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(Dementia)
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House of Representatives Standing Committee on Health and Ageing

Inquiry into Dementia: Early Diagnosis and Intervention

Submission from

Cognitive Dementia & Memory Services (CDAMS) Victoria

2 May, 2012

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INTRODUCTION

The need for early recognition and diagnosis of dementia and the consequent benefits of this has been well documented[1] yet as many as two thirds of people with dementia do not receive a formal diagnosis and of those that do the average time between symptoms and diagnosis is 3.1 years[2]. A timely diagnosis is essential to enable people to benefit from early intervention in the form of treatment, support, advanced planning and understanding of their condition[3].

For the majority of people their GP is the first point of contact when they notice changes in their (or their family members) memory or thinking. Their GP, as the central point of contact, also plays a crucial role in the provision of advice and coordination of their ongoing care throughout their journey with dementia. It is therefore critical that GP's have a good understanding of dementia, their role in the recognition and ongoing management of the condition and of the referral pathways available to them. Unfortunately this is not always the case. Understanding of early dementia symptoms and their differentiation from normal ageing and depression is at times lacking. The service system available to support people with dementia is also complex and varies nationally making it difficult to establish consistent identified referral pathways.

Dementia diagnosis and management is a complex, time consuming process and one that is difficult to achieve within the usual consultation time frames in most GP clinics. (Current remuneration under the MBS does not adequately cover the increased demands of good dementia management and care. In addition there are growing expectations for GP's to be central to the management of a range of complex chronic medical conditions with a focus on reduced reliance on the hospital system, further impacting on their time and availability. GP's need to be well supported in their role in dementia care through adequate education, easily identified referral pathways to appropriate support services and adequate specialist services for assistance with diagnosis and advice, particularly for the more complex presentations in younger onset dementia, people from CALD backgrounds, people with intellectual disabilities or those with atypical presentations .

The Ministerial Task Force in Dementia Services – "Dementia Care – Building a Pathway to Excellence (Victoria 1997)[4] recognised this need specifically in its recommendation that "a state network of specialist diagnostic and management services be established". As a result Cognitive Dementia and Memory Services (CDAMS) were established across the state of Victoria in 1997 ensuring equity of access to consistent specialist multidisciplinary assessment and diagnosis, advice, referral and education for people experiencing memory loss or changes to their thinking and for those who care for them. With ongoing government support these services have grown and expanded to include 10 metropolitan and 7 regional services in Victoria. 2011-12 total recurrent funding for CDAMS is now approximately $6.78M. Activity data for 2010-11 indicates approximately 24,550 contacts and approximately 4,160 clients

The CDAMS role is

- To provide **early diagnosis** and appropriate preventative treatment and advice

- To be a **publicly visible and accessible** specialist consultancy for people with cognitive impairment and their carers. CDAMS offers its consultancy service throughout the pathway of dementia but does not provide case management

- To offer **information and advice to any person or service in contact with a person with a cognitive impairment**. CDAMS will also provide referral to any service appropriate to the needs of the individual with cognitive impairment and their carer.

As the population ages, an increasing number of individuals will experience age-related dementias and with it there will be a growing demand for expert diagnosis, advice and support from individuals, families, and health providers. Efficient, effective and creative solutions will be required. The strategies suggested in this submission have been developed in collaboration with the Victorian Statewide CDAMS network and are based on the needs and gaps identified through the collective experience of the 17 CDAMS in Victoria over the past 14 years.

RECOMMENDATIONS:

EARLY DIAGNOSIS AND ADVICE:

Opportunities to address the issues that are the focus of this inquiry, such as quality of life, prolonged independence, social engagement and future planning rely on first recognising, identifying and diagnosing dementia in a timely manner, however availability of accurate diagnosis and advice is extremely variable across the nation and in general is lacking. Ensuring availability of timely diagnosis and advice will require a multi pronged approach including education and up-skilling of GP's, practice nurses, and service providers, provision of specialist services to provide assistance and advice particularly in more complex presentations, along with increased community awareness of dementia and the benefits of early diagnosis

Recommendation 1:

Expansion of existing CDAMS and of CDAMS style specialist multidisciplinary assessment and diagnostic services across Australia ensuring equity of access to timely diagnosis, advice and referral to services and community support.

A comprehensive review of CDAMS, completed in 2003 by the Australian Institute of Primary Care[5]**,** concluded '*that the CDAMS is providing an effective early diagnosis, assessment and support service for people with cognitive difficulties, particularly older people with dementia, and their families or carers. Review of the local and international literature indicates that the Victorian clinics are at the leading edge of good practice in early intervention with cognitive impairment. The CDAMS service model is supported by users of the service: clients, referrers and other stakeholders reported high levels of satisfaction with the service*". The review found that the key strengths of the CDAMS clinics include the following:

- Comprehensive multidisciplinary assessment
- A knowledgeable and committed staff
- Availability of a consistent statewide network of clinics.

The CDAMS are a secondary service for GP's where the diagnosis is unclear. Without access to a secondary referral pathway primary care is unlikely to embrace the primary diagnostic role.

Whilst Victoria is in the fortunate position to have CDAMS clinics across the state, they are unable to meet current demand for specialist diagnosis let alone the increasing demands that will develop as the baby boomer population reach the age of 65. Waiting lists are on average between 4 to 6 months for initial assessment. Further expansion of the CDAMS in Victoria is also needed.

