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Services for Australian
Rural and Remote Allied Health

Submission to the
Senate Standing Committee on Committee Affairs

Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)

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Introduction

Services for Australian Rural and Remote Allied Health (SARRAH), welcomes the opportunity to provide a submission to the Senate Standing Committee on Community Affairs inquiry into: *Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD*).

SARRAH is nationally recognised as the key peak body representing rural and remote Allied Health Professionals (AHPs), working in both the public and private sector.

SARRAH's representation comes from a range of allied health professions including but not limited to: Audiology, Dietetics, Exercise Physiology, Occupational Therapy, Optometry, Oral Health, Pharmacy, Physiotherapy, Podiatry, Psychology, Social Work and Speech Pathology.

These AHPs provide a range of clinical and health education services to individuals who live in rural and remote Australian communities. AHPs are critical for the management of their client's health needs, particularly in relation to chronic disease and complex care needs.

SARRAH maintains that every Australian should have access to equitable health services wherever they live and that allied health professional services are basic and core to Australians' health care and wellbeing.

General comments

A diagnosis of dementia impacts on both the person and their carer/s. Lack of awareness, understanding, community services, dementia expertise, respite and residential care increase the challenges of living with dementia in rural and remote Australia. There is a need to provide comprehensive, integrated services for people with dementia living in these settings. People in rural and remote Australia are often more resourceful, think more laterally (innovative) and tend to be self-reliant because services are not as plentiful as in metropolitan areas. There is potentially a culture whereby people in the bush value their privacy, fear the stigma associated with dementia and how having dementia will affect them within the community. As a family they will try to cope alone for longer, improvising until they can no longer cope and sometimes leaving it too late to find a specific way to help the sufferer or the carer(s).

The *Living Longer Living Better* aged care reform package[1] currently in the process of being implemented by the Australia Government recognises dementia as a significant chronic disease in Australia, making it the ninth National Health Priority Area. The reform package provides for $268.4 million over five years to tack dementia.

People with dementia need access to a range of health care and social services. These services include GPs, community services, allied health services, hospital, day care, in home care, personal care and residential care. With increasing remoteness access to these types of services declines, particularly those which provide the expertise and are specifically designed to cater for people with dementia.

The role of the AHP and the services they provide is poorly understood in the care and management of people with dementia. A person with dementia and their carer(s) can benefit from access to a range of services delivered by AHPs including:

- Physical health and wellbeing
    - Exercise (physiotherapy, exercise physiology)
    - Falls prevention (physiotherapy, occupational therapy, pharmacy, optometry)
- Nutrition and diet (dietetics, oral health)
- Swallowing and communication (speech pathology, audiology)
- Emotional and psychological wellbeing (psychology, social work, occupational therapy)
- Activities of daily living (occupational therapist, optometry, audiology, podiatry)
- Participation in the community (occupational therapy, social work).

Support services for people with dementia in rural and remote communities should aim to:

- Enable the person with dementia to remain at home for as long as possible.
- Help the carer cope with daily living, and develop strategies to support the person with dementia whilst that person is at home and during any transition from home to respite and/or residential care.
- Select and train appropriate residential and community staff in dementia care. There is opportunity to develop local roles for support workers and allied health assistants.
- Raise community awareness and help develop strategies with all who may come into contact with the person with dementia on how to deal with that person.
- Show the value of providing specialised dementia support services in a targeted fashion within a rural and remote setting.
- Liaise with specialist dementia services for local support as required.

SARRAH recommends:

1. Providing funding for targeted community education programs in rural and remote settings for health professionals and ancillary staff working in acute community and residential care. For example “Recognising and responding to dementia” workshop developed by the Dementia Training Study Centre and the Centre for Remote Health, an inter-professional workshop for medical and care staff.
2. Developing clear pathways from identification through to assessment and diagnosis of dementia.

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[1] Australian Government. Living Longer. Living Better – Tackling Dementia. May 2012. Available online: http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-aged-care-review-measures-factsheet-10.htm. Accessed 1 May 2013.

