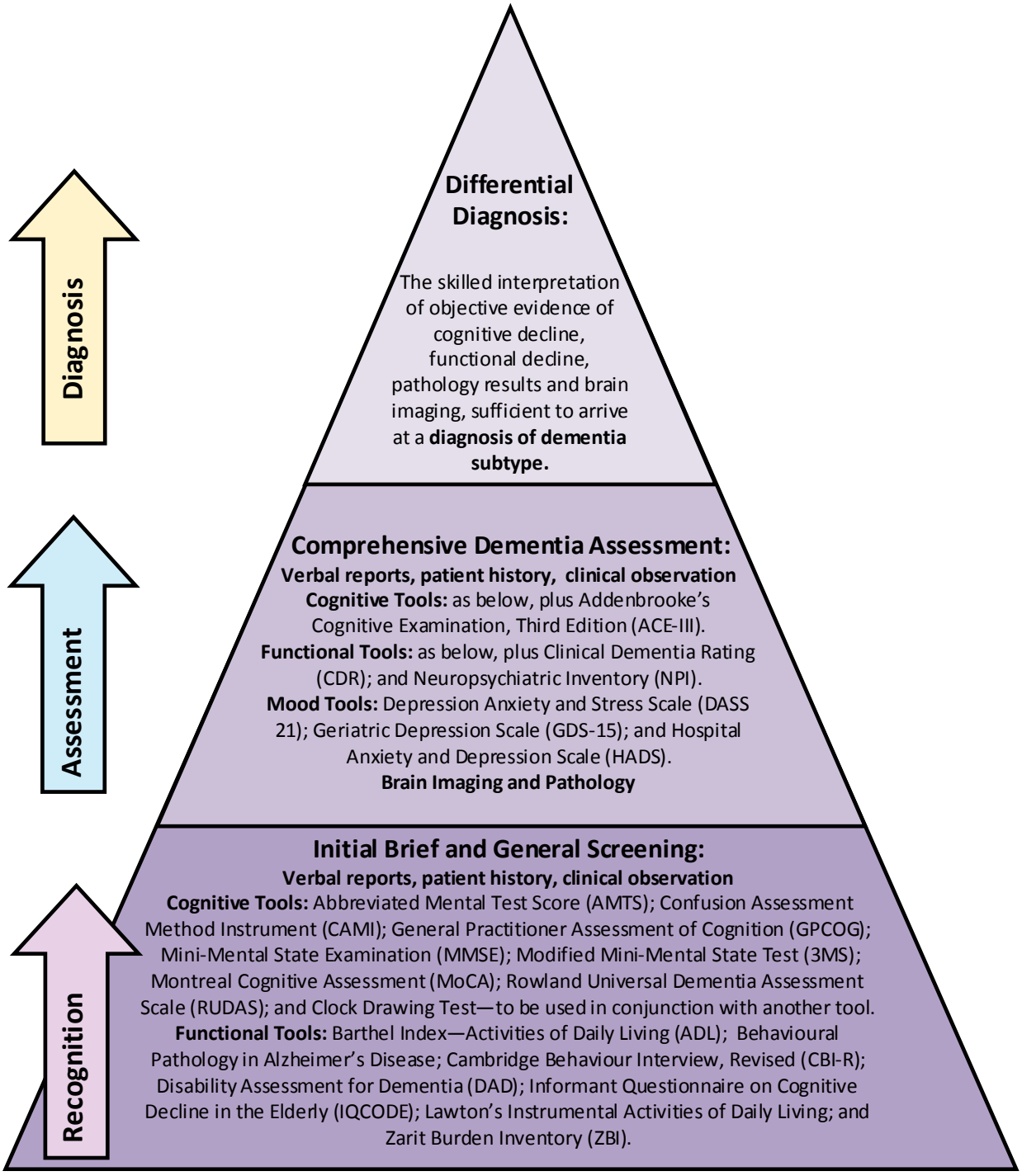
Pathology Testing

Medical tests are used to assist in dementia assessment, identify contributing factors, and rule out other acute or chronic medical conditions as underlying causes. These tests include full blood count (FBC); thyroid function test (TFT); liver function test (LFT); calcium; magnesium; phosphate; glucose; serum B12; folate; urea and electrolytes; and urinalysis. Other tests to be considered, where indicated, include C-Reactive Protein (CRP), HIV, VDRL, and Vitamin D. Although less common, genetic testing is also used when indicated (for example, when Familial Alzheimer's disease is suspected), and should be undertaken in the context of genetic counselling.

Investigations

Brain imaging investigations, such as a Computerised Tomography (CT) without contrast or Magnetic Resonance Imaging (MRI), are often used to identify brain atrophy consistent with different dementia subtypes and to exclude other cerebral pathologies (such as focal stroke or tumour). A chest x-ray and/or ECG can also assist in ruling out other medical causes for the presenting symptoms, as well as ensuring that appropriate pharmalogical treatment can be initiated upon diagnosis, if indicated.

SCREENING AND ASSESSMENT **TOOLS**



Screening and assessment tools must only be administered by health professionals who are competent in the administration and scoring of the tool and the interpretation of results (i.e. the context of the impaired/unimpaired score). The health professional must also understand the limitations of the tool that is being used. In other words, the competency of administration, scoring, and interpretation of the tool forms part of the health professional's scope of practice.

There are a number of validated screening and assessment tools that are recommended to be used in supporting a diagnosis of dementia (see **Resources – Other** section), these include:

Cognitive Screening Tools

- Abbreviated Mental Test Score (AMTS)
- Addenbrooke's Cognitive Examination, Third Edition (ACE-III)
- Confusion Assessment Method Instrument (CAMI)
- General Practitioner Assessment of Cognition (GPCOG)
- Mini Mental State Examination (MMSE) – note: this tool is copyrighted
- Modified Mini Mental State Test (3MS)
- Montreal Cognitive Assessment (MoCA)
- Rowland Universal Dementia Assessment Scale (RUDAS)
- Clock Drawing Test (CDT) – used in conjunction with any of the above.