Recommendation 2

Increase education for GPs about dementia, including guidelines for best practice in relation to dementia diagnosis, care and referral pathways.

GPs are usually the first port of call for families and patients when there are concerns about cognition and memory. Many provide excellent service for their patients and understand the service system well, although unfortunately this is not always the case. The service system is complex and the range of programs available varies widely, nationally, making it difficult to keep abreast of support options that are available to clients and their families. Some GPs find it difficult to separate dementia from normal ageing and depression, or to understand the management of the degeneration that would be expected to occur in dementia, particularly the emergence of behavioural and psychological symptoms of dementia.

A more detailed understanding of methods to screen for and assess dementia would enable GPs to diagnose those with less complex presentations and identify those that may need to be referred on to specialist services (such as CDAMS) for more detailed assessment and management. Additionally guidelines for treatment and referral pathways for timely support along the dementia continuum are likely to be of benefit and would assist to create a quality treatment program on a national level. These should include information on the medications available to assist with dementia and their prescription guidelines.

Recommendation 3:

Simplification of the process for authority scripts for cholinesterase inhibitors for people diagnosed with possible Alzheimer's disease.

The current system for prescribing Alzheimer's disease medications on authority scripts is complex and many GP's are unable to navigate their way through the process despite their use being established for 10 years now. Feedback from our consumers and their families indicates that as a result of this complexity these medications are often aborted due to misunderstanding of the requirements for repeat testing and continuation rather than lack of tolerability of the medication. A simplification of the process would be beneficial and ensure that people who are eligible for these medications, and likely to benefit from them, can do so.

Access to these medications would further improve if GP's with appropriate training were able to confirm the diagnosis and then prescribe medication instead of the current system where diagnosis must be made by a specialist before the GP can prescribe. This would however require a commitment by GP's and the primary care system to address all the issues around a diagnosis of dementia including driving, future planning, education and referral to services. (appendix 1).

A proactive system of support from the HIC pharmacy advisor with prompts to the prescribing doctor at appropriate times during the trial period for clients on these medications may also be of benefit. A particular issue that CDAMS have noted is the difficulty that occurs at the point of the first dose escalation 4 to 8 weeks after initiation. A common, understandable, error is for the GP to request authority from the HIC for the higher dose but to indicate on the request that this is for a "continuation" rather than indicating that it is still part of the "initiation". In the current system "continuation" does not occur until the end of the 24 week trial period (after the escalation to the higher dose). As "continuation" has been indicated repeat cognitive testing with the required level of improvement is requested by the HIC. The required improvement in cognition is unlikely to have occurred at the time of the first dose escalation with the result that many patients are then informed that they are no longer eligible for an authority script. Had "continuation" not been indicated until the end of the 24 week trial, and after sufficient time on a therapeutic dose, they may well have qualified. A system where the HIC does not request repeat cognitive test scores until someone has been on one of these medications for close to 24 weeks would simplify this process.

Recommendation 4:

Increase education for GP Practice Nurses so they can detect and support patients with dementia more appropriately

Practice nurses are common in many GP clinics now. They have contact with a wide cross section of the primary care population especially older people and so are, an excellent point of contact for detecting dementia. With additional knowledge and training Practice Nurses could provide earlier detection, education, referral, support and care planning for people in the very early stages of memory problems to improve their outcomes and quality of life. Additionally they could support their GPs to collect some of the information required to formulate a diagnosis of dementia and in the appropriate management of patients with dementia across the dementia journey.

Recommendation 5:

Revision of the MBS to ensure GP's and some specialists, including Neurologists, are adequately remunerated for the additional time required for the assessment, diagnosis and ongoing support of people with dementia. This should also include remuneration for the additional support that is provided to families, sometimes independently of patient visits.

Assessment and diagnosis of dementia is a complex process that requires additional time to test the client and to interview the family or other care providers. This is not adequately allowed for in current MBS items, acting as a disincentive to clinicians and GP's to provide the level of comprehensive service required. Items to enable dementia specific extended consultations for GP's, would go some way to addressing this. The current MBS items also do not allow Neurologists (frequently involved in dementia diagnosis and management) access to the same item numbers for comprehensive assessment and management plans that Geriatricians and Psychiatrists have. Consideration should also be given to similar item numbers for Neurologists.

Recommendation 6:

Increase the availability of medical specialists to improve options for diagnosis and advice for people living in rural and remote areas, including telehealth models.

Access to medical specialists who can assess for dementia, and provide advice on the prescription of dementia medications is very limited in rural and remote areas nationally. Accessing specialists often means significant travel for both the patient and in some cases the specialist. This can make early diagnosis more difficult as distance and lack of access delays, and in some cases prevents, help seeking. Creative models (including telehealth) to support local health services in the diagnostic process and the provision of ongoing management need to be developed and evaluated. Early work on this area has been done in Cairns (Dr Edward Strivens, Geriatrician, in collaboration with Queensland University) and has recently been funded in Victoria through Department of Health to the CDAMS network.

Recommendation 7:

Identify best practice in the assessment and diagnosis of dementia in CALD, ATSI and intellectual disability populations, making these models more widely available and better resourced.

