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(Dementia)
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SUBMISSION TO HOUSE OF REPRESENTATIVES' STANDING COMMITTEE ON HEALTH AND AGEING

Inquiry into Dementia:
Early Diagnosis and Intervention

ALZHEIMER'S AUSTRALIA TAS
Launceston and Devonport offices

INTRODUCTION

Alzheimer's Australia is the leading organisation providing national policy and advocacy for the 280,000 Australians currently living with a diagnosis of dementia. Each state organisation provides a range of programs specifically designed to meet the needs of persons living with dementia, their families, and carers, as well as the education needs of professionals working in the dementia field.

Alzheimer's Australia Tasmania operates three offices in Tasmania, which are situated in Hobart, Launceston, and Devonport.

Counsellors in the north of Tasmania hold grave concerns with regard to the difficulty clients experience accessing accurate and timely diagnoses of dementia, and greatly appreciate the opportunity that this inquiry presents.

This is a combined submission from the counsellors working within the Launceston and Devonport offices of Alzheimer's Australia Tasmania, made in consultation with a small number of clients; both persons living with dementia and their primary carers.

The following pages address the individual terms of reference of this inquiry into dementia: early diagnosis and intervention.

Signed,

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Counsellor.

On behalf of Tammy Jones, Kim Curley, Alison Smith, and Angela Watkins, counsellors in the Launceston and Devonport offices of Alzheimer's Australia Tas.

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

Independence means "freedom from dependence on or control by another person, organisation or state" (Encarta Dictionary).

When a person is independent, as most of us are lucky to be for the greater part of our lives, it may be difficult to understand how confronting it is for people who are slowly but surely, bit by bit, losing their independence to dementia.

Quality of life is a subjective matter, and there can be little doubt that feelings of independence can greatly add to a person's well-being. The degenerative nature of dementia means that a person's abilities to undertake practical, creative, and productive activities, and make both daily and future-oriented decisions, change over time. Independence and self-esteem are closely related in this context.

For many people, remaining "independent" may involve receiving some level of support from carers, family, friends, and support services. Over time, the amount of support provided needs to increase in order to provide adequate assistance for a person living with dementia to remain in their own home for as long as they desire, and/or are capable of doing so.

Daily, in our counselling roles, we meet inspirational carers; those people caring for a spouse, parent, relative, or friend living with dementia. It is these carers who are largely responsible for helping people with dementia maintain their independence. Caring for a person with dementia 24 hours a day, 7 days a week is an exhausting, and often unacknowledged, role. As counsellors, we provide education, and give support and encouragement to carers, but there is so much more that they need.

Many carers get little time to themselves, and operate largely on nervous energy, as they take on the daunting responsibility of caring for a person living with dementia. Many carers sacrifice relationships, financial stability, quality personal time, personal pastimes and interests to undertake their caring role. Most carers resist respite and residential care for as long as they are both physically and mentally able, so that their loved ones can remain in their care and experience relative independence for as long as possible.

Support which is person-centred, or person-directed, meets the needs of the person with dementia, assisting him or her to remain independent to the extent that this is possible. The aim is for the person to maintain as happy and fulfilling a life as is possible, given the diagnosis of dementia.

There are no cures for dementia; however there are some medications that can provide relief from symptoms. Access to these medications, if only on a trial basis, is essential, as some medications have been shown to slow the progress of symptoms, and improve quality of life for those living with the disease. Mark, a 60-year-old client living with fronto-temporal lobar dementia, after initially being improperly diagnosed with depression, said that, "proper diagnosis [at age 51 years] has led to the right treatment and support." He believes that he now has "a new life" and "the knowledge to manage [his] condition with dignity and respect." This has led to his "quiet hope for the future."

Day care centres are an excellent example of supports which assist people with dementia and their carers with respite. Often, carers are reluctant to give up care to another person or organisation, but accessing appropriate respite is essential to ensuring the continuing capacity to care.

Ultimately, should the person with dementia live long enough, there will be a need for the provision of some level of support in order that the maximum independence can be maintained. With the right social, structural, and organisational support provided to a person who is living with dementia, and their carer, independence can be maintained for a greater length of time than would be possible without this support.

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

There is stigma attached to the use of the word “dementia,” and the community’s lack of understanding about dementia leads to loss of opportunities for social engagement for people living with dementia and their carers, as most find that friendships fall away.

People living with a diagnosis of dementia, and particularly their carers, find that the community’s lack understanding of dementia leads to a drop-off in opportunities for social engagement. Dementia is a socially-isolating disease, and those people living with dementia who retain insight into their condition, experience embarrassment and lowered self-esteem.

When we hold educational courses for persons living with dementia and their carers, we find that one of the most positive things to occur is the bonding between people participating in the courses. Often, people have not met another person experiencing dementia, or had the opportunity to speak with another carer of a person with dementia. Although the learning from the courses is greatly appreciated and beneficial, this opportunity to meet with others experiencing dementia is life-changing in terms of the recognition for people that they are not alone in their suffering. We find that people bond very quickly with others in our groups, and that they find support in hearing each other’s stories.

