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(Dementia)
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Attachment 1

SUBMISSION

by the

DEPARTMENT OF HEALTH AND HUMAN SERVICES

to the

INQUIRY INTO DEMENTIA: EARLY DIAGNOSIS AND INTERVENTION

by the

HOUSE OF REPRESENTATIVES STANDING COMMITTEE ON HEALTH AND AGEING

Tasmanian
Government

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INTRODUCTION

TASMANIA'S AGEING POPULATION

Demographic change is a major issue for Tasmania. Tasmania's population is ageing more rapidly than any other Australian jurisdiction and the median age in Tasmania is the highest in the nation. Over the next 20 years, the proportion of Tasmanians aged 65 years and over is projected to grow by 80 per cent. The number of Tasmanians aged 85 years and over has been projected to increase from around 9 700 persons in 2008–2009 to 19 300 persons over the next 20 years, and to 41 200 persons by 2050.[1]

Dementia is closely linked with age. The recent Monzino 80-Plus Study[2] found that the prevalence of dementia increased in a linear fashion with increasing age, with 24 per cent of over 80s and 55 per cent of over 90s affected.

This is of particular concern for Tasmania, which already has the oldest population in Australia. Significantly, the proportion of both the 65+ age group and the very old (85+ age group) is rising, with a likely increase in the 85+ age group of 7 231 people between 2008 and 2028.

In line with these projections, it is anticipated that future demand for aged care services will increase at a significantly faster rate than planned increases in their supply. A shortfall is likely to arise as Australian Government aged care funding is currently allocated on the basis of the number of people aged 70 years and over in a population. People aged 80 years and over comprise the most rapidly increasing service group in Tasmania.[3]

The proportion of the population aged 65+ is expected to rise from 15 per cent currently, to around 27 per cent by 2056. As a result, Tasmania is likely to have more people with dementia, per head of population, than any other state. In 2010, about 6 000 Tasmanians had dementia. By 2050, it is anticipated that this will increase out to over 27 000.

Dementia prevalence projections

	2010	*2015*	*2020*	*2030*	*2040*	*2050*
Aust (no)	*245 414*	*326 531*	*405 897*	*627 534*	*920 921*	*1 194 128*
Tas (no)	*6 321*	*8 100*	*9 996*	*15 526*	*22 357*	*27 630*

Source: Access Economics - Keeping dementia front of mind: incidence and prevalence 2009-2050 (Final Report for Alzheimer's Australia, 2009)

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[1] Tasmania's population projections are available on the Tasmanian Demographic Advisory Council's website: http://www.dcac.tas.gov.au/

[2] A Population-based study of dementia in the oldest old: the Monzino 80-plus Study (Published by BMC online May 2011)

[3] Department of Premier and Cabinet (DPAC), *Tasmanian Government Submission to the Productivity Commission Health Workforce Study for the Council of Australian Governments,* DPAC, Hobart, 2005.

In 2009, there were approximately 1 750 new cases of dementia in Tasmania. By 2050, this is projected to increase five-fold to approximately 8 870 new cases in that year alone.

Tasmania has the most dispersed population of any state or territory, with approximately half of its 507 000 people living in Southern Tasmania, in and around Hobart, and half scattered over the North, North West and West Coast of the island. This impacts on the State's capacity to provide safe and cost-effective health care services to a significantly larger proportion of its population than in the larger states.

Of the new cases of dementia in Tasmania in 2009, approximately 43 per cent lived in Hobart while 57 per lived outside the capital. Those relativities contrast, for example, with Victoria where just under 70 per cent of new cases live in Melbourne while 30 per cent live outside the capital.

Projections suggest that, by 2050, the number of people with dementia living in Hobart will increase to approximately 11 400 while the number living in the rest of Tasmania will increase to about 14 900.

