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Submission to the House of Representatives Standing Committee on Health and Ageing

Inquiry into Dementia: early diagnosis and intervention

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This Submission is based on the views of the National Rural Health Alliance but may not reflect the full or particular views of all of its Member Bodies.

House of Representatives Standing Committee on Health and Ageing
Inquiry into Dementia: early diagnosis and intervention

Terms of Reference

Australia's population is ageing and over the next 20 years the number of people with dementia is predicted to more than double. Early diagnosis and intervention has been shown to improve the quality of live for people with dementia, as well as for family members and carers.

The Committee will inquire into and report on the dementia early diagnosis and intervention practices in Australia, with a particular focus on how early diagnosis and intervention can:

- improve quality of life and assist people with dementia to remain independent for as long as possible;
- increase opportunities for continued social engagement and community participation for people with dementia;
- 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; and
- how best to deliver awareness and communication on dementia and dementia-related services into the community.

Introduction – dementia in rural and remote communities

The expected increase in the proportion of people with dementia is a particular issue for rural and remote Australians. The proportion of older people outside Major cities is higher in all except the very remote communities.

The proportion of Aboriginal and Torres Strait islander people is higher in communities outside the Major cities. The prevalence of dementia in the Australian Indigenous population is five times the rate for the non-Indigenous population. Dementia presents at an earlier age in the Indigenous population, the perception of dementia is different across communities and situations and it is often not viewed as a medical condition. The health and social conditions Indigenous people currently experience put them at a greater risk of developing dementia compared to non-Indigenous people; and access to services are problematic due to a lack of transport and services which take into consideration language, cultural or other circumstances unique to Indigenous people and their communities.[1]

However, relative rates of dementia by geographical location are hard to come by. Interpretation of the data that is available, for example about pathways through aged care, is complicated by the fact that early diagnosis of dementia is less likely where access to primary care, let alone gerontology, is poor. Further, most people with moderate to severe dementia

[1] Arkles RS, Jackson Pulver LR, Robertson H, Draper B, Chalkley S, Broe GA (2010) Ageing, cognition and dementia in Australian Aboriginal and Torres Strait Islander peoples: a life cycle approach. A review of the literature. Australian Indigenous Health*Bulletin* 10(4) . Australian Indigenous Health*Info*Net. http://healthbulletin.org.au/articles/ageing-cognition-and-dementia-in-australian-aboriginal-and-torres-strait-islander-peoples-a-life-cycle-approach/

will need a level of care that is less likely to be available outside the cities, which may in turn limit the choices available to them and their families in their local communities or even result in worse prospects for survival if they do remain without sufficient care.

This paucity of information about dementia in country areas is particularly concerning given that many of the risk factors for the condition are more prevalent in those areas, including pre-existing heart or lung disease and physical disability. Protective lifestyle measures such as controlling cardio-vascular risk factors (eg diabetes, high blood pressure and smoking) and keeping physically active are taken up to a lesser extent. Further, country people are less likely to drink only a moderate amount of alcohol, take a daily walk or have completed secondary education, all of which are associated with higher rates of dementia.

On a more positive note, rural and remote communities are often characterised by resilience and strong social networks and the incidence of depression is not significantly worse than for city people. These factors should help to limit the prevalence of dementia and provide a good basis for the care of those with the condition. However, when things go wrong, support services are harder to come by and health outcomes are worse, as measured most starkly by the higher rates of suicide among country men in all age groups.

Poor access to primary care generally in country areas, including shortages of medical specialists and allied health professionals of any kind, let alone those that specialise in dementia, mean there is less likelihood of early diagnosis and treatment for people in those areas. The smaller aged care services with fluctuating numbers, that struggle to be sustainable in rural and remote communities, are also less likely to have the capacity to provide specialised dementia care – although the more flexible care arrangements possible can contribute to more personalised care for local people with dementia.

The way it can be

"My husband has dementia and we thought we could manage here in our home among familiar faces and places. My daughter lives in the city but there's less confusion and hustle and bustle here. Everyone knows our family and people will look out for me and for my husband.

But we live right on the outskirts of town and it's a big block that's getting out of hand. I worry that he'll wander into the bush out the back. If I turn around, no one will see him go. The neighbours are too far away. And the trucks on the highway out the front are still moving very fast.

