Living with dementia in country South Australia

Phil Saunders
Alzheimer's Australia SA

The Living with Dementia in Country SA Project

There are over 7,100 people living with dementia in South Australia’s country regions. This group of consumers experience particular challenges which are exacerbated for those living in remote regions and for those from diverse groups. Many more people in these communities are impacted by the disease, including family members and health and other professionals providing services for them. These numbers are expected to triple by the middle of this century.

To build an up to date, evidence-based picture of the situation facing country people living with dementia, their families and carers, Alzheimer’s Australia SA undertook the Get Your Voice Heard: Living with Dementia in Country SA project. From July to November 2012, the project provided dementia consumers and service providers across country South Australia an opportunity to discuss issues affecting the lived experience of dementia consumers and to explore practical ways of improving their situations.

Methodology

Alzheimer’s Australia SA used a ‘focus group’ approach for its consultations, including ‘Post-it Note’ exercises and ‘Comment’ sheets. Sessions were held separately for consumers and service providers. One hundred and forty five consumers attended seventeen forums and one hundred and seventy six service providers attended fifteen forums. People unable to attend were also invited to make comment. A further seventeen consumers and twenty eight service providers did so.

Commonalities in responses were observed across consumer and service provider sessions and across regions.

The information received was analysed using the stages of the dementia journey:

1. Awareness of Dementia and Risk Reduction
2. Assessment and Diagnosis
3. Post Diagnostic Support: Early Intervention
4. Support and Management: Coordination and Care Management
5. Support and Management: Community Services
6. Continuing Care, Including Residential Aged Care and Hospital Care
7. End of Life: Palliative Care

Top issues and key actions

During the sessions participants were invited to highlight the Top Three Issues facing consumers in their region and Three Key Actions that should be provided to assist them.

Consumers identified Support and Management: Community Services (36%), Continuing Care (16%) and Support and Management: Coordination and Care Management (11%) as their top issues. Service

---

1 Definitions:
‘Consumers’ are people living with dementia, their families and carers.
‘Carers’ are family members or close acquaintances who provide unpaid care and support to the person living with dementia.
‘Care workers’ are people who provide care support in a paid capacity.
‘Service providers’ are organisations, either government, non government, not for profit or businesses which provide a range of direct or indirect services for people living with dementia, their families and carers.
providers identified Support and Management: Community Services (49%), Continuing Care (13%) and Awareness and Diagnosis (both 8%) as their top issues.

Consumers identified Support and Management: Community Services (32%); Continuing Care (18%) and Support and Management: Coordination and Care Management (17%) as their key action priorities. Service providers identified Support and Management: Community Services (49%) and Awareness and Diagnosis (both 11%) as their key action priorities.

**Awareness and risk reduction**

**Stigma**

Whilst increasing awareness of dementia was reducing stigma, nevertheless social and emotional stigma, real or perceived, remained a huge issue, particularly in smaller communities where there was "a feeling all the community knows your business" and "people don’t talk about it."

Associated with this general stigma was denial by family members and social resistance by friends with the result that circles of friends and their support disappeared. Engaging carers in these circumstances was “very hard because they did not acknowledge their family member had dementia and did not seek services.”

The issue then became how to destigmatise dementia in small communities and overcome the lack of awareness and understanding of dementia in order to promote early diagnosis and associated intervention.

**Awareness and understanding**

Underpinning stigma was the limited or lack of awareness of dementia in the community. People were not getting enough information about dementia and the signs to look for in loved ones. Consumers were keen to make dementia “more obvious” to the community at large with an awareness of the illness and what to expect.

Consumers were “hungry for knowledge,” keen to have a much greater understanding of dementia as a disease, its stages, the triggers, the symptoms, the early signs, medical advancements, prevention, cure and approaching the family and the person living with dementia.

A large number of strategies for increasing community awareness of dementia were outlined, including an up to date interactive website for information and counselling; more information from doctors on diagnosis; “more and better” dementia information sessions for families, the general community and care professionals; a national awareness campaign that reached country regions; a national ‘recovering the stories’ project promoting positive role models of people living with dementia; ‘shop front’ dementia clinics and regular visits from Alzheimer’s Australia SA for resources and information.

**Timely diagnosis**

**Getting an assessment/diagnosis**

Limited community knowledge and awareness resulted in people not seeking help from medical professionals, in particular their GP, when symptoms of dementia initially appeared, but much later, leading to diagnosis in mid and later stages of the disease.