THE BURDEN OF CARE AND IMPACT ON OTHER SERVICES

Accompanying the growth of dementia prevalence and its associated disease burden will be an increase in health and aged care costs. Expenditure on dementia in Australia has been projected to increase from $3.85 billion in 2002-2003 (4.5 per cent of total health and aged care spending) to $17.84 billion in 2032-2033 (7.2 per cent of the total).

On a population share basis, that translates to approximately $450 million in Tasmania, equivalent to more than half of the total State Government expenditure on all acute health and hospital services in 2010-2011.

Spending on dementia will become the third greatest source of health and aged care spending within about two decades – about 1 per cent of all Australian GDP.

About half of those with moderate to severe dementia live in the community-either alone in the early stages, or with family or carers in the later stages. As the condition progresses, it is very likely (about 90 per cent) that the person with dementia will exhibit the Behavioural and Psychiatric Symptoms of Dementia (BPSD). These constitute a major source of carer burden and become a principal reason for placement into residential aged care.

The burden of care is enormous for families, service providers, and the health system. Nursing home residents with dementia and BPSD will sometimes prove difficult for the facilities to manage. Sometimes, the only option evident to facilities is to call an ambulance and arrange transfer to a public hospital. Unfortunately, the acute sector is also often an inappropriate and unsafe place to manage these symptoms.

People with dementia require special care to minimise the impact of behavioural and psychiatric symptoms of dementia. Ideally, this care would take place in their home or other familiar environment, and around half of those diagnosed with dementia do continue to live in the community. However, carer burden is high, and residential care placements become common, particularly in the later stages.

The pressure on public hospitals to accommodate people waiting for residential placement is anticipated to increase under current aged care planning and funding arrangements, at least until the necessary and broadly agreed aged care reforms can be implemented and effort resumed in building the capacity of aged care services to meet the demand pressures growing daily.

Many long stay older patients in hospitals have dementia. It is generally agreed that any stay in hospital, particularly a prolonged stay, poses a safety risk for older patients. Additionally, while the occupancy cost of hospital beds is certainly significant, the opportunity cost to hospitals through avoidably occupied beds also imposes pressures on other part of the system, including elective surgery waiting times.

In Australia, the mean length of stay for all hospital separations, for people who stay at least one night is 8.6 days, compared with a mean of 19.6 days for separations with any diagnosis of dementia and 30.1 days for separations with a principal diagnosis of dementia (AIHW 2007).

During 2010-2011, 535 long stay older patients, with an Aged Care Assessment Team (ACAT) approval for alternate long term care, waited a combined total of 18 893 days in Tasmania's public hospitals until they were able to gain access to appropriate aged care services outside the hospitals[4].

Using a subacute care bed-day cost for those patients of $898 per day[5], those days during 2010-2011, represent close to $17 million expenditure on patients who had completed their hospital episode, were ready for discharge but were unable to be leave due to the unavailability of either residential or community aged care services.

It is inevitable that population ageing will have a significant impact on hospitalisation rates in Tasmania. The rate of hospitalisation doubles between people aged 40 and 59 years and those aged 60-79 years, with a further rate increase (greater than 50 per cent) for persons aged 80 years and over.

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[4] Tas PATAC Data

[5] Note: Calculations are based on DoHA's National Hospital Cost Data Collection 2007-08 and the National Admitted Patient Data Collection 2007-08, and have been indexed by health costs. (Media Release - *Empty beds or an empty surplus.* Nicola Roxon and Wayne Swan *06.08.10*)

With that highly likely increase in demand it is critical that avoidable hospitalisations and long-stays by older people with dementia are able to be better managed and minimised.

THE IMPETUS FOR REFORM AND DEVELOPMENT

In preparing this submission, DHHS notes the considerable prominence given to two recently released reports in relation to the planning and performance of dementia care in Australia.

In one, a new Alzheimer's Australia report, the Minister for Mental Health and Ageing, the Hon Mark Butler noted strongly critical feedback received from over 1 000 older Australians, their families and carers through 16 'conversations' on aged care reform held recently in local communities across Australia.