Please note: The Kimberley Indigenous Cognitive Assessment (KICA) and the modified KICA are not recommended for use in the New England North West region. The RUDAS tool is recommended for people from culturally and linguistically diverse (CALD) communities.

Functional Screening Tools

- Barthel Index – Activities of Daily Living (ADL)
- Behavioural Pathology in Alzheimer's Disease
- Cambridge Behaviour Interview, Revised (CBI-R)
- Clinical Dementia Rating (CDR)
- Disability Assessment for Dementia (DAD)
- Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)
- Lawton's Instrumental Activities of Daily Living
- Neuropsychiatric Inventory (NPI)
- Zarit Burden Inventory (ZBI)

Mood Screening Tools

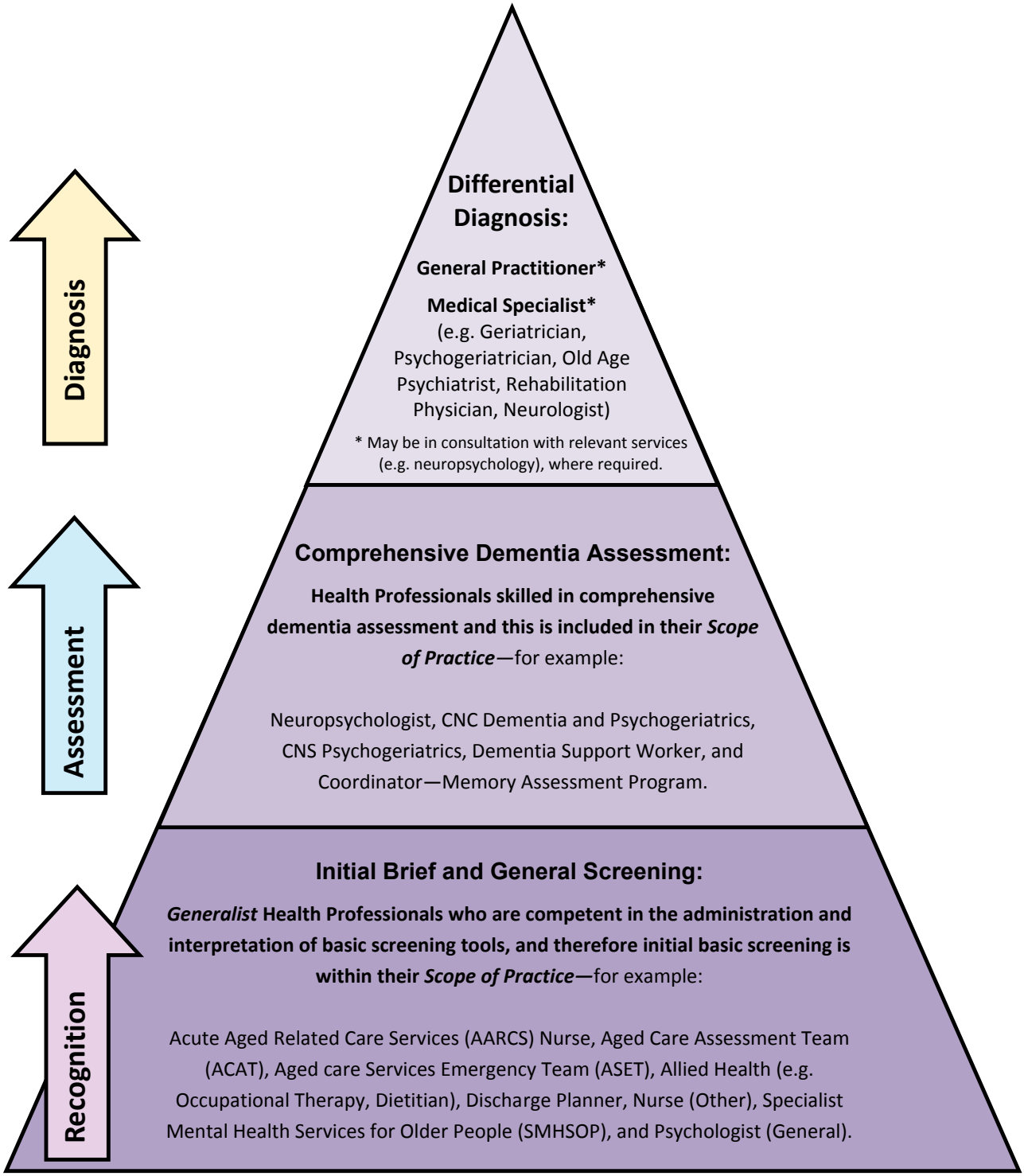
- Geriatric Depression Scale
- Hospital Anxiety and Depression Scale (HADS)
- Depression, Anxiety, and Stress Scale (DASS-21)

Neuropsychological Testing

For complex cases with multiple issues (i.e. comorbidities), and where diagnosis is unclear, comprehensive neuropsychological assessment may be warranted.

Unlike cognitive screening tools, neuropsychological tests can generate a comprehensive differential cognitive profile that can assist in identifying the subtype of dementia and rule out other possible causes (such as depression).

SCREENING AND ASSESSMENT **CLINICIANS**



DEMENTIA **ASSESSMENT SERVICES**

Undertaking a dementia assessment can be a complex process that requires considerable time. Dementia assessment services provide support to both General Practitioners and Medical Specialists by providing comprehensive bio-psychosocial assessments to assist with the diagnosis of the type of dementia that affects the individual and provide direction on future care, management and support options. These specialist services may be particularly relevant for complex cases or where it is difficult to determine the presence of dementia or the specific subtype.

Dementia assessment services are staffed by clinicians with dementia specific skills and experience, who have been trained to administer and interpret comprehensive dementia assessment tools. The services provide feedback on the results and outcomes, along with recommendations, to the individual, as well as to their carer and/or family. This information is also communicated to their General Practitioner to enable continuum of care. If required and/or requested by the General Practitioner, a referral to a dementia specialist physician (for example, Geriatrician, Psychogeriatrician, Neurologist, or Rehabilitation Specialist) may also be made in consultation with the person suspected with having dementia and their family.