Assessment and management of people from Culturally and linguistically diverse (CALD), Aboriginal and Torres Strait Islander (ATSI) and intellectual disability populations is even more complex and time consuming than that of the general population. Models of best practice need to be identified and funding set at levels to adequately remunerate GP's, specialists and clinicians for the extra time and skill required to support these populations, including access to adequately trained interpreters.

Of note with regard to the needs of people with intellectual disability and dementia is the work done by Dr Jenny Torr at the Center for Developmental Disability in Victoria (CDDHV). (Note Dr Torr will be making a separate detailed submission to this inquiry).

With regard to CALD and ATSI populations traditional diagnostic tools (in particular cognitive tools) are often of limited value due to their cultural bias and the lack of norms for these populations. Whilst some work has been done to address this for example with the Kimberley Indigenous Cognitive Assessment tool (KICA)[6] in Western Australia and the Roland Universal Dementia Assessment Scale (RUDAS)[7] these are not yet widely known or utilised. The use of adequately trained interpreters is imperative to ensure assessment, care planning and education is not misinterpreted however the level of competency of interpreters varies. It is recommended that additional training be provided to interpreters working in this field.

Recommendation 8:

Increase community and service systems understanding of dementia and its' progression through community awareness programs and targeted education and inclusion of dementia education at an undergraduate level in health related courses.

The general community has difficulty understanding dementia, how it differs from normal ageing and the ongoing degeneration that occurs with the illness. This lack of knowledge can lead to delays in early recognition and reporting of symptoms as well as difficulty adapting as the illness progresses. Common cognitive tools such as the Mini Mental Status Examination (MMSE), and Abbreviated Memory Test (AMT) are often used with limited understanding of their limitations. These are screening tools, and do not give accurate information about diagnosis, cognitive function or competency. In addition GPs, health care workers and service providers do not always have a good understanding of the specifics of dementia at each stage of the pathway and the likely care needs, again leading to delays in recognition, diagnosis and timely support for people with dementia and their families.

Further education is required to raise community and health professionals understanding of dementia, its assessment, the disease symptoms, pathway and the service system available to support the person with dementia and their families. In the case of health professionals and care providers this will require targeted, funded education programs particularly, but not solely, to those involved in provision of services to the aged care population. Tertiary institutions should also be encouraged to increase the level of undergraduate education provided in this area so that future health professionals have a better understanding of this condition.

AFTER THE DIAGNOSIS.

Timely and accurate diagnosis of dementia is critical as is appropriate ongoing management of the condition with adequate support for the person with dementia and for those that care for them. Service providers also need to be adequately trained and supported in their role in order to provide quality dementia care throughout the continuum of the illness. An increased focus on appropriate community based care, particularly in the early stages of the illness is strongly supported by CDAMS. Along with recommendations regarding community based care two common key issues requiring attention and better systems in the early stages of dementia are future planning and driving.

We welcome the recent Government announcement (20th April 2012) regarding “Living Longer, Living Better – Benefits for older Australians currently receiving care”. The increased funding in the reform package will hopefully bring welcome improvements to support and care at home, greater choice and flexibility in the services received in people’s homes and greater recognition of the needs of carers and those from culturally diverse backgrounds. In particular we welcome the additional funding for those with dementia and hope that the findings from this inquiry will help to inform the best utilisation of this new funding when it eventually becomes available and ensure that service improvements are developed with the specific needs of people with dementia and their families in mind.

Recommendation 9:

Development of, and funding for, models such as dementia support workers (specialists) that enable the provision of ongoing, consistent advice and support for clients and their families.

Specialist diagnostic services such as CDAMS are not funded at present to provide comprehensive ongoing support to clients and their families after a diagnosis of dementia. To do so would result in reduced access to their specialist diagnostic skills as their time would quickly be taken up managing the demands of what is usually a long process of cognitive decline in those they have diagnosed with dementia. Specialist diagnostic services should remain that – diagnostic. Options are however required for the provision of ongoing support and advice that is consistent and of a high quality.

An issue that has been identified in the CDAMS in Victoria is that with earlier diagnosis clients and families are often not ready for or in need of services at the point of diagnosis apart from some initial education and information. This group is perhaps more at risk than those that are diagnosed further along the dementia pathway and linked to the service system at the point of diagnosis. They often tend to manage alone initially and, apart from some possible contact with their GP, are not connected to the service system. Information, provided at the time of diagnosis, about available supports and contacts, can be lost during this time and they often remain outside the service system until a crisis occurs. This is particularly so with the emergence of Behavioural and Psychological Symptoms of Dementia (BPSDs) that can lead to distress for the person with dementia and their families and carers. These symptoms can develop early in some forms of dementia. In many instances such crises could have been avoided with more timely access to services and supports. A system of regular contact, monitoring and advice would likely avoid such situations. Models such as dementia support workers, proactive telephone outreach or adequately remunerated regular visits to GP's, well educated in the needs and stages of dementia and appropriate referral pathways, need to be explored further to ensure these clients and their families avoid a crisis and do not "fall between the cracks". Appropriate multidisciplinary specialist services to address the diagnosis and management of those with BPSDs in the community, can support this model of care.

Recommendation 10:

Improved nationally consistent approaches to the appointment and management of EPOA's and advanced care plans/health directives, including systems for registration, version control and to assist in determining capacity at the appropriate time.