It was pleasing that while Minister Butler conceded that the aged care system is not meeting the needs of dementia sufferers and their families, he announced that tackling dementia will be a key consideration in the Government's assessment of the Productivity Commission report, Caring for Older Australians released in August 2011.

In a second high profile report, *Dementia: A public health priority*, released early in April of this year, both the World Health Organisation (WHO) and Alzheimer' Disease International (ADI) called on Australia's federal government to restore dementia as a national public and social care priority.

In 2005, Australia established itself as an international leader in dementia policy when the then government funded the $320 million Dementia Initiative – making dementia a national health priority. While the international bodies pinpointed that initiative as one of the "best dementia plans in the world" they noted that the plan was terminated in the 2011 Federal Budget, and that the Australian Government has not committed to any substantial new funding for dementia beyond 2013.

While reassurance by the Australian Government that aged care is a high priority is welcomed, DHHS agrees with the experts and families who stress that aged care reforms must address the specific problem of dementia, as dementia is driving the aged care crisis in Australia.

DHHS appreciates the enormous challenges faced by all governments in their development of aged care public policy during this time of demographic change and growing demand.

While in tackling this challenge now, the Inquiry must acknowledge that many of the well-evidenced and widely-supported recommendations made in previous aged care inquiries, including those addressing dementia, have not been implemented, the imperatives for change now are massively stronger than ever before.

CURRENT DEMENTIA CARE PLANNING AND ACTIVITY IN TASMANIA

The Tasmanian Department of Health and Human Services (DHHS) strongly supports a national and strategic approach to the promotion and advancement of dementia care development across all states and territories.

DHHS notes that the Commonwealth, through the Department of Health and Ageing (DoHA), is leading the development of a new *National Framework for Action on Dementia* (NFAD) following the expiry of the previous national framework in 2010 It is hoped that that this initiative will provide a basis for immediate and longer-term planned action and investment in dementia care. DHHS continues to work with the Commonwealth and other states and territories towards the development of this important national strategy.

As with the previous NFAD, a major issue will present in securing a workable commitment across all jurisdictions to develop and implement a truly national strategic framework. While some larger jurisdictions are relatively well resourced to support the national initiative, smaller states and territories, including Tasmania, may struggle to meet any proposed cost-shared service system reforms or major development initiatives.

The recent and ongoing national health reforms have assigned responsibility to the Australian Government for aged care services delivered to people aged 65 and over (50 years for Indigenous Australians), with State and Territory Governments (apart from Victoria and Western Australia) now being solely responsible for disability services to those under 65 years.

The impact of dementia, however, extends beyond aged care policy and program boundaries. State operated and funded health and hospital services will need to continue planning and adapting to meet the accelerating demand and the special needs of older people with dementia, and their families and carers. The Tasmanian Government will also continue to have primary responsibility for the planning and provision of services to younger people with dementia who need care and support services.

DHHS is pleased that the Inquiry's Terms of Reference acknowledge the importance of early diagnosis and intervention in improving the quality of life people with dementia, as well as for family members and carers.

Evidence from extensive consultations with families, service providers and clinicians across Tasmania supports that view and indicates that developments in dementia care should focus on in six priority key priority areas, including:

1. improving the diagnosis of dementia
2. offering practical information and education on dementia for families and carers
3. better coordinating and case managing services for people with dementia where needed
4. clinically supporting aged care services and GPs in the community

5. broadening the knowledge and understanding of dementia within hospitals and health services and
6. acknowledging dementia as a terminal illness and supporting appropriate end of life care.

Accordingly, DHHS is currently developing a program across its three area health services, aimed at achievement of the six objectives through a statewide peer support program of practical consultancy and education for aged care providers and clinicians.

Over the past year or so, a visiting program out of the Southern Tasmania Area Health Service with GPs, aged care providers and primary health services in the North and North West has been very successful.

The program aims to strengthen the understanding and skills of residential and community aged care providers, acute hospital staff, general practitioners and other services providing services and support to people with dementia, together with their carers and families.