We also run a Day Club, seven days a week. This provides social engagement for persons living with dementia, and respite for their carers. Such opportunities help carers to cope, and allow the caring role to continue for longer.

One support opportunity provided by our service, which has become extremely popular, is our Sunday Roast. Each Sunday we provide a two-course, home-cooked roast meal and dessert for people living with dementia and a carer or family member. At a cost of $10 per head, this is exceptional value, but more valuable still is the sharing of stories that occurs while people share a meal together. So often, carers feel that they cannot eat out, socially, in the company of the person living with dementia, particularly if they exhibit difficult behaviours. In a setting like ours, where support workers are educated in dementia care, and other people at the table also experience dementia, these behaviours are not an issue. People are free to enjoy their meal, safe in the knowledge that no judgement about them or their loved one is being made.

Additionally, we provide a social club for carers (in cooperation with the Commonwealth Respite and Carelink Centre), and many carers attend each month to share the highs and lows of their caring role, participate in meditation, listen to guest speakers, and share a lunch meal together. Many have said that this group is “life-saving.”

Another support group meets once a month for those carers contemplating the need to arrange respite or full-time residential care for their loved one. This can be an extraordinarily difficult transition period for carers, many of whom experience feelings of failure and guilt at having to give up their caring role. There are issues of identity, too, that emerge for these carers, who no longer have a full-time caring role after long periods of care. Many are lost as to what to do with themselves.

Consequently, our counsellors believe that opportunities for people with dementia and their carers to engage in social activities are invaluable. We are continuing to investigate ways in which opportunities for social engagement of our clients can be increased.

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

When persons living with dementia are denied accurate and timely diagnoses they are denied adequate time to organise their financial and legal affairs, and opportunities for self-determination in relation to their future care needs.

We held a “Living with Memory Loss” course in Launceston, last month. One of our clients phoned last week to say that since our session on legal matters, she and her husband had completed wills, powers of attorney, powers of enduring guardianship, and advance care planning documents. She expressed her gratitude and relief that, through access to our course, she was made aware of the importance of her husband completing legal documentation while he was still competent to do this. The couple discussed the dementia diagnosis with their lawyer, and gave the lawyer a copy of the “Capacity Toolkit: Information for government and community workers, professionals, families and carers in Tasmania.”[1] The lawyer was able to assess the client's capacity at the time, fully aware of the diagnosis of dementia and the implications for the couple.

Another client said that she “pretty much started on wills and powers of attorney after speaking with” one of our counsellors, a few years ago, and that she “probably wouldn't have thought about it without prompting” (Gill, carer for her husband).

So many times, we have discussions with clients living with dementia who are unaware of the importance of putting their legal affairs in order before dementia progresses to the extent that they lack legal capacity. They do not know, for example, that it is illegal to access another person's bank account without proper legal authority. Occasionally, clients' bank account access cards have (legally and appropriately) been repossessed by bank tellers because of this lack of knowledge. Carers have not understood that the bank requires them to have powers of attorney in order to legally access another person's bank account; it is not enough that the account holder has given verbal permission, has given details of a PIN, or can no longer understand financial matters sufficiently to access accounts.

Occasionally, too, clients have been told by lawyers that they do not need both a power of attorney and powers of enduring guardianship. This advice from lawyers is astonishing, as these two documents deal with discrete legal issues and are not in any sense interchangeable. Better understanding is needed by lawyers in relation to dementia, determining legal capacity, and the imperative for legal affairs to be organised whilst legal capacity remains.

It has been heartening to see that, in more recent times, it has become fairly common practice (in our area, at least) for residential aged care facilities to suggest that incoming residents, or their families, complete an advance care plan for new residents. These documents help to initiate a conversation

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[1] Developed by the NSW Department of Justice and Attorney General, and modified for Tasmania by the Department of Health and Human Services, Tasmania.

about future health care decisions, and prepare the resident and the family for dealing with issues relating to health care which may arise in the future. This written record of the person's preferences in relation to future care help inform the staff in the residential aged care facility, and treating medical professionals, of the person's wishes.

Accurate and timely diagnosis, and appropriate discussions regarding the progressive and (ultimately) terminal nature of dementia by medical practitioners, is essential. It allows the person receiving the diagnosis, (and, ideally) their carer, and family, access to information needed to plan for the future, whatever this may hold. To delay or withhold a diagnosis and probable prognosis is to deny people their dignity and their basic human rights.

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

Education is needed in order to break down stigma and misconceptions in relation to dementia, to help people to recognise the signs and symptoms of the disease, and to seek diagnosis and support in the early stages of the disease. Medical professionals also need dementia education and awareness in relation to dementia and support services.

One difficulty that counsellors in the north of Tasmania experience is the lack of knowledge and understanding that medical professionals exhibit in relation to dementia, and the range of support services which are available to persons living with dementia and their carers.