One of the most important advantages of timely diagnosis of dementia is that in the early stage of dementia people are able to take control of their lives and make provision for a future when decision making will be more difficult. To achieve this the diagnosing service must not only provide information about surrogate decision making but be able to make a clear and justifiable statement about the ability of the person with dementia to give an enduring power in case of legal challenge in the future. This will require considerable time, appropriate training and a funding model.

Furthermore, laws and processes for enduring powers of attorney and advanced health directives vary between the states. In some states these documents are not registered making "version control" and ability to check their relevance and status difficult.

Enduring powers of attorney can currently be witnessed by a number of people, most of whom do not have an adequate understanding of capacity in cognitively impaired people. They are often signed without any true assessment of the persons' capacity, therefore putting some people at risk of abuse by those that might seek to be appointed as their powers of attorney. Clearer guidelines and education regarding the assessment of capacity are required for the legal profession, health workers and for those that are able to act as witnesses. The NSW Capacity tool kit[8] is a good example of this.

We would support the implementation of the recommendations from the Victorian Law Reform Commission (2010)[9]. Of particular relevance to this inquiry are the following:

- National harmonisation of power of attorney laws through the standing committee of Attorney Generals. (*Recommendation 2*)
- Education and practical resources to help witnesses fulfil their role including checklists to assess a principals (person making the POA) understanding of the nature and effect of the document and information about how to identify evidence of duress and evidence that may displace the presumption of capacity. (*Recommendation 20*)

- Develop and implement a register for powers of attorney and through the standing committee of Attorney Generals actively promote and support the development and implementation of a national register for power of attorney documents. (*Recommendation 66*)
- Develop targeted information and resources about powers of attorney for those working in the legal, health and community sectors. This information should be developed in consultation with relevant sector organisations and disseminated through appropriate media. (*Recommendation 86 & 87*)
- Develop a training program on powers of attorney for workers in the legal, community and health sectors in conjunction with relevant professional associations and encourage workers in these sectors to participate in this training. (*Recommendation 86 & 87*)
- Encourage tertiary institutions to incorporate information about powers of attorney into relevant courses for the health and community sectors. (*Recommendation 86 & 87*)

Broad community education and promotion of powers of attorney would also be beneficial in raising the profile and importance of making future plans in a timely manner ie before problems arise.

Recommendation 11:

Increase availability of specific rehabilitation and training packages for people in the early stage of their condition and for their carers that include education about strategies to improve and manage daily function and behavioural changes.

Programs that aim to assist clients and their families to adjust to the diagnosis of dementia and develop strategies to deal with the emerging symptoms and changes are already in existence, such as the "Living with memory loss program" run by Alzheimer's Australia, various memory strategy programs developed to assist people with mild cognitive impairment or preclinical dementia (such as the LaTCH Australia[10] program or the Maxcog[11] – both developed in Victoria) as well as carer education programs such as "Creative ways to care"[11] (developed by Commonwealth Carelink and Respite Service Southern Region). These programs empower clients and their families to better manage their condition themselves however funding for these is limited and availability patchy across both metropolitan and rural areas.

Recommendation 12:

Provision of subsidised access to specialist Occupational Therapy driving assessments where indicated as well as improved alternative transport options, including revision of eligibility criteria for taxi schemes.

Ensuring continued mobility in the community (whether as a driver if safe or utilising alternative forms of transport) enables social connectedness, decreased reliance on family and services and enhances self esteem and mood.

The recent revision of the Aust Roads medical guidelines[13] for driving requires that all people with a diagnosis of dementia have a conditional license that is regularly reviewed. A diagnosis of dementia will bring forward the time when a driver needs to retire from driving however does not necessarily preclude someone from driving. Traditional cognitive tests are not highly predictive of who is safe to continue driving, particularly in the very early stages of the condition. As a result those newly diagnosed in the very early stages of dementia generally require an on road driving assessment with a specialist Occupational Therapist if they wish to continue driving. Such tests are limited in their availability and are not subsidised so are very costly to individuals. Consideration needs to be given to the provision of greater access to reasonably priced driving assessments for patients with dementia so that they can be tested quickly and economically as to their safety on the road. In particular rural patients are very disadvantaged in relation to driving assessments and ceasing driving. This can cause families and patients to resist or delay assessment and diagnosis of dementia. Increased options for assessment and alternative sources of support with transport would assist patients to give up driving when it is appropriate. In this regard the current taxi schemes are biased towards physical disability. Criteria should be revised to ensure those with cognitive changes due to dementia are eligible in the earlier stages of their condition.

In addition, education to the general community that driving is a responsibility not a right, their duties of disclosure regarding medical conditions that might affect their driving and the consequences of not doing so, would also assist people to understand the issue and perhaps be better prepared for the eventuality that they may need to relinquish driving at some stage due to any number of conditions

Recommendation 13:

Increase HACC services so that more intense support at home is available to dementia patients.

HACC services are an essential first line of support for carers and patients in the early stages of dementia. With the ageing population and increased demand these services are stretched and only minimal coverage is available in many areas. Patients can receive less than optimal support due to funding constraints and a higher emphasis on assistance for physical disability.