The program also aims to examine case management capacity across the state and to trial a single point of response and referral for residential aged care facilities and GPs for specialist advice and consultancy about residents/patients, particularly in relation to issues associated with dementia.

Clinicians advise that there are two main inhibitors of early diagnosis of dementia, the limited capability and confidence of many GPs in making a diagnosis and a reluctance by many other GPs to make a diagnosis in the absence of an appropriate range and level of necessary services (including post-diagnosis advice and counselling to support the person with dementia and their family from the point of diagnosis.

The first issue must be addressed through clinical education and the second by expanding, improving and better integrating dementia services.

It is very important to note that, in using the term 'early diagnosis', dementia experts and services agree that this should occur at a point at which a diagnosis can be reliably made and where a need for that diagnosis is evident for both the individual and/or their family and/or their carer, to enable them to plan for managing the progression and the end result of the disease.

It is a reality that dementia is incurable and that its course is inevitably terminal unless overtaken by some other cause of death. The disease involves functional decline, including a loss of cognition, that can be best coped with and managed by the person with dementia and their family through advanced planning. The best time to do that planning is as early into the disease as possible, while the person can be involved in the decision making about their own care and their affairs.

In supporting the potential value of early diagnosis, experts warn that it must be accompanied by the availability of properly case managed care services and support. Early diagnosis of dementia in the absence such services, supports or a cure, can have limited benefit and potentially adverse outcomes, including a premature weakening of independence.

COMMENTS AGAINST THE SPECIFIC TERMS OF REFERENCE

1. IMPROVE QUALITY OF LIFE AND ASSIST PEOPLE WITH DEMENTIA TO REMAIN INDEPENDENT FOR AS LONG AS POSSIBLE.

Without substantial reform, DHHS considers that the current national funding, regulatory and program arrangements underpinning aged care across all settings will fail to meet the needs of our older population into the future, particularly those with dementia.

In the absence of sufficient and accessible aged care services, older people are being prematurely admitted to, or spending extended periods in, hospitals when residential or community aged care would be safer, cheaper and less stressful.

The residential aged care service sector has become financially unattractive to new or even existing providers due to the lack of economies of scale.[6] Reviews of residential aged care funding arrangements by the Productivity Commission in 1999 and Professor Hogan in 2004, both commissioned by the Australian Government, found that significant structural reform is necessary.

The Aged Care Alliance, which is made up of 28 aged care organisations in Tasmania, has recently projected that the number of aged care support packages needed to meet growing demand in Tasmania will have to more than double over the next 15 years. [7]

Aged and Community Services Tasmania (ACST) has found that, if aged-care providers are to even maintain current inadequate levels of care, total beds and support packages will need to increase from approximately 6 000 to 12 000 by 2027,

Although residential aged care will continue to play a vital role in meeting the needs of ageing Australians, it is expected that community aged care services will have an increasingly central part to play in aged care. The increasing need for more community aged care services is highlighted by the cost benefits of community based health services and the associated prevention of early admission to acute and residential care. This need is reinforced by the preference of most people who require support to live at home in the community for as long as possible.

ACST has warned that the hundreds of elderly Tasmanians at home who are unable to access a community-care package are more likely to get sick or have a fall and end up in hospital. In last year's national allocation round for aged-care packages Tasmania received no additional funding for at-home care. While the state did receive funding for up to 646 extra aged-care beds, ACST noted that only 92 of those were taken up by nursing homes because the funding did not cover the actual cost of establishing the beds.

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[6] Browne, D "Alarm on Aged Care Services" *The Mercury*, 6 August 2010.

[7] The Mercury Newspaper, 03.04.12

It is anticipated that in the future there will need to be an overall increase in all community aged care services, with a particular focus towards meeting the needs of people with dementia and other neurodegenerative diseases associated with ageing. Feedback from aged care assessment teams suggests that service expansion in programs that provide assistance with personal and instrumental activities of daily living will be the most effective response. Key functional areas that impact on admission to residential care, such as continence, mobility and cognition, will need to be given the greatest priority.[8]

Carers will need to be provided with greater support in their role, with their needs recognised and met through the provision of counselling, respite (in home and day centre attendance) and education in how to care for the person they are caring for, as well as self-care.