He used to drive me in to do the shopping but that's not on any more. I'm lucky there is a train - many country towns have no public transport - but it's only once a day. He goes outside to look for me if I'm out of sight for a minute. I'm sure his medicines are all topsy turvy but he hates it if I meddle and it's so hard to get him into town to the doctor and the pharmacist.

I really don't know where to turn. People try to help but they can't be calling in and doing things for us all the time. There's not any aged care in town – while that's not what we want, I'm really worried about how I'd get to visit him if it comes to that."

Addressing the Terms of Reference

Improving quality of life and assisting people with dementia to remain independent for as long as possible

In *Older Australia at a glance* the AIHW reports that in older people dementia is more likely than other health conditions to be associated with severe or profound limitations in self-care, mobility and communication, is more likely to be the main health condition resulting in disability, and is very likely to be associated with multiple health conditions. Other long-term health conditions associated with dementia are gait disturbance, slowed movements, fractures, arthritis, osteoporosis and urinary tract infections. The oral health of older people with dementia is also significantly worse than that of their unaffected peers.

No one could argue with the desirability of improving quality of life and assisting people with dementia to remain independent for as long as possible. The Alliance strongly supports a national effort to develop best practice responses to dementia, including the suggested identification of dementia as the ninth National Priority Area.

However, the particular interest of the Alliance is to make sure that best practice in dementia care is fairly applied to people in rural and remote Australia. For this to occur, we need improved access to well-coordinated primary care for older people in rural communities, including better links with gerontologists and allied health professionals, other medical specialists and oral health care professionals.

> I worked all day Monday and Tuesday this week at the hospital. One of my patients was an aged care resident with advanced dementia. His wife/carer is making a heroic effort, obviously at great emotional cost. Another patient was a bloke who is caring for his wife at home. Similar picture. I guess the most important thing we can do is to ensure that the new "block funding" structures for small rural hospitals has adequate funding for both residential care and carer support. There must be regular respite available.

Table 1 shows the extent of the shortages across almost all health professionals increasing by remoteness. It is important to note that nurses are the most distributed of all the health professions and that Remote Area Nurses and Aboriginal Health Workers are key primary health professionals in remote communities.

It will take the application of sustained measures to redistribute the health workforce, and the passage of some considerable time, to remedy these shortages. And as is the case for a number of other areas - oral health for example - access to the more specialised care required is a prerequisite of better dementia care in rural and remote communities.

Some of the necessary workforce strategies, including increased opportunities for rural students to train as health professionals through the University Departments of Rural Health and Rural Clinical Schools, as well as strategic planning to improve rural health workforce through Health Workforce Australia, are already underway and will make a contribution to dementia care as well as to health care more broadly.

Table 1: Persons employed in health occupations, per 100,000 population, by Remoteness Areas, 2006

Occupation	Major cities	Inner regional	Outer regional	Remote	Very remote	Australia
Medical practitioners	324	184	148	136	70	275
Medical imaging workers	58	40	28	15	5	51
Dental workers	159	119	100	60	21	143
Nursing workers	1,058	1,177	1,016	857	665	1,073
- Registered nurses	978	1,056	886	748	589	979
- Enrolled nurses	80	121	129	109	76	94
Pharmacists	84	57	49	33	15	74
Allied health workers	354	256	201	161	64	315
Complementary therapists	82	82	62	40	11	79
Aboriginal and Torres Strait Islander health workers	1	4	10	50	190	5
Other health workers	624	584	524	447	320	602
Other health services managers	32	33	28	28	18	31
Total health workers	2,777	2,536	2,166	1,827	1,379	2,649

Source: ABS, Census of Population and Housing, 2006.

However, the health professionals already available locally in rural and remote communities will remain significant players into the future for early diagnosis and treatment of dementia, for which they will require additional support and training. Innovative approaches to team dementia care, such as outreach services, telehealth consultations with specialists and other work to complement the work of local health professionals, will be an important part of this strategy.

Remote learning will also provide important opportunities for rural and remote health professionals to maintain and improve their knowledge and capacity to contribute to earlier diagnosis and treatment of dementia.

The aged care sector is already stretched thin in rural and especially remote communities and better coordination between local primary and acute care, city hospitals and specialists and aged care is necessary. The provision of a few hours of community support services each week, such as cleaning and assistance with shopping, is no doubt welcome to people with early dementia and their families and carers in rural and remote communities.