Dementia Assessment services in the New England North West utilise a standardised referral form (see **Referral Form** section) and referral pathway, and contact details are as follows:

HealthWISE - Memory Assessment Program (MAP)

Location: Armidale, Glen Innes, Guyra, Inverell, Tenterfield, Uralla, Walcha and surrounding areas

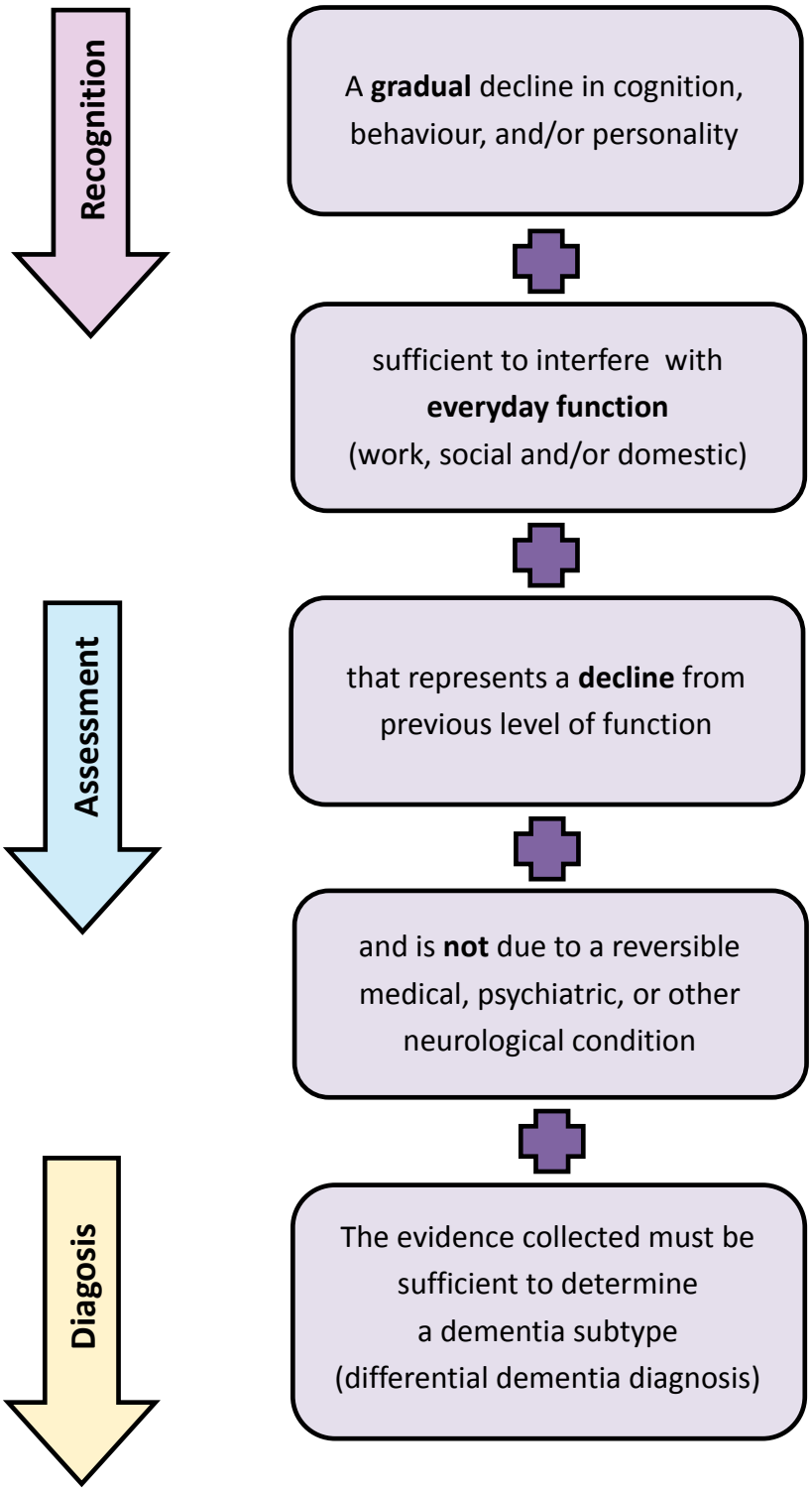
- Coordinator – Memory Assessment Program, Armidale Office
  Phone: 02 6771 1146

Hunter New England Local Health District – Cognition and Memory Service (C&MS)

Location: New England North West Region

- Clinical Nurse Consultant Dementia, Armidale Community Health
  Phone: 02 6776 9600
- Clinical Neuropsychologist, New England Older Adults Neuropsychology Service
  Phone: 02 6776 9600
- Psychogeriatric Clinical Nurse Specialist, Narrabri Community Health
  Phone: 02 6799 2800
- Clinical Nurse Consultant Psychogeriatrics, Tamworth Community Health
  Phone: 02 6767 8100
- Clinical Nurse Consultant Dementia/Delirium in Acute Settings, Tamworth Rural Referral Hospital (Hospital inpatient referral only)
  Phone: 02 6767 8212

DIFFERENTIAL DEMENTIA **DIAGNOSIS**



DIAGNOSING DEMENTIA

Dementia is a clinical syndrome consisting of a cluster of symptoms. There are over fifty subtypes of dementia, and each is associated with specific neurodegenerative pathology occurring in the brain. The most common forms of dementia are Alzheimer's dementia, vascular dementia, and mixed Alzheimer's and vascular dementia, followed by Lewy body dementia, frontotemporal dementia, and dementia due to Parkinson's disease. Other less common forms include alcohol-related dementia, HIV-associated dementia and dementia due to Huntington's disease. For more information about dementia subtypes, go to the **Alzheimer's Australia** website.

In order to diagnose the specific subtype of dementia (and most likely associated brain pathology), a comprehensive assessment will need to be undertaken – including a timeline of cognitive and functional decline. As part of this process, a treatable or comorbid condition may also be identified.