Another difficulty is the lack of access to medical specialists experienced by people living in the north of Tasmania; particularly specialists who can provide a timely and accurate diagnose of dementia, and provide access to medications to relieve symptoms of dementia.

Often, people experience delays of 3 and 12 months between when a referral is made by a GP to a specialist and an appointment being available.

Pat, a carer for her husband, Terry, said that Terry's GP had refused to give a referral for Terry to see a specialist when requested. The GP had advised that Terry had dementia and that a referral was not necessary as he thought medications would not work. When the couple sought assistance from a new GP, who referred Terry to a specialist, the specialist advised that if Terry had been able to take medication to treat his dementia earlier, he may not have deteriorated at the same rate as he has done. This is extremely disappointing for Pat, who lives with the consequences daily.

Another carer, Pauline, cares for her husband, Rod. Changes to Rod's behaviour were noted about 8 years ago, and a referral was made to a specialist. The specialist diagnosed Rod with an unspecified form of dementia in 2008. The specialist died shortly thereafter. A request for referral to another specialist for follow-up was not refused by the GP, but just never made. The GP has prescribed medication for Parkinsons' Disease, despite no diagnosis of Parkinson's Disease having been made. A referral to a specialist was promised prior to Easter, but (to date) has not been made. The couple were not provided with any information on dementia following the GP's diagnosis.

Another client, Mary, has had huge difficulty getting a diagnosis for her husband, John. John has been a very capable man, but has lost a great deal of the capacity needed for his work. This drop in capacity has caused John to retire early, and he has seen numerous specialists since that time. Mary has been accused of being an over-protective wife, and on at least two occasions has been told that she is seeking a diagnosis only so that she can leave her husband. Since a diagnosis of vascular dementia has been made, John's GP has asked Mary, again, when she plans to leave John. Mary has found the doctor's attitude paternalistic, condescending, insulting, and demeaning. Mary is keen to stay with and support John, but has experienced mental trauma as a result of her dealings with her husband's GP. Counsellors within our service find this doctor's attitude towards Mary unacceptable and inhumane.

Another client, Peter, had volunteered to participate in a university study about dementia. The psychologist running the study had noticed some cognitive decline over a 12-month period, and suggested Peter see his GP for further investigation in relation to dementia. In December 2011, Peter's wife, Lyn had concerns about the GP's referral to a local specialist as no appointment had been forthcoming. Peter was experience increased anxiety and memory loss, which naturally caused Lyn concern. Discussions between one of our counsellors and a person from Older Person's Mental Health resulted in a referral to a visiting specialist from Hobart being made on Peter's behalf. The referral was lost at the hospital, and meanwhile an appointment with the original specialist eventuated, which resulted in the cancellation of the appointment with the alternative specialist. Peter has now been diagnosed with Alzheimer's Disease and prescribed Aricept to slow the process of dementia, but the delay in diagnosis and medication has meant that Peter has lost some of his abilities in relation to activities of daily living.

Feedback from many clients suggests that when a diagnosis is made, the person diagnosed with dementia and their family members are rarely provided with appropriate information on the nature or progression of the disease, or avenues for support in relation to dementia. Most people find their own way to our service, instead of via information from their GP, despite the fact that all practices in the Launceston region receive our newsletter and advice in relation to education sessions, and service availability. When medical professionals do not provide appropriate information and support to persons experiencing dementia it would seem appropriate that they refer them to services who can provide information and support.

The University of Tasmania's Wicking Dementia Research and Education Centre has been involved in a project in relation to palliative care and dementia, and this project has provided education to medical professionals (general practitioners and practice nurses), and staff (registered nurses, enrolled nurses, health care assistants, and allied health professionals) working in acute care settings and residential aged care facilities. Education sessions aimed to increase awareness of dementia as a terminal illness and the benefits of a palliative approach to dementia care. Families of people experiencing dementia in residential aged care facilities also benefited through the provision of education sessions, and the introduction of case conferencing through the Wicking dementia and palliation project. Our service has been involved in this project, and we are aware that the project has benefited the professionals and individual family members involved.

Wicking has also been involved in another project which has provided practical experience opportunities in a residential aged care facility for medical, nursing, and paramedic students. These opportunities will be highly influential in the education of these professionals, and will provide them with a working knowledge of what happens for older persons when they enter residential aged care facilities. Hopefully, this will improve the understanding and support for older persons in care, generally, and persons in care living with dementia, specifically. Preliminary feedback from students, and from staff working in the aged care setting, are positive. As counsellors, we believe that this first-hand experience will be invaluable to improving dementia care in the future. These types of opportunities need support from government, as they do impose a cost, in terms of staff time for supervision, to the residential aged care facilities.

Currently, it would appear that many general practitioners do not have adequate knowledge of dementia, due to limited education and experiential opportunities. Further professional development opportunities, of the type mentioned above, may assist these professionals to provide access to their patients to timely and accurate diagnosis, and referral to appropriate services for support.