Realistically, more frequent services and higher levels of care, including assistance with medications, continence and various behavioural challenges as well as care for other clinical conditions, will become necessary as the person's dementia deteriorates. While the greater costs in providing this higher level of care for people with dementia are starting to be recognised in the Government's recently announced reforms through Dementia Supplements for approached Home Care package recipients, the particular challenges of providing this level of care at home in rural and remote communities will require further exploration.

Earlier diagnosis and treatment will need to take into consideration basic requirements such as safe housing in a secure environment, with transport options for people with dementia and

their families in rural and remote communities, backed up by aged care support at home for people with dementia and their families and other informal carers.

There is also a particular need for improved focus on dementia care for Aboriginal and Torres Strait Islander people. For example, a recent CRANAPlus newsletter referred to a study in the Kimberley Region of Western Australia which reports that, despite the five-fold higher prevalence of dementia among Aboriginal than non-Aboriginal Australians, they and their caregivers are struggling to cope. [2] A culturally safe model of dementia care for remote Aboriginal communities is clearly urgently needed.

Increase opportunities for continued social engagement and community participation for people with dementia

The Alliance welcomes this focus on continued social engagement and community participation for people with dementia, which is an important part of early and ongoing treatment. It is important for Government to build its investments across Australia in social engagement programs for people with dementia, rather than focus only on clinical care and subsidising medicines that at best provide delays in progression in certain subgroups of people affected. Early diagnosis should result in early interventions such as education and support for people with dementia and their families and carers, as well as improved access to clinical and aged care services.

Some of the innovative approaches already being used by people in rural and remote communities provide good back up and support for people with dementia and their families that could be built upon and extended more widely.

Drop-in centre

A drop-in centre with a shop front in Charleville, a town of about 5,000 people, provides a well-known and used local meeting place and source of information for older people. Activities at the centre are promoted through local radio and newspaper. There is an enthusiastic local coordinator and a team of volunteers, so there is always someone about during business hours.

They include local presenters such as the police talking about safety in the home, a dietitian demonstrating low-fat cooking, a physiotherapist running sessions in Tai Chi or water exercise or falls prevention.

Local people can work in the vegetable garden, play cards or pool, or participate in regular morning walks with the added safety and incentive provided by the group. Information about local healthy ageing strategies and aged care services is available through the centre.

RHealth, Southern Queensland

[2] Smith K, Flicker L, Shadforth G et al. Gotta be sit down and worked out together: views of Aboriginal caregivers and service providers on ways to improve dementia care for Aboriginal Australians. Rural and Remote Health 11:1650 (Online) 2011, available at http://www.rrh.org.au

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.

The Government's recent announcement that it will progressively establish a single gateway to aged care services is welcome. It should simplify the search for advice on financial and legal affairs and preparations for longer-term planning, potentially including for more specialised care for people with dementia. However, the *My Aged Care* website will not necessarily reach or even be technologically accessible to people living in rural and remote communities. It will be critical that rural and remote health care providers are well informed about the avenues for obtaining such support.

Centrelink and the Australian Tax Office have also played their part in ensuring that rural communities obtain the financial and legal advice they need during drought and bushfire. This has included social workers and financial advisors to provide more detailed advice and a bus that travels into local communities. It would be valuable for public policies and expenditures to build on and replicate such grassroots support, including for the benefits these initiatives can provide for people with dementia and other degenerative conditions.

Respite in remote areas

Respite care includes a range of short-term care options to provide temporary relief for people caring for family members who might otherwise require permanent placement in a facility outside the home. For example, Frontier Services provides aged care and respite services to outback Australia across 85 percent of the continent, including a mobile van (affectionately called 'Troopy') that moves from one community to another to provide local respite care sessions.

Some rural communities have developed healthy ageing centres to provide information, activities and services for older people in response to local needs (like the example above in Charleville). The benefits of such services are likely to be easier to access than those of a national website, for example, or even what is available through a regional coordinator. The immediate benefits include a local face, a contact point for local information, a safe meeting place with social benefits, opportunities for volunteer participation, links with local health and aged care providers through programs and activities and informal support for carers.