Front line workers often have limited knowledge or understanding of dementia, including the early symptoms, how to adjust their approach to these and the extra time that this might require. In the early stages of dementia people could benefit from the active service model that HACC services now provide but only if the workers have a good understanding of the early symptoms of dementia and possible approaches to assisting people to adjust to these. Further education, and mentoring is needed to assist these workers to provide an active model of support focused on helping people to learn to adapt and adjust to their changing cognition. Links to mentoring and advice from trained dementia support workers may also be of assistance and benefit in planning appropriate approaches for individuals with dementia.

HACC service workers also have an important role in recognising early dementia symptoms or the changing needs of those diagnosed with dementia and therefore require a good understanding of dementia, its progression and the service system to enable timely advice and referral as the needs of the person increase. As already mentioned education and guidelines regarding the potential needs of people with dementia and appropriate referral pathways for support and advice would be beneficial. (Note: The Victorian Department of Health is currently developing such guidelines with broad consultation across the sector).

Recommendation 14:

Increase in-home respite to support carers to get a break and therefore provide quality care for longer periods.

Carers of people with dementia face many obstacles to their own self care. One of the main obstacles is getting the person with dementia to agree to care from service providers, freeing up time for carers to attend to their own needs. In-home respite is beneficial to both carer and care recipient as it causes minimum disruption to daily life. People with dementia have the opportunity to develop a connection to a professional carer in their own familiar environment. This increases their circle of support and shares the burden of care more healthily with the community. In-home respite funding through HACC is limited. Families would benefit from greater access to this service through increased government funding.

Recommendation 15:

Increased funding and flexibility for Community Aged Care Packages, that takes into account the additional challenges of declining cognition in dementia.

Community Aged Care Packages (CACP's) allow people with dementia and other aged related problems to maintain a good quality of life in their community. CDAMS clinics see patients on a daily basis who would benefit from these packages. However lack of funding causes waitlists, leading to a delay in access to the vital support that these packages can provide. With the growing number of people being diagnosed with dementia this problem will increase further. In addition the nature of dementia and the challenges that declining cognition imposes on a broad range of daily functions, often results in more complex needs that are not adequately managed within the usual funding formula of a CACP's. We support the National Dementia initiative[15] recommendation of a separate funding formula for those with cognitive impairment, even in the early stages of dementia, particularly if the person is isolated or has limited other supports from family or community. Similar to EACH packages, consideration should be given to Dementia CACP's as well.

CONCLUSIONS

As the population ages, an increasing number of individuals will experience age-related dementias and with it there will be a growing demand for expert diagnosis, advice and support from individuals, families, and health providers. Whilst the benefits of early diagnosis, including issues that are the focus of this inquiry, such as quality of life, prolonged independence, social engagement and future planning are well recognised they are reliant on first recognising, identifying and diagnosing dementia in a timely manner. As a service that focuses on assessment and timely diagnosis the CDAMS has made a number of recommendations that address the gaps in this area, in particular that a CDAMS style program should be funded and available nationally together with more support and education to GP's and to other service providers to facilitate the early recognition and management of the condition. With accurate timely diagnosis the door is open for more effective early intervention and management and we have included a number of recommendations in relation to this. Of particular interest to our service is simplification of the PBS requirements for the prescription of dementia medication, national consistency and improved processes for future planning such as enduring powers of attorney and advanced health directives, assistance for people with dementia to retire from driving at the appropriate time and more options for appropriate support at an earlier stage in the disease continuum including rehabilitation and flexible services in the home and community.

We thank you for the opportunity to provide a submission to this inquiry and would be happy to provide further clarification on any points.

Elizabeth Rand
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REFERENCES

1. World Alzheimer's Report. The Benefits of Early Diagnosis and Intervention. Alzheimer's Disease International, September 2011.

2. Speechly. C (2008). *The pathway to dementia diagnosis*. Medical Journal of Australia, 189, 487-9

3. Phillips, J., Pond, D., & Goode, S., (2011) *Timely diagnosis of Dementia: Can we do Better?* Alzheimer's Australia Paper No 24. Available: www.fightdementia.org.au/research-publications/alzheimers-australia-numbered-publications.aspx.

4. Dept of Human Services Victoria - Dementia Care in Victoria, Building a Pathway to Excellence. Final Report Ministerial Task Force on Dementia Services in Victoria. 1997

5. Dept of Health, Victoria - *Review of the Cognitive Dementia and Memory Service (CDAMS) clinics – final Report* January 2003 http://www.health.vic.gov.au/agedcare/publications/cdams.htm

6. LoGiudice D, Smith K, Thomas J, Lautenschlager NT, Almeida OP, Atkinson D, & Flicker L. *Kimberley Indigenous Cognitive Assessment tool (KICA): Development of a Cognitive Assessment Tool for Older Indigenous Australians*. International Psychogeriatrics 18:2, 269-280, 2006.

7. Storey, J., Rowland, J., Conforti, D., & Dickson, H., *The Rowland Universal Dementia Assessment Scale (RUDAS): a multicultural cognitive assessment scale.* International Psychogeriatrics (2004), 16:1, 13-31

8. New South Wales Government, Attorney General's Department, *Capacity Toolkit* (2008), 18 <http://www.lawlink.nsw.gov.au/lawlink/

9. diversityservices/LL_DiversitySrvces.nsf/vwFiles/CAPACITY_TOOLKIT0609.pdf/$file/CAPACITY_TOOLKIT0609.pdf>.