Dementia can be diagnosed when there is a gradual decline in cognition, behaviour and/or personality that:

- interferes with everyday function (work, social and /or domestic function); **and**
- represents a decline from previous levels of functioning and performing; **and**
- cannot be explained by an acute or chronic medical condition, neurological condition, delirium, or a major psychiatric disorder.

Where the diagnosis of dementia and the dementia subtype remains uncertain, a review is recommended after six or twelve months. For a summary of the assessment and management of dementia, refer to the research article **Dementia: 14 essentials of assessment and care planning** (Brodarty, Connors, Pond, Cumming and Creasey 2013).

It is also recommended that the assessment process include the identification of current issues and management goals, in discussion with the person with cognitive impairment, their carer and/or family, for the purpose of developing a comprehensive care plan. The care plan is a living document which requires regular review every three to six months, including the review of any medications and carer burden.

Hunter & New England HealthPathways – Cognitive Impairment

The HNE **HealthPathways** website provides best practice guidelines in assessment, diagnosis and management of cognitive impairment and dementia. The website also provides referral pathways and patient information to support General Practitioners and other health professionals.

To log-on, enter the Username – hnehealth, and the Password – p1thw1ys.

MANAGEMENT OF DEMENTIA

In accordance with Alzheimer's Australia guidelines people with dementia have the right to:

- a timely and thorough assessment by medical and health professionals;
- sensitive communication of diagnosis that includes explanation of symptoms and prognosis;
- adequate information to make life choices and enable future planning;
- as much involvement in the decision-making process as possible; and
- ongoing support and management.

An early diagnosis of dementia assists in discriminating the specific subtype, so that the appropriate medications and management can be provided. It also affords the person and their family as much time as possible to adjust to the diagnosis and plan for the future (source: **Alzheimer's Australia**).

Prognosis

The course of dementia varies from person to person, and depending on the subtype and underlying brain pathology. The median survival from onset is estimated at seven years for Alzheimer's disease, however other dementia syndromes can take longer to progress, and others take less time. Younger onset dementia tends to progress more rapidly. Almost all people with dementia eventually develop psychological or behavioural problems. Most people will eventually require assistance to perform even simple tasks, and will require assistance with decision-making.

Medication

In dementia, where the predominant brain pathology is thought to be Alzheimer's disease, cholinesterase inhibitors (e.g. Donepezil, Galantamine, Rivastigmine, Memantine) can be effective in slowing the progression of the disease process and subsequent impact on cognition and activities of daily living. In Australia, a Medical Specialist must confirm the diagnosis of Alzheimer's disease for the person to be eligible for subsidised Alzheimer's medications. Other medications that can be used to manage symptoms associated with dementia include anti-anxiolytics, anti-depressants and anti-psychotics, but the benefits of such medications should always be discussed in detail with the person living with dementia and their carer and/or family.

Counselling

For people who are experiencing psychological distress and are having difficulty adjusting to a new diagnosis of dementia, or who are in the early stages of dementia and have symptoms of stress, anxiety or depression, counselling and focused psychological intervention may be beneficial. Some therapeutic techniques may include mindfulness, Acceptance and Commitment Therapy, and/or Cognitive and Behavioural Therapy.

Other Considerations

Other conditions to be considered in dementia management are: pain; dental health; constipation; hydration; and dietary imbalances, malnutrition and weight loss. People living with dementia are also at greater risk of falls and delirium, and may experience sleep disorders and visual dysfunction. As the dementia progresses, the person may also experience further co-morbidities related to frailty.

THINKING AHEAD - DRIVER RETIREMENT

While it is possible for many people with dementia to continue to drive after receiving a diagnosis, it is important to raise the prospect of no longer driving soon after diagnosis. The impact of not driving on the person with dementia, carers and family members, and the subsequent loss of independence and associated self-reliance on mobility, can be overwhelming. It is therefore good practice to introduce the possibility of this event in short, regular discussions, so those involved can start planning. This may involve investigating local transport options, the availability of community and volunteer transport, and the support that might be offered by family, friends and/or neighbours.

Staying on the Move with Dementia

Drivers who have been diagnosed with dementia are legally required to report to the Driver Licencing Authority – in NSW, this is the Roads and Maritime Services (RMS). They must then undergo a medical assessment by a doctor, and may also be required to have a practical driving assessment, conducted by an occupational therapist. The driver may then be approved for a conditional licence, but due to the progressive nature of dementia, will be required to undergo at least an annual review of their licence. If it is determined that the driver is no longer able to drive, but they continue to drive and are involved in an accident, they may be prosecuted and their insurance cover may not be valid. If their doctor is aware that they are continuing to drive, the doctor is legally authorised to contact the Driver Licencing Authority.

For further information, refer to the **Staying on the Move with Dementia** booklet, on the **Alzheimer's Australia** website.

Assessing Fitness to Drive

The dementia and cognitive impairment standards are included as a separate section within the neurology chapter of the Assessing Fitness to Drive guidelines. Guidance on the assessment and management of dementia with respect to driving has been significantly expanded, and applies to all forms and causes of dementia (e.g. AIDS, organ failure, Huntington's), not just Alzheimer's disease. A diagnosis of dementia now necessitates a conditional licence for private drivers, reflecting the progressive nature of the condition and the need for ongoing monitoring.

For further information on assessing fitness to drive, go to the **Austroads** website.

THINKING AHEAD - ADVANCED CARE PLANNING

Dementia affects people differently. However, sooner or later their abilities will decline and the person with dementia will require support in making decisions about their health, day to day living, financial and legal matters. Planning ahead is very important for people diagnosed with dementia. It is recommended that advice is sought from legal and health professionals to complete a will; enduring power of attorney; enduring guardianship; and an advance care directive while the person still has capacity. For more information, go to the **Planning Ahead** or **Start2Talk** websites, and to access Aboriginal and Torres Strait Islander resources, go to the **HealthInfoNet** website.