Diagnosis was a long process which worked against the need for an early, timely diagnosis that would enable the earliest possible access to treatment and support for the families and carers and the associated planning for the future. The time taken caused considerable frustration and distress in many instances.
Readiness/ability by the GP to diagnose dementia
Timely diagnosis relied heavily on the GP’s ability and readiness to diagnose. Participants were concerned at the varying degrees of GP knowledge and/or interest in dementia. They sought more education and training for GPs on dementia, so that the GPs were better able to identify, diagnose and refer to specialists and to the support that was available regionally and state-wide.

Most doctors had a good reputation, but were seen as overworked, such that getting an appointment could be difficult, again delaying diagnosis.

Regular movement of doctors through country locations caused difficulties with continuity of service, in developing relationships and with the GPs recognising symptoms in the patients.

Once a diagnosis was made GPs were seen to have a responsibility in assisting the consumers in managing the disease; to provide information about further support and to be more responsive to their role as care coordinator, particularly in smaller communities where no other person fulfilled this role.

Doctors from overseas
Doctors coming from overseas struggled. They were seen as “wonderful,” but challenged by the language difficulties, their lack of knowledge and understanding of Australian culture and attitudes toward treating people living with dementia. Getting out to the wider region beyond the country centres was also a challenge for them. Participants wanted more support for these doctors, for example, “a briefing for them on arrival in the region.”

Specialists
In rural areas a diagnosis took longer due to access to specialists—geriatricians, neurologists and psychiatrists. Nearly all were visiting, with waiting times of four to six months.

Participants sought wider access to specialist services without having to travel long distances, including greater use of technological advances where appropriate. Consumers sought additional assistance for travel to metropolitan Adelaide where that was necessary.

Post diagnosis—early intervention
Immediate support following the diagnosis of dementia through information about the dementia and information about and referral to, services, was seen as critical by consumers who “didn’t know who to talk to or what to do.”

Participants sought collaboration between doctors and dementia support agencies in the region; local partnerships to support early intervention and to integrate people with dementia into community based services. Consumers wanted someone to speak to personally for advice “face to face.”

Support and management: coordination and care management

Navigation
Participants expressed concern at consumers’ capacity to “work through the maze of caring organisations,” to access help and support easily.

Consumers expressed concern at either the lack of information about services or being "snowed under with information," “left to work it out on their own.” Similarly, service providers recognised their own responsibilities in assisting in service navigation.

Dementia link workers
Dementia Link Workers, who provided the "on the ground help" to “take people on the journey” were seen as invaluable. As “dedicated specialists in the area” they were recognised as the most appropriate
person to assist consumers to navigate the support system by providing advice, one on one support, gaining access to help and linking consumers with appropriate services.

**Collaboration**
A lack of coordination between services was recognised as a significant barrier to service delivery in many regions. Working collaboration was “often dependent on the staff with the time,” rather than built into service systems.

Working well together through “Coordination, Collaboration, Communication” of available activities and information for consumers included collaboration from a much earlier point with “stronger, more active relationships with other service providers to see how we can consolidate services to get more for consumers” and consolidating and progressing dementia working parties and collaborative projects.

**Support and management: community services**

**Availability of services**
There was a lack of, or limited amount of, appropriate dementia specific services and resources across country South Australia. “Receiving the right support” included increasing services so that there were no waiting periods, with a continuity of individualised patient-centred care through the dementia journey.

Service providers were concerned that providing appropriate individual services to meet the growing needs in the region without accompanying increases in funding, people, infrastructure and aged care facilities meant that “we are supposed to turn miracles; how are we going to do that?”

**People living with dementia**
Issues raised in discussing services for people living with dementia included appropriate and sufficient care at home; providing emotional and social support; the importance of family support and listening to the carer; the lack of programs and stimulation for people with dementia; day care centres that could not cope with people with high care dementia, medication rounds; people living alone and the time service providers had for each client.

There was a call for increased resources for the development of ‘shop-front’ centres where people living with dementia could go for activity, social support, support groups and community engagement. Specific activities and programs for people living with younger onset dementia were particularly mentioned.

**Carers**
Similarly, providing support for carers was recognised as important to enable people with dementia to live at home longer, and for the maintenance of the carers’ own health and wellbeing.

Participants were particularly concerned about the impact on carers’ health of isolation, depression, exhaustion, high stress levels, the ability to make personal modifications and to deal with behavioural issues and their concern about the future. Carers had great difficulty in taking care of themselves, in seeking help.

Exacerbating the impact of caring on physical and emotional health were increased financial responsibilities, particularly for women in families where the husband had traditionally undertaken the financial roles.

Carers saw the value in education and training for themselves about dementia and their caring role. They sought support through meeting places for family and friends; regular support groups with guest speakers and sharing experiences; special groups for crisis care, for males and for carers whose family
member had been placed in residential care and a “register of people who allow themselves to go forward to meet and chat with each other.”

**Packages**

Care packages such as EACHD and