10. Law Reform Committee, Parliament of Victoria, *Inquiry into Powers of Attorney* (2010)

11. Kinsella, G et al; *Early Intervention for Mild Cognitive Impairment: A Randomised Controlled Trial*. Journal of Neurology, Neurosurgery & Psychiatry 2009; 80:7 730-736

12. Maximising thinking and Memory Abilities – An individualised information resource for people with mild cognitive impairment and early dementia. Wicking Trust in collaboration with Australian Institute for Primary Care and Ageing, Southern Health Vic and Latrobe University. http://www.latrobe.edu.au/aipca/projects/mci/index.htm

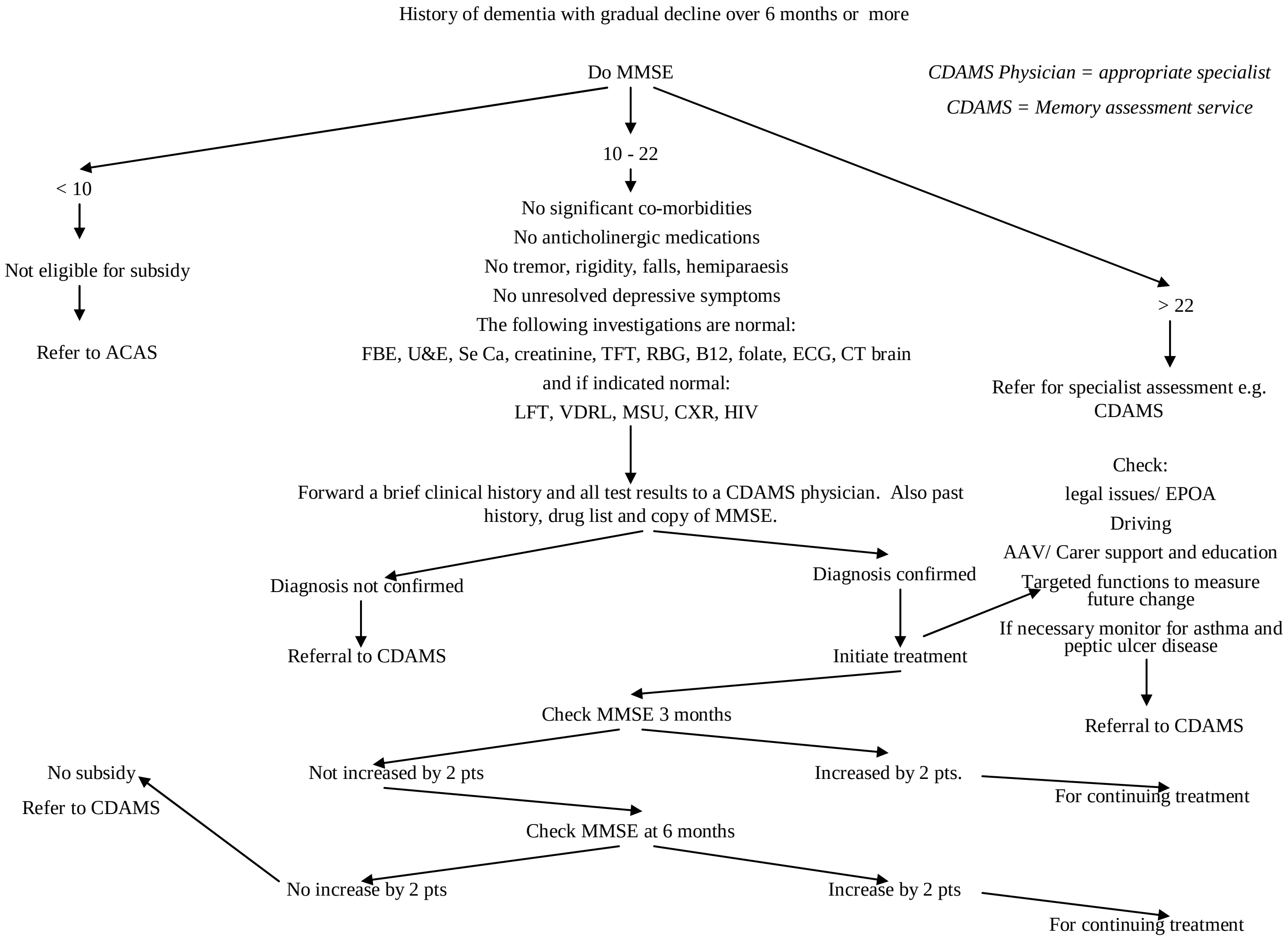
13. *Creative Ways to Care program* – Commonwealth Carelink & Respite Service Southern Region Victoria http://www.carersouth.org.au/creative-ways-care-0

14. Aust Roads National Transport Commission (2012) - *Assessing Fitness to Drive*

15. Dept of Health & Ageing – *Dementia Initiative National Evaluation – Overview and Summary of Main findings. Final Report.* LAMA consortium. 2009