3. Expanding services delivered by Geriatricians and AHPs with expertise in the diagnosis, assessment, treatment and management of BPSD for people in rural and remote communities through the Rural Health Outreach Fund, e-health technologies and Medicare. For example increasing access to AHPs through Medicare and Medicare Local programs.
4. Employing and supporting key workers/case managers to ensure timely diagnosis, management, treatment and the provision of emotional and social support.
5. Providing funding to aged care services and facilities to enable best practice guidelines to be implemented and achieved.
6. Creating flexible care arrangements to support both the person with BPSD and their carer(s) providing the most appropriate level of care.
7. Implementing the National Disability Insurance Scheme (NDIS) providing an opportunity for the focus on integrated, coordinated care for people with dementia under the age of 65.
8. Funding the Aged Care Gateway package to tackle dementia for those over the age of 65 announced under the ‘Living Longer Living Better Aged Care Reform Package’, providing information and support on dementia, with particular reference to rural and remote regions.
9. Establishing and funding programs for research into the assessment, diagnosis, treatment and management of BSPD to achieve evidence based practice and appropriate planning of services, with particular reference to service in the rural/remote context.

Comments against the Terms of Reference for the Inquiry

a) The scope and adequacy of the different models of community, residential and acute care for Australians living with dementia and BPSD, with particular reference to:

(i) Commonwealth-provided support and services;

(ii) State- and territory-provided services; and

(iii) Services provided by the non-government sector.

People living with dementia need access to services and support, as do their carer(s). Special arrangements are required for dementia care under the NDIS, with particular focus on flexible funding packages for carer(s) to purchase the service supports that they need.

It is irrelevant whether the support and services are delivered by the Commonwealth, State and Territories, or by the non-government sector. Governments and service providers need to ensure that people have access to the services and support they need, whether it is acute care, care to remain in the community or residential care irrespective of the sector providing the service. Services and support need to be integrated and coordinated with information readily available. To provide community, residential and acute care for Australians living with dementia and BPSD a number of factors need to be considered.

These include:

- Education and awareness raising;
- Diagnosis, assessment and management;
- Emotional and social support;
- Community service access;
- Respite and residential care;
- Distance and travel; and
- Indigenous people.

Education and Awareness Raising

Community education needs to be available through the development of culturally appropriate resources, the provision of suitably trained staff living locally to deliver education programs using these resources, and through the use of technology based online information channels. This should include providing education programs for school aged children. Education programs should include:

- Knowledge and understanding of dementia for carers;
- Training for health professionals and service providers; and
- Awareness and understanding of dementia in the broader community, including those working in the financial and legal services, retail and hospitality sectors.

Education of health professional staff about dementia should be provided; its diagnosis and course of the various manifestations of the disease. This should include the difference between dementia, depression and delirium especially for those working in acute settings. For example:

- Provide greater dementia education for rural and remote health professionals to increase their abilities to identify, assess and diagnose early dementia.
- Deliver appropriate online inter-professional training to AHPs in order to ensure they are competent in managing people with dementia, particularly when they do not work solely in that area.
- Provide dementia training modules similar to those available in the vocational sector such as the Aged Care Certificate III and IV training for care workers.
- Establish flexible dementia training courses to allow access to training modules and/or skill sets by health workers, community workers and carer(s) to meet local needs.
- Develop appropriate resources for Indigenous family carers and people with dementia, in consultation with Indigenous people.
- Educate and train health professionals at the tertiary level to facilitate better use of culturally appropriate tools and personnel to identify, assess and diagnose dementia; understand key worker/case management roles; and the treatment and management of dementia.
- Use of social media, newsprint, television, magazines and other print material for community education and to raise awareness.
- Increase access to dementia networks for support in management of dementia.

Diagnosis, Assessment and Management

Diagnosis and Assessment

Access to health professionals with expertise in dementia in rural and remote areas is limited. Models of care for people with dementia, including access to health professionals with the skills in diagnosis and early assessment must be developed and implemented. A clear pathway from identification to diagnosis such as that recommended in the Dementia Service Coordination in Aboriginal Communities in Central Australia report[2]. This could include the use of visiting multi-professional specialist teams and the use of e-health technologies to facilitate timely diagnosis, assessment and management. Visiting specialist teams can be used as a resource to provide education and training to up skill the local health professional workforce and carers.

Diagnosis of dementia needs to be managed more effectively. In remote communities there are very few people diagnosed with dementia, particularly amongst Indigenous populations, despite the fact that research in the Kimberley indicates that the prevalence of dementia in Aboriginal communities is more than five times that of the non-Aboriginal population. Those with reversible causes of cognitive decline may not be promptly identified due to lack of resources or limited knowledge of staff about dementia. Culturally appropriate cognitive assessments must be utilised in conjunction with interpreter services to ensure accurate diagnosis and consequently more funding may be required for these interpreter services. A clear pathway for diagnosis needs to be consistent across all regions.