If there is concern about the welfare or financial situation of a person who has lost capacity, and decisions need to be made for that person, an application can be made to the Guardianship Division of the NSW Civil and Administrative Tribunal for a Guardianship or Financial Management Order, to appoint someone to make decisions on behalf of the person. For further information, go to the **Guardianship Division** website.

Will

A Will is a legal document that sets out which beneficiaries will receive the assets, money and property of someone when they die. Making a Will is the only way a person can ensure their assets will be distributed according to their wishes when they die.

Enduring Power of Attorney

A person can sign an enduring power of attorney if they are legally competent at the time of signing. An enduring power of attorney is a legal arrangement that enables a nominated person to look after the financial affairs of another person should they become unable to do so themselves. The benefit would be that a person with dementia can choose someone themselves to act on their behalf should the need arise.

Enduring Guardianship Appointment

An Enduring Guardian can make decisions on behalf of another person, in areas such as accommodation, health and services, if they lose the capacity to make their own decisions at some time in the future. An Enduring Guardian cannot make decisions about money or assets, although these decisions can be made by an Enduring Power of Attorney.

Advanced Care Directives

Every competent adult has the legal right to accept or refuse any recommended health care. This is relatively easy when people are well and can speak for themselves. Unfortunately, during severe illness people are often unconscious or otherwise unable to communicate their wishes – at the very time when many critical decisions need to be made. An Advanced Care Directive refers to the process of preparing for likely scenarios near the end of life and usually include assessment of, and dialogue about, a person's understanding of their relevant history and condition, including values, preferences, and personal and family resources.

Retirement from Work

While those employed in job roles where cognitive and functional impairment may affect the safety of themselves and others will need to consider other employment options, people diagnosed with dementia in the early stages of the disease may benefit from the sense of purpose and the social benefits of remaining employed. Employers are required to consider the diagnosis in relation to the job role, and provide reasonable support to those diagnosed with dementia, for example, by providing increased supervision, adjusting duties, or working with the employee to create a transition to retirement plan.

Assessing Capacity to Make Decisions

The NSW Justice Department provides guidelines for the assessment of a person's ability to make significant decisions or decisions that have legal consequences. **The Capacity Toolkit** is available free-of-charge to health and legal professionals, as well as people living with dementia and their carers. In assessing capacity, the assumption is always that the person has capacity to make decisions, and that a person may only lack capacity in one decision-making area. It is also important to remember that it is the decision-making process that is being assessed, not the decisions that are being made.

DEMENTIA **MANAGEMENT SERVICES**

Dementia Management Services

Alzheimer's Australia – National Dementia Helpline

The National Dementia Helpline provides information and support to people living with dementia, their carers, families and friends, as well as people concerned about their memory. The Helpline provides practical information and advice, advocacy, and referral to other services. This confidential service is available 9:00am to 5:00pm, Monday to Friday (excluding Public Holidays).

Phone: 1800 100 500

Hunter New England Local Health District – Cognition and Memory Service (C&MS)

Location: New England North West Region

C&MS provides support to people living with dementia, their carers and family, as well as referral to additional management and support services, if needed. The service also uses input and advice from other aged care clinicians within the Health Service, such as specialist Aged Care Nurses (Acute to Aged Related Care Service – AARCS, Aged care Services in Emergency Teams – ASET, Nurse Practitioner), Aged Care Assessment Team (ACAT), Geriatrician, Psychogeriatrician and Specialist Mental Health Services for Older Persons (SMHSOP) clinician.

- Clinical Nurse Consultant Dementia, Armidale Community Health

  Phone: 02 6776 9600

- Dementia Support Worker Armidale Community Health

  Phone: 02 6776 9600

- Dementia Support Worker, Inverell Community Health

  Phone: 02 6721 9600

- Psychogeriatric Clinical Nurse Specialist, Narrabri Community Health

  Phone: 02 6799 2800

- Dementia Support Worker, Narrabri Community Health

  Phone: 02 6799 2800

- Clinical Nurse Consultant Psychogeriatrics, Tamworth Community Health

  Phone: 02 6767 8100

Aged Care Support Services

Commonwealth Respite and Carelink Centres

Commonwealth Respite and Carelink Centres provide information and linkages to local short-term and emergency respite care and other support services. The service is available Monday to Friday 8am to 8pm, and Saturday 10am to 2pm.

- Phone: 1800 052 222 during business hours or 1800 059 059 outside business hours

My Aged Care

My Aged Care is funded by the Australian Government and provides information about aged care and support services. It is the central referral portal for accessing Commonwealth Government subsidised services, including meals on wheels, allied health services, and domestic and personal care assistance. It is also the portal for requesting an assessment from the Aged Care Assessment Team (ACAT), which can lead to an approval for more comprehensive support, such as Home Care Packages (which includes case management), and/or approval for respite or permanent accommodation in a Residential Aged Care Facility.

- Phone: 1800 200 422 or go to the **My Aged Care** website

Carer Support Services

Carer Gateway

The Carer Gateway is a national online and phone service, funded by the Australian Government, providing practical information and resources to support carers. The interactive service finder helps carers connect to local support services.

- Phone: 1800 422 737 or go to the **Carer Gateway** website

Dementia Behaviour Management Support Services

Dementia Behaviour Management Advisory Services (DBMAS)

DBMAS is funded by the Commonwealth Government and operated by Dementia Support Australia (DSA). This 24 hour service can help in the care of people living in aged care facilities or in the community with severe and persistent behavioural and psychological symptoms of dementia (BPSD).

- Phone: 1800 699 799 or go to the **Dementia Behaviour Management Advisory Service** website

Hunter New England Local Health District – Transitional Behavioural Assessment & Intervention Service (T-BAsIS)

Location: New England North West Region

The TBAsIS unit is a multidisciplinary assessment facility for people aged over 65 years, or Aboriginal or Torres Strait Islander persons who identify as being an older person, who have a documented dementing process or a loss of cognitive function which is not immediately attributable to a functional mental health diagnosis or delirium. Referred clients are screened for admission suitability in consultation with the T-BASIS Unit's admission / discharge committee.