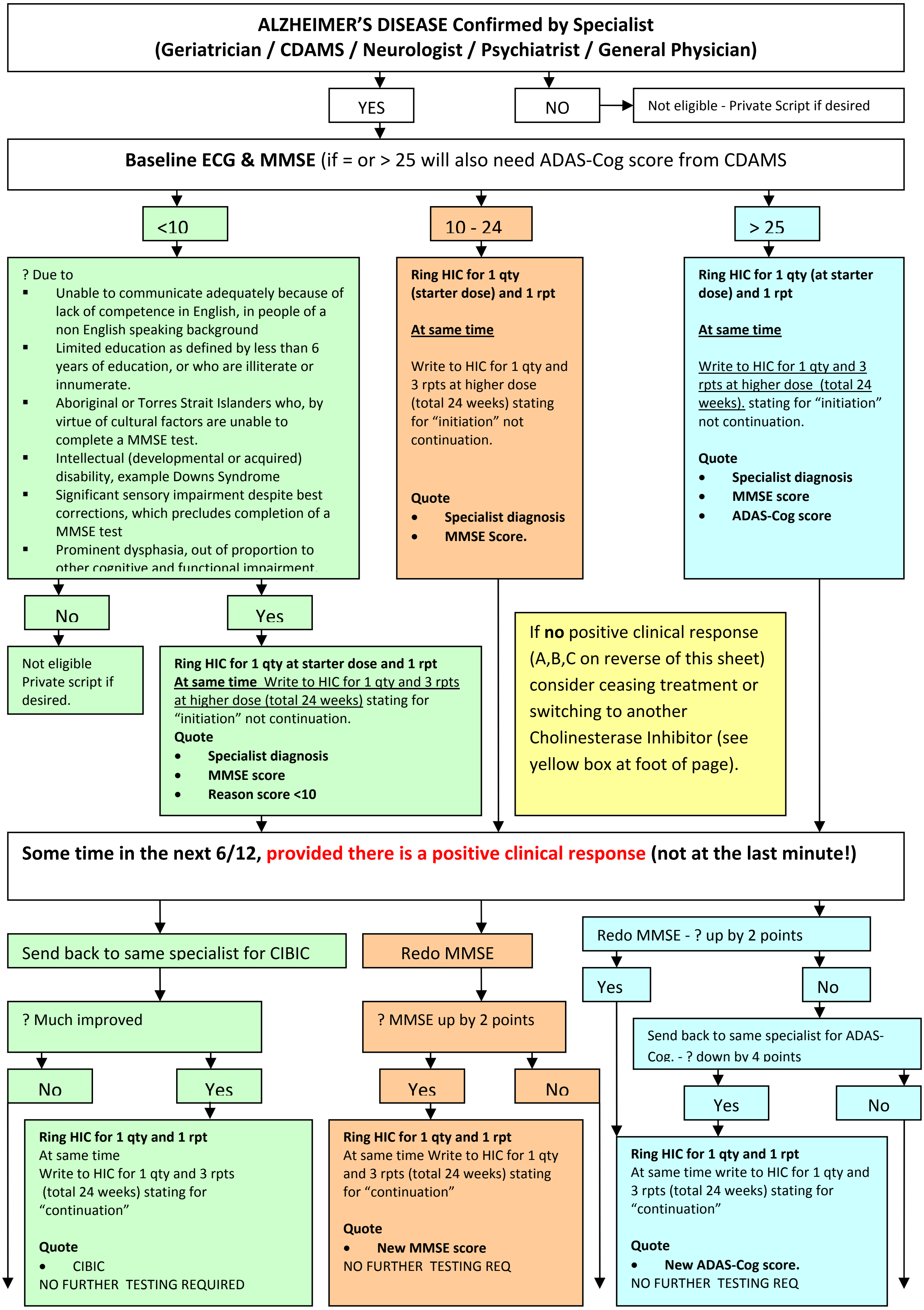
APPENDIX 1

MEDICATION ALGORITHM FOR THE PRESCRIPTION OF A CHOLINESTERASE INHIBITOR FOR DEMENTIA.



CDAMS Physician = appropriate specialist

CDAMS = Memory assessment service



ALZHEIMER'S DISEASE Confirmed by Specialist
(Geriatrician / CDAMS / Neurologist / Psychiatrist / General Physician)

YES

NO → Not eligible - Private Script if desired

Baseline ECG & MMSE (if = or > 25 will also need ADAS-Cog score from CDAMS

<10

? Due to
- Unable to communicate adequately because of lack of competence in English, in people of a non English speaking background
- Limited education as defined by less than 6 years of education, or who are illiterate or innumerate.
- Aboriginal or Torres Strait Islanders who, by virtue of cultural factors are unable to complete a MMSE test.
- Intellectual (developmental or acquired) disability, example Downs Syndrome
- Significant sensory impairment despite best corrections, which precludes completion of a MMSE test
- Prominent dysphasia, out of proportion to other cognitive and functional impairment.

No

Not eligible
Private script if desired.

Yes

Ring HIC for 1 qty at starter dose and 1 rpt
At same time Write to HIC for 1 qty and 3 rpts at higher dose (total 24 weeks) stating for "initiation" not continuation.
Quote
- **Specialist diagnosis**
- **MMSE score**
- **Reason score <10**

10 - 24

Ring HIC for 1 qty (starter dose) and 1 rpt

At same time

Write to HIC for 1 qty and 3 rpts at higher dose (total 24 weeks) stating for "initiation" not continuation.