Diagnosis rates often determine the level of services available, so that low diagnosis rates means less services. Diagnosis could be enhanced in remote communities with greater access to Geriatricians via e-health technologies. Commonwealth support is required for more frequent visits to rural and remote communities by Geriatricians and dementia support teams such as the Rural Health Outreach Fund (RHOF).

There is an opportunity to develop new positions within rural and remote communities for example: local support staff, allied health assistants and/or community health workers.

Current research relating to dementia care must be used to inform service planning. Further research to inform service planning and provision must be expanded, funded and supported. Research is required to provide evidence on the cost effectiveness of allied health interventions in dementia management and care.

Education and support should be provided to specialist health professionals, such as dentists, to ensure the ‘normal’ health needs of people with dementia are met.

Management

People with dementia and their carer(s) require access to a range of allied health services to assist in managing the condition and maintaining health and wellbeing. For example access to key workers and case managers with knowledge in dementia as required which may include a:

- Dietitian for advice regarding nutrition.
- Speech Pathologist for swallowing and communication support.
- Podiatrist for foot care.
- Psychologist and Social Worker for psychological, emotional and social support.

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[2] Jensen, H. Bell, D., Flicker, L. LoGuidice, D., Atkinson, D. and Smith, K. Dementia Service Coordination in Aboriginal Communities in Central Australia. Western Australian Centre for Health Aging. The University of Western Australia. 2012

- Occupational Therapist for support in activities of daily living, falls prevention and community participation.
- Physiotherapist for mobility support and falls prevention.

Exercise and other activities for people with BPSD increases cardiovascular fitness, cognitive function and positive behaviour[3] mobility and physical functioning with long term exercise programs[4]. Consideration needs to be given to:

- Access for all people with BPSD, to long term individual and group exercise and activity programs conducted by AHPs in all parts of Australia, located both in the community and within residential care.
- Promote and enhance exercise and other activity programs to those with BPSD within the community including all respite and residential care facilities.
- Enhance education programs of undergraduate and post graduate AHPs to recognise and promote exercise and other activities for those with BPSD.
- Access for BPSD carers to subsidized community exercise and other activity group programs run by AHPs.

Emotional and Social Support

There is limited access to formal and structured support services in rural and remote regions such as counselling, advocacy and carer support groups. Some informal support is available through family and social networks however such support is generally limited.

Consequently the role of carers must be better acknowledged and supported.

The emotional, financial, social and psychological needs of a person living with dementia and their carer/s/family and friends needs to be provided.

Support, guidance and advice on effectively managing the challenging aspects of dementia should be available locally by professionally facilitated and trained counselling services. Carers, family and friends as well as the person with dementia require this support. For example access to face-to-face counselling services, dementia specific support groups to discuss practical solutions on how to manage symptoms such as incontinence or keeping the person calm.

Also access to a Psychologist and Social Worker to provide emotional and social support may be broadened through expanding access to enhanced primary healthcare Medicare funded allied health services.

Community Service Access

There needs to be more information made available to the community about services for people with dementia and greater coordination of these services designed to keep the person in their own home for as long as possible. For example services may include: case

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[3] Heyn, P. Abreu, B.C & Ottenbacher,K.J. (2004) The effects of exercise training on elderly persons with cognitive impairment and dementia a meta analysis. *Archives of physical medicine and Rehabilitation* 85 (10) 1694-1704

[4] Pitkälä, K., Savikko, N., Poysti,M., Strandberg,T.& Laakkonen, M-L. Efficacy of physical exercise intervention on mobility and physical functioning in older people with dementia: A systematic review. *Experimental Gerontology* 48 (2013) 85–93

management; community nursing and a range of allied health; respite and personal care; domestic, handyman, gardening, laundry and transport.

Increased funding and availability of services needs to occur for people with dementia in rural and remote areas to address the following factors:

- Support in the home is more cost effective than in residential or hospital based care.
- Higher cost of providing services or transport to access services either by the person or by the service provider.
- Work conditions and wages to improve recruitment and retention of dementia trained health professionals including infrastructure requirements.

Respite and Residential Care

There needs to be options for flexible respite and residential care in rural and regional areas to overcome access barriers created by distance and isolation. The provision of respite for ‘time out’ by carers enhances their ability to cope with in-home care over longer periods. For example flexible options may include:

- In-home, day centres, after hours, mobile and/or emergency respite services.
- Culturally relevant services
- Low and high care residential facilities.
- Dementia specific and secure facilities within the local community, or within access for family and friends.

Distance and Travel

The higher financial burden experienced by people with dementia and their carers living in rural and remote areas must be recognised. Access to service providers and support for carers is limited by distance and isolation.