- Phone: 02 6767 8450 or Fax: 02 6766 9135

RESOURCES - TRAINING AND EDUCATION

Dementia – Training and Education

Australian Practice Nurse Association (APNA) – Timely Diagnosis of Dementia

Free online and face-to-face (three hour) training funded by the Australian Government aims to improve knowledge and skills, and provide resources to improve the timely diagnosis and management of dementia in primary care. The website also includes the *Building Dementia Practice in Primary Care* guidelines. For more information, go to the **APNA** website.

Dementia Training Study Centres (DSTC)

The Dementia Training Study Centre is a consortium between Alzheimer's Australia and a number of Australian Universities. The **DTSC** website contains free online courses, recorded guest lectures, upcoming face-to-face events, information and links to resources.

Health Education and Training Institute NSW (HETI) and MyLink

Online course modules are available to Local Health District staff on both the **HETI** and **MyLink** websites. Screening and assessment information and templates are also available on MyLink.

NSW Health Dementia Care Competency & Training Network

The **Dementia Care** website has been developed for a wide range of clinicians, and aims to promote person centred practice to improve health care. The website contains the Dementia Care Competency Framework, upcoming events, access to 4-12 week courses, newsletters, and a library of resources.

ThinkGP

Online education modules range from one to six hours, and attract Continuing Professional Development points. Topics related to dementia include: recognising dementia in general practice; timely diagnosis of dementia; developing a plan for managing dementia in general practice; and recognising and managing Behavioural and Psychological Symptoms of Dementia (BPSD) and physical comorbidities of dementia. For more information, go to **ThinkGP – Aged Care** webpages.

University of Tasmania – Understanding Dementia

Understanding Dementia is a free, university-quality, nine-week online course available to health professionals and the community, including people living with dementia and their carers. The course includes basic nervous system anatomy and function, the differences between normal ageing and dementia, how to recognise and manage dementia, and palliation. For more information about the online course or the Bachelor of Dementia Care, go to the **Understanding Dementia** website.

RESOURCES - OTHER

Assessment Tools – Training, Information and Templates

Note: Screening and assessment templates are available to NSW Health staff on **MyLink**.

Dementia Collaborative Research Centres – Dementia Outcomes Measurement Suite (DOMS)

The **DOMS** website contains a collection of validated assessment tools, including those listed in this booklet. The website provides assessment templates for the following dementia aspects: behaviour, cognition, delirium, function, quality of life and staging.

Cognitive Assessment – Addenbrookes Cognitive Examination Third Edition (ACE-III)

A link to the ACE-III template, training in the administration of the ACE-III (provided by ACE-III Trainer on the **Glasgow University** website), and a mobile app is available from the **DOMS** website.

Function Assessment – Cambridge Behavioural Inventory – Revised (CBI-R)

A template for the CBI-R assessment can be found on the **NeuRA - Medical Research Institute** website.

Mood Assessment – Geriatric Depression Scale (GDS-15)

Information about the GDS-15 assessment tool can be found on **The Hartford Institute for Geriatric Nursing's** website, and the link to a test form and apps can be found on the **DOMS** website.

Clinical Practice Guidelines and Information

Alzheimer's Australia and Agency for Clinical Innovation (ACI): Allies in Dementia Health Care

Two resources have been developed to support health professionals, and people living with dementia and their carers, to understand the role of allied health professionals in the management and care of dementia. For more information, go to the **ACI** website.

Australian Commission on Safety and Quality in Health Care – A Better Way to Care

There are three resources available on the **Better Way To Care** website for health service managers, clinicians, and consumers, aimed at improving the care of patients with cognitive impairment (dementia and delirium) in hospitals.

Cognitive Decline Partnership Centre – Clinical practice guidelines and principles of care for people living with dementia in Australia

The guidelines were released in February 2016, to provide health professionals in all health settings, and carers, with access to recommendations for care based on current evidence. For more information and to download a copy of the guidelines, go to the **Alzheimer's Australia** website.