The introduction of EACH Dementia packages has been welcomed by Tasmanian service providers but many remark that the small number currently available goes nowhere near meeting demand.

Industry experts and consumer advocacy bodies claim that aged care choice for consumers is limited by under-funding and unnecessary program boundaries. In the 2009 round of applications for aged care places in Tasmania there was significant under-subscription for residential places and significant over-subscription for community places. There are long waiting times for residential care in some geographic areas and empty beds in others.

A significant disparity exists in the viability and availability of aged care services between population centres and country areas, with the Tasmanian Government topping funding for aged care services in rural and remote areas.

The comparatively high cost of rural aged and dementia care services is of particular concern in Tasmania. With 58 per cent of the population living outside Hobart the limited availability and choice of support services means that older people in some communities are often not able to remain at home as long as they might if they lived in a larger population centre.

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[8] Patterson, C *Independence: Support for the elderly in their communities: HACC Consumer Consultation Report 2009* Tasmanian Council of Social Services, 2010.

2. INCREASE OPPORTUNITIES FOR CONTINUED SOCIAL ENGAGEMENT AND COMMUNITY PARTICIPATION FOR PEOPLE WITH DEMENTIA.

DHHS recognises that strategies that support positive ageing and social inclusion may mitigate the impact of an ageing population. The Tasmanian Government has a strong approach to positive ageing, with the aim of enabling older Tasmanians to remain independent, healthy and socially connected. This approach is outlined in the Tasmanian Government's *Second Five Year Plan for Positive Ageing*, which is available on-line.[9]

Clinicians, service providers and consumers agree that an appropriate level of case management to coordinate access to specialist care is essential in securing the best care and social outcomes for people with dementia, their carers and family.

Continuing healthy levels and patterns of social engagement and community participation can be very important activities for people with dementia and their families.

In any area of care, supporting the carers to cope with and meet their own care and social needs arising out of their role is critical in securing and enabling their support in meeting the needs of those in their care.

Without help, many carers lack the capacity and the resilience to even successfully procure, and then manage, the bewildering range of basic services that may be needed by a person with dementia as the condition progresses. Fewer still are able to build social dimension into their care without assistance and support.

Extensive feedback from consumers points to an overwhelming need for a key contact point or case manager for people with dementia, their carers and families. Case management should be available from diagnosis onwards as the condition progresses and as the needs for both the individual and the carer develop and increase.

3. HELP PEOPLE WITH DEMENTIA AND THEIR CARERS TO PLAN FOR THE FUTURES, INCLUDING ORGANISING FINANCIAL AND LEGAL AFFAIRS AND PREPARING FOR LONGER-TERM OR MORE INTENSIVE CARE REQUIREMENTS.

Dementia is now the third leading cause of death in Australia, and as Palliative Care Australia (PCA) noted recently, the palliative and end of life care needs of patients with dementia, their families and carers, are very specific.[10]

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[9] See http://www.dpac.tas.gov.au/divisions/cdd/seniors/tasmanian_plan_for_positive_ageing

[10] Media Release: Palliative Care Australia Inc, 11.04.12. -Action needed to improve end of life care for Australians with Dementia.

There is a general lack of recognition in the community and in some care settings, that dementia is a terminal condition. There is however a growing recognition of the importance of planning for end of life care. Further education is required for health workers and the community in this field to ensure that people with dementia have access to palliative care and assisted to retain their dignity in the final stages of their lives.

There is also little recognition that dementia is a condition that may require palliation towards the end of life. There is some evidence that clinicians do not always recognise pain, discomfort or distress in people with dementia. It is difficult for health workers to assess if a person with end stage dementia, who is confused and unable to communicate, is suffering pain. There is evidence that pain and discomfort are under treated due to the difficulty of assessment.