How best to deliver awareness and communication on dementia and dementia-related services into the community

Local community services and existing networks are critical avenues for rural communications. The funding patched together from diverse sources to perform this information and communication role could become more systematic through the proposed regional planning role of Medicare Locals or through the recently announced Carer Support Centres.

Men's sheds

There are growing problems with men's health. Isolation, loneliness and depression are now looming as major men's health issues, especially in rural areas. *Men's sheds* is a uniquely Australian movement dedicated to promoting the health and wellbeing of men and to supporting their communities. A *men's shed* is a place for social interaction, for gaining information on health and wellbeing, and for making things together. They are locally based and structured to service the particular needs of their local community.

The *men's shed* movement is supported by Mensheds Australia which supports the planning, development and operation of *men's sheds*. They provide advice on 'getting going', on-going operations and becoming sustainable in terms of management structure, programs and funding through commercial activities and partnerships. Guidance is provided on building the links to the community, developing leadership and a culture of learning and innovation and communication with both members and the community.

For information see www.mensheds.com.au

A wide variety of providers and local interest groups contribute to local communications. They include the Divisions of General Practice and Medicare Locals, State or local government community programs, support groups for dementia, diabetes or heart conditions, service clubs, aged care providers, carer groups and many more. It would be important to ensure that improved communications and resources for people with dementia and their carers are developed with these existing programs and local level communication channels in mind, rather than setting up in opposition to them.

More

"Our Men's Shed has an 'outreach' program aimed at the men in our local nursing home. We bring the men to our shed 2 times a month for two hours.

One of the groups (8) come from the dementia unit. I am seeking ideas how we might stimulate them with small activities.

We have enlisted our members to become "Buddies". These men will use machinery etc., with the men from the home undertaking sanding and painting activities.

Some projects we have in mind are a photo frame with their picture. Kite making then flying them on the field outside our shed. Gardening in our new glass hot house currently under construction. Making a recycled christmas tree to be entered in our town's Recycled Christmas tree competition. General toy making, although one of the men asked me to asist him make a rocking horse. I think I can find a simple construction to suit a 3 year old.

If you can offer other ideas on what we can do please become part of this discussion.

Jonesy of Sussex Inlet NSW"

Men's Shed Forum [http://www.theshedonline.org.au/discussions/topic/1217]

Attachment

Member Bodies of the National Rural Health Alliance

ACHSM	Australasian College of Health Service Management
ACRRM	Australian College of Rural and Remote Medicine
AGPN	Australian General Practice Network
AHHA	Australian Healthcare & Hospitals Association
AHPARR	Allied Health Professions Australia Rural and Remote
AIDA	Australian Indigenous Doctors' Association
ANF	Australian Nursing Federation (rural members)
APA (RMN)	Australian Physiotherapy Association Rural Member Network
APS	Australian Paediatric Society
APS (RRIG)	Australian Psychological Society (Rural and Remote Interest Group)
ARHEN	Australian Rural Health Education Network Limited
CAA (RRG)	Council of Ambulance Authorities (Rural and Remote Group)
CHA	Catholic Health Australia (rural members)
CRANAplus	CRANAplus – the professional body for all remote health
CWAA	Country Women's Association of Australia
FS	Frontier Services of the Uniting Church in Australia
HCRRA	Health Consumers of Rural and Remote Australia
ICPA	Isolated Children's Parents' Association
NACCHO	National Aboriginal Community Controlled Health Organisation
NRHSN	National Rural Health Students' Network
PA (RRSIG)	Paramedics Australasia (Rural and Remote Special Interest Group
PSA (RSIG)	Rural Special Interest Group of the Pharmaceutical Society of Australia
RACGP (NRF)	National Rural Faculty of the Royal Australian College of General Practitioners
RDAA	Rural Doctors Association of Australia
RDN of ADA	Rural Dentists' Network of the Australian Dental Association
RHW	Rural Health Workforce
RFDS	Royal Flying Doctor Service
RHEF	Rural Health Education Foundation
RIHG of CAA	Rural Indigenous and Health-interest Group of the Chiropractors' Association of Australia
RNMF of RCNA	Rural Nursing and Midwifery Faculty of the Royal College of Nursing Australia
ROG of OAA	Rural Optometry Group of the Australian Optometrists Association
RPA	Rural Pharmacists Australia
SARRAH	Services for Australian Rural and Remote Allied Health