Royal Australian College of General Practitioners (RACGP) – Dementia

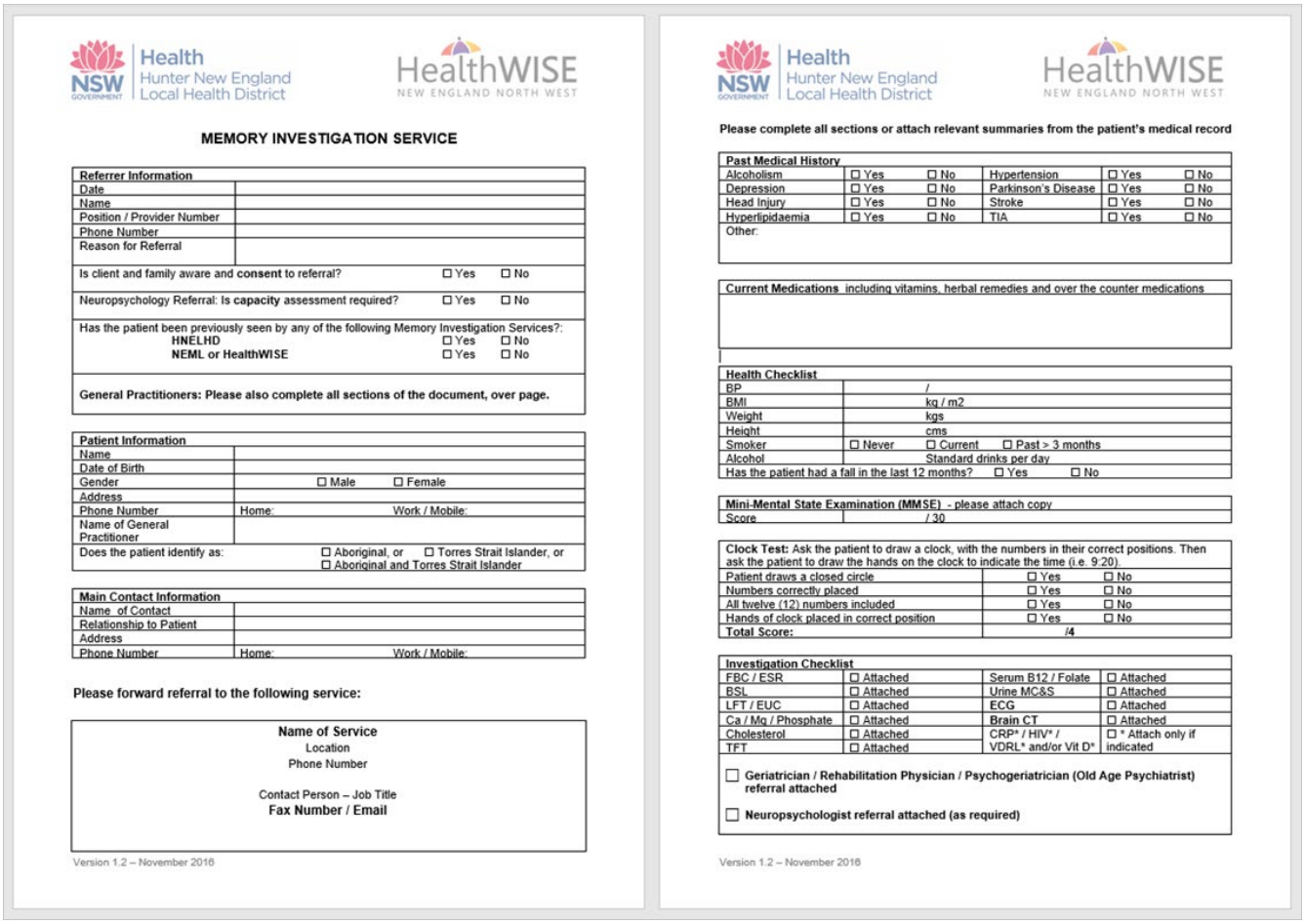
The **RACGP's** *Medical care of older persons in residential aged care facilities guidelines* (**Silver Book**) contains information on the assessment, cognitive testing, and management of dementia, including the management of medication and behavioural and psychological symptoms. An electronic version of the Silver Book can be found on the RACGP website.

REFERRAL **FORM**

New England North West dementia assessment services, provided by HealthWISE and HNELHD, utilise a single, standardised referral form across the region. For service contact details and locations, refer to the **Dementia Assessment Services** section.

HealthWISE require a GP to complete the standardised referral to access the Memory Assessment Program, as well as provide a copy of test results and a referral for the Geriatrician. HNELHD accept referrals from GPs, service providers, hospital staff and the general public. On receipt of the referral, the HNELHD clinician contacts the referred person's usual GP to notify them of the referral, and to request pathology and brain imaging (if not already provided).

Both services then make an appointment with the person with memory concerns, their carer and/or family, to undertake a comprehensive assessment and gather other supporting information, such as a history of cognitive and/or functional decline. Both services are also able to refer the person to the HNELHD Neuropsychologist, if required. A report is then sent to the General Practitioner, and the appropriate Medical Specialist (if required, and if the General Practitioner has provided a referral), in consultation with the person with memory concerns, their carer and/or family.



Health
Hunter New England
Local Health District

HealthWISE
NEW ENGLAND NORTH WEST

MEMORY INVESTIGATION SERVICE

Referrer Information	
Date	
Name	
Position / Provider Number	
Phone Number	
Reason for Referral	

Is client and family aware and **consent** to referral? ☐ Yes ☐ No

Neuropsychology Referral: **Is capacity** assessment required? ☐ Yes ☐ No

Has the patient been previously seen by any of the following Memory Investigation Services?:
HNELHD ☐ Yes ☐ No
NEML or HealthWISE ☐ Yes ☐ No

General Practitioners: Please also complete all sections of the document, over page.

Patient Information		
Name		
Date of Birth		
Gender	☐ Male ☐ Female	
Address		
Phone Number	Home:	Work / Mobile:
Name of General Practitioner		
Does the patient identify as:	☐ Aboriginal, or ☐ Torres Strait Islander, or ☐ Aboriginal and Torres Strait Islander	

Main Contact Information		
Name of Contact		
Relationship to Patient		
Address		
Phone Number	Home:	Work / Mobile:

Please forward referral to the following service:

Name of Service
Location
Phone Number

Contact Person – Job Title
Fax Number / Email

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Please complete all sections or attach relevant summaries from the patient's medical record

Past Medical History				
Alcoholism	☐ Yes ☐ No	Hypertension	☐ Yes	☐ No
Depression	☐ Yes ☐ No	Parkinson's Disease	☐ Yes	☐ No
Head Injury	☐ Yes ☐ No	Stroke	☐ Yes	☐ No
Hyperlipidaemia	☐ Yes ☐ No	TIA	☐ Yes	☐ No
Other:				

Current Medications including vitamins, herbal remedies and over the counter medications

Health Checklist	
BP	/
BMI	kg / m2
Weight	kgs
Height	cms
Smoker	☐ Never ☐ Current ☐ Past > 3 months
Alcohol	Standard drinks per day
Has the patient had a fall in the last 12 months?	☐ Yes ☐ No

Mini-Mental State Examination (MMSE) - please attach copy	
Score	/ 30

Clock Test: Ask the patient to draw a clock, with the numbers in their correct positions. Then ask the patient to draw the hands on the clock to indicate the time (i.e. 9:20).		
Patient draws a closed circle	☐ Yes	☐ No
Numbers correctly placed	☐ Yes	☐ No
All twelve (12) numbers included	☐ Yes	☐ No
Hands of clock placed in correct position	☐ Yes	☐ No
Total Score:	/4	

Investigation Checklist			
FBC / ESR	☐ Attached	Serum B12 / Folate	☐ Attached
BSL	☐ Attached	Urine MC&S	☐ Attached
LFT / EUC	☐ Attached	ECG	☐ Attached
Ca / Mg / Phosphate	☐ Attached	Brain CT	☐ Attached
Cholesterol	☐ Attached	CRP* / HIV* /	☐ * Attach only if
TFT	☐ Attached	VDRL* and/or Vit D*	indicated

☐ **Geriatrician / Rehabilitation Physician / Psychogeriatrician (Old Age Psychiatrist) referral attached**

☐ **Neuropsychologist referral attached (as required)**

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MBS ITEM NUMBERS

In addition to standard consultation items, the following items may be used with a patient suspected of or having dementia.