DHHS supports the view expressed by PCA, that older Australians deserve a well-funded, flexible, high quality system of palliative care based on their needs and those of their loved ones. As explained by PCA, in the case of people with dementia, this means having access to palliative care from diagnosis, and including the person with dementia in decision-making about their care, while they still have the capacity to be involved.

DHHS agrees with Dr Yvonne Luxford, CEO of PCA, that people want to be able to die well and with dignity, and involving them in decisions about their care is an important way to ensure this. A strong social marketing program on Advanced Care Directives is required to educate the community on what they are and the benefits of completing one. Health professionals need the resources to implement ACD as part of the care pathway.

Accurate and timely diagnosis is crucial in underpinning advanced care planning as the symptoms, prognosis and treatment can vary with the type of dementia a person has.

The impact of the symptoms can be better managed with diagnosis early in the onset of the disease. There is evidence that medications in some instances can maintain functionality and stabilise symptoms.[11] With the presentation of dementia related symptoms, the importance of confirming dementia as the diagnosis needs to be stressed, as there are a number of treatable and reversible conditions such as depression, delirium and other neurological problems that can mimic the symptoms of dementia.

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[11] Phillips, J., Pond, D,. & Shell, A 2010, 'Quality dementia standards: no time like the present: the importance of a timely diagnosis', Alzheimer's Australia, <u>www.aag.asn.au/filelib/No_time_like_the_present.pdf</u>

General Practitioners are often the first point of contact when concerns about cognitive function or memory arise. It is, therefore, important to support GPs in making a diagnosis of dementia by providing the tools to improve assessment processes and outcomes. The creation of strong links between specialists and GPs is also important in the care of people with dementia.

Regardless of whether the formal diagnosis of dementia is made by a GP or Geriatrician, there is a need to provide appropriate information and support from the point of diagnosis onwards. The need for support will be ongoing and, for planning purposes, it is ideal that a referral to a relevant service provider is made at the time of the diagnosis.

People with dementia and their carers attest to the importance of a supportive person, with good knowledge of the condition and services available, to assist them to plan for the future. It is at the point of diagnosis where this connection is most valuable, and as far as practicable, be able to refer back to this case manager throughout the progression of the condition.

Again, the availability of good case management can greatly assist all parties in planning for and managing the functional decline and needs associated with the course of the disease.

4. HOW TO BEST DELIVER AWARENESS AND COMMUNICATION ON DEMENTIA AND DEMENTIA RELATED SERVICES INTO THE COMMUNITY.

With the anticipated growth in the number of people with dementia, and the range of providers involved in their care and support, DHHS has identified a clear need for improved information and education.

There is often little understanding in the community about the progression of dementia. Information is often not readily made available either to individuals diagnosed with dementia or to their families or carers.

Even in health care services, the domains and stages of dementia are often not well known or recognised. Better education and knowledge would assist those caring for, and people with, dementia to minimise disturbance, disruption and distressing behaviour.

Over the past year or so, a visiting dementia education program lead by a Hobart based geriatrician has achieved great success. The program has been delivered to general practitioners, aged care providers and primary health services in all regions of Tasmania. The program has also included a very popular program of public seminars in local communities.

DHHS has also identified an urgent need to disseminate information to the community as a whole regarding the nature of dementia and the importance of lifestyle modification in reducing the personal risk of developing dementia.

The risk factors for both vascular and Alzheimer type dementias are shared with those of Stroke and Ischemic Heart Disease. Education about dementia could be grafted onto existing strategies for prevention of vascular disease and diabetes. In addition, even after a diagnosis of dementia or cognitive impairment has been made, in some cases, lifestyle changes can influence progression of the disease progression and allow the person to maintain independence.

A concerted focus on dementia prevention should be an important aspect of community education and health promotion. Dementia prevention ties easily into existing health promotion activities and should be incorporated into public health campaigns by population and public health bodies.