Quote
- **Specialist diagnosis**
- **MMSE Score.**

> 25

Ring HIC for 1 qty (at starter dose) and 1 rpt

At same time

Write to HIC for 1 qty and 3 rpts at higher dose (total 24 weeks). stating for "initiation" not continuation.

Quote
- **Specialist diagnosis**
- **MMSE score**
- **ADAS-Cog score**

If **no** positive clinical response (A,B,C on reverse of this sheet) consider ceasing treatment or switching to another Cholinesterase Inhibitor (see yellow box at foot of page).

Some time in the next 6/12, provided there is a positive clinical response (not at the last minute!)

Send back to same specialist for CIBIC

? Much improved

No

Yes

Ring HIC for 1 qty and 1 rpt
At same time
Write to HIC for 1 qty and 3 rpts (total 24 weeks) stating for "continuation"

Quote
- CIBIC

NO FURTHER TESTING REQUIRED

Redo MMSE

? MMSE up by 2 points

Yes

No

Ring HIC for 1 qty and 1 rpt
At same time Write to HIC for 1 qty and 3 rpts (total 24 weeks) stating for "continuation"

Quote
- **New MMSE score**

NO FURTHER TESTING REQ

Redo MMSE - ? up by 2 points

Yes

No

Send back to same specialist for ADAS-Cog. - ? down by 4 points

Yes

No

Ring HIC for 1 qty and 1 rpt
At same time write to HIC for 1 qty and 3 rpts (total 24 weeks) stating for "continuation"

Quote
- **New ADAS-Cog score.**

NO FURTHER TESTING REQ

Cognitive Dementia &
Memory Service (CDAMS)

TREATMENT WITH ACETYLCHOLINESTERASE INHIBTORS.

"CDAMS IS A DIAGNOSTIC SERVICE – WE HAND BACK TO THE GP FOR PRESCRIBING"

CDAMS is qualified to recommend authority approval to GP's for PBS CI scripts.

How to obtain a script See flow chart on reverse side

Determination of efficacy

We recommend that principal determination of efficacy should be in the hands of the patient's carer if they are a reasonable informant. However on occasions carers are suffering from significant stress and/or depression and may not be able to objectively judge treatment response. When carers are unsure of the treatment response asking questions in the following domains is useful:

- **A**ctivities of daily living
- **B**ehaviour
- **C**ognitive function

If medication is believed to be of overall benefit to the patient and carer then the Government requires the patients to undergo testing in order to qualify for ongoing therapy (See also on reverse side).

- If *MMSE* was used as the base (original score 10 – 24) then an *increase in 2 or more points* is required.
- If the *ADAS-Cog* was used as a baseline (original MMSE score > or = 25) then a *decrease of 4 points or more is required* (repeat done by CDAMS)
- Should the original MMSE be <10 then the CIBIC (Clinicians Interview Based Impression of Change) should be performed (CDAMS can provide this service) and patients must be classified as "very much improved" or much improved" in order to qualify for ongoing therapy.

❖ *Only patients who require either ADAS-Cog or CIBIC will be reviewed by our clinic.* If patients have had a good response clinically to a given medication but do not meet the Government's criteria for ongoing therapy then a new application for *initial* supply of an alternative cholinesterase inhibitor can be applied for. If after trialing all available acetylcholinesterase inhibitors the criteria for ongoing supply under the PBS are not fulfilled, then a private script could be issued although this does pose a significant financial burden on the patients and their families.

❖ The **expected response rate is about 50% at best.** No definitive comparative trials between the available agents have been published and there is no preferred drug. They all appear to have equivalent efficacy. *Interestingly patients who did not tolerate one acetylcholinesterase inhibitor often tolerate a second or a third.*

Our suggested protocol (not in order of preference).

- **Donepezil** (*Aricept*) **(once daily)**
  Commence 5 mg (one 5mg tablet or 1/2 a 10mg tablet) nocte. Increase to 10mg nocte after a month if well tolerated. Minimum efficacious dose = 5mg.
- **Galantamine CR** (*Reminyl prolonged release capsulesl*) **(once daily dose)**
  Commence 8mg daily with food. Increase to 16mg after at least four weeks. Can be increased to 24mg mane if desired.
- **Rivastigmine** (*Exelon*) **(twice daily dose)**
  Commence 1.5 mg twice daily with food. Increase at four weekly intervals to 3 then 4.5 and finally 6 mg BD cc if possible. Minimum efficacious dose = 3 mg BD
  Please note Rivastigmine is now also available as a transdermal patch which is said to produce less nausea and vomiting than the oral form, hence it is usually used in preference to oral rivastigmine, but these adverse reactions may still occur. The commencement dose of the rivastigmine transdermal patch is one 4.6mg/24 hour patch applied once daily, increasing to one 9.5mg/24hours patch daily, if well tolerated after 4 weeks. The patch should be removed daily and new patch applied. The skin sites for application should be rotated. Local skin reactions may occur.

DISCLAIMER

It is imperative to make oneself familiar with potential adverse effects of these medications (especially bradyarrhythmias) and to monitor carefully for them, especially in patients with cardiac and respiratory co-morbidities or who are taking the relevant medications. **WE RECOMMEND YOU COMPLETE A BASELINE ECG.**