Assessment for Dementia

The four time based health assessments (MBS Items 701, 703, 705, 707) can be used to undertake memory assessments, as part of a comprehensive assessment, on patients who are:

- 75 years and older;
- Aboriginal and Torres Strait Islander (aged 55 years or older);
- a permanent resident of a residential aged care facility; and/or
- a refugee or other humanitarian entrant.

Management of Dementia

Patients diagnosed with dementia are eligible for a GP Management Plan and/or Team Care Arrangement:

- 721 – Prepare a GP Management Plan (GPMP);
- 723 - Coordinate a Team Care Arrangement (TCA);
- 732 – Review a GP Management Plan and/or Review a Team Care Arrangement;
- 729 – Contribute to a Multidisciplinary Plan.

If the patient has a TCA they are eligible for up to five allied health services per calendar year.

Mental Health Support

If your patient is suffering from depression and anxiety they are eligible for a GP Mental Health Care Plan to treat their depression/anxiety. This plan is not to be used to manage dementia as dementia is not a mental illness. These plans can also be used for the carers of people living with dementia, who may be effected by depression, anxiety or other mental illness. The MBS item numbers are:

- 2700, 2701, 2715 or 2717 - Preparation of a GP Mental Health Treatment Plan;
- 2712 - Review of a GP Mental Health Treatment Plan; and
- 2713 - GP Mental Health Treatment Consultation.

Patients who have a GP Mental Health Care Plan are eligible for referral for up to ten individual and ten group sessions per calendar year. It is expected that they will only be referred for services on an as required basis.

Home Medicines Review (HMR)

Dementia patients with complex medication needs can receive a home visit with an accredited pharmacist to improve their medication management. An HMR (MBS Item Number 900) can be claimed with a GPMP or TCA. The HMR service is not available to in-patients of a hospital, day hospital facility or care recipients in residential aged care facilities. Permanent Residents of a residential aged care facility are eligible for a Residential Medication Management Review (RMMR).

Case Conferencing

These case conferencing items are for GPs to organise and coordinate, or to participate in, a meeting or discussion held to ensure that their patient's multidisciplinary care needs are met through a planned and coordinated approach. The MBS Item Numbers are:

- 735, 739, 743 -Organise and coordinate a GP Case Conference;
- 747, 750, 758 - Participate in a GP Case Conference.

This information has been summarised from the MBS online. Please refer to MBS Online when interpreting and applying these item numbers.

WEBSITE LINKS

Dementia Management Resources

Alzheimer's Australia	**www.fightdementia.org.au**
Austroads	**www.austroads.com.au**
Carer Gateway	**www.carergateway.gov.au**
Dementia: 14 essentials of assessment and care planning	**http://medicinetoday.com.au**
Dementia Behaviour Management Advisory Services (DBMAS)	**http://dbmas.org.au**
HealthInfoNet	**www.healthinfonet.ecu.edu.au**
Medicare: MBS Online	**www.mbsonline.gov.au**
My Aged Care	**www.myagedcare.gov.au**
NSW Civil and Administrative Tribunal: Guardianship Division	**www.ncat.nsw.gov.au**
NSW Justice Department: Capacity Toolkit	**www.justice.nsw.gov.au**
Planning ahead	**http://planningaheadtools.com.au**
Start2Talk	**http://start2talk.org.au**

Dementia Education and Training

Australian Practice Nurse Association (APNA)	**www.apna.asn.au**
Dementia Training Study Centres (DTSC)	**http://dtsc.com.au**
NSW Dementia Care Competency & Training Network	**http://dementiacare.health.nsw.gov.au**
Think GP – Aged Care	**https://thinkgp.com.au**
University of Tasmania – Understanding Dementia	**http://www.utas.edu.au**

WEBSITE LINKS

Dementia Partnership

HealthWISE New England North West	**www.healthwisenenw.com.au**
Hunter New England Central Coast Primary Health Network (HNECC PHN)	**www.hneccphn.com.au**
Hunter New England Local Health District (HNELHD)	**www.hnehealth.nsw.gov.au**
HNE HealthPathways	**https://hne.healthpathways.org.au**
Patient Info	**www.patientinfo.org.au**

Dementia Assessment Tools

Dementia Collaborative Research Centres – Dementia Outcomes Measurement Suite (DOMS)	**www.dementiakt.com.au/doms/**
Glasgow University: Addenbrooke's Cognitive Examination 3rd Edition (ACE-III) training	**http://www.nes.scot.nhs.uk/**
Hartford Institute for Geriatric Nursing: Geriatric Depression Scale (GDS-15) information	**https://consultgeri.org/try-this/general-assessment/issue-4**
NeuRA – Medical Research Institute: Cambridge Behavioural Inventory – Revised (CBI-R)	**http://www.ftdrg.org/wp-content/uploads/cbi_caregiver.pdf**

Dementia Clinical Practice Guidelines and Information

Agency for Clinical Innovation: Allies in Dementia Health Care	**www.aci.health.nsw.gov.au**
Australian Commission on Safety and Quality in Health Care: A Better Way to Care	**www.safetyandquality.gov.au**
Alzheimer's Australia - Cognitive Decline Partnership Centre: Clinical practice guidelines and principles of care for people living with dementia in Australia	**www.fightdementia.org.au**
Royal Australian College of General Practitioners (RACGP): Medical care of older persons in residential aged care facilities guidelines (Silver Book)	**www.racgp.org.au**

NEW ENGLAND NORTH WEST
DEMENTIA CARE INFORMATION

FOR CLINICIANS AND HEALTH WORKERS