The specific transport needs of people with dementia in rural and remote areas needs to be identified with a view to overcoming the hardships created by lack of locally available services. Strategies to consider include greater use of school and community buses during down times as well as volunteer drivers.

The carer’s allowance or carer payment for those in rural and remote settings is expected to cover the higher cost of caring for the person with dementia in these areas.

Technology, where available, should also be considered in overcoming the tyranny of distance for example telehealth facilities may enable greater access to services and offset some travel costs.

Indigenous People

Coordination of services for Indigenous people living in rural and remote communities needs to be enhanced through the provision of sufficient staffing, evidence based retention and recruitment strategies and education of the workforce regarding sound care planning.

There needs to be an increase in the employment of Indigenous health workers (with an appropriate career path) employed in residential care settings where there are a high percentage of Indigenous residents. Cultural safety education and training should be provided for all staff to deliver appropriate activities.

b) Resourcing of those models of care.

The overall reform and development of the Australian Primary Health Care (PHC) system, especially as these apply to rural and remote areas is likely to produce benefits for dementia care and a range of priority health areas in the community. Whilst dementia care in itself is unlikely to lead or drive these reforms, continuing the PHC reform should be the overarching goal, and if achieved would positively impact on dementia care and many other areas.

Allied health services are critical to the quality of life for a person with dementia in maintaining mobility, independence, communication, safe swallowing, nutrition and management of cognitive decline. These services should be accessible and flexible regardless of where the person resides and consequently a range of strategies should be considered including:

- Residential aged care facilities should be mandated to provide a minimum acceptable level of allied health services to residents in their facilities. Local options include allied health services delivered by the private sector. Where not available locally flexible options such as visiting services and telehealth may be considered.
- Review MBS (Medical Benefits Schedule) rebates for home/residential care visiting including expanding MBS items for chronic conditions in particular Australians with dementia. Currently 5 consultations per year for all allied health services is inadequate. A person with dementia may require many multiple consultations from a range of allied health providers including a psychologist, social worker, dietician, speech pathologist, exercise physiologist or physiotherapist. The number of consultations should be increased with adjustments to rebates where services are conducted at the person's home or residential aged care facility.
- Community capacity building to enhance the local professional, service and volunteer resources providing services and support to people with dementia in rural and remote communities.
- Workforce enhancement through inter-professional student clinical placements in allied health, specifically working with people with dementia. Engage with the education sector to support allied health workplace learning placements within community, respite, aged care and dementia residential settings to assist in:
  - Training an allied health workforce in dementia management skills.
  - Increasing access to allied health services through supervised student clinics for people with dementia.
  - Building a resource for clinical placements within these sectors that dovetails with the Clinical Training Fund aims.
- Wages should be sufficient to recruit and retain qualified and dedicated staff in all levels of aged care. There should be equitable conditions and pay so workers are not disadvantaged and that the complexity of their work is recognised.

c) The scope for improving the provision of care and management of Australians living with dementia and BPSD, such as:

(i) Access to appropriate respite care, and

(ii) Reduction in the use of both physical and chemical restraints.

Access to regular respite care can assist people with dementia to live at home for longer, and enhances the health and safety of their carers. The time a person is in respite care at a larger regional centre creates an opportunity for them to receive an assessment and program planning by an AHP, particularly for those from rural and remote areas.

Respite care facilities need to be available in small, including remote communities. Options for respite care may include: in-home, mobile services, day centres or clubs based on a person's interests prior to dementia.

Respite care should be well coordinated and easy to access with information readily available to the community.

Residential care settings should be designed to provide a home like setting for people and modelled on the latest research to improve the quality of life for residents and to reduce anxiety, within prescribed safety requirements.

The implementation of patient centred care policies by all service providers will assist in ensuring that appropriate care is provided for all people with dementia. This care should include activities and living environments that suit the individual. Reasons for challenging behaviours should be addressed and services such as the Dementia Behaviour Management Support Services need to be expanded. Research on the management of behaviours needs to be further funded and underpinned by a plan for implementation.

Home medication reviews should be conducted regularly to reduce any negative impact. Support should be provided to local pharmacists to provide medication audits and consultation with GP's and other prescribers. Such audits are essential to ensure that the person with dementia is on appropriate levels and types of medications, and that the carer(s) understand the medication regime.

Conclusion

SARRAH, as the peak body representing AHPs delivering health services to people residing in rural and remote communities across Australia, is well positioned to work with Governments and other stakeholders to address the factors that impact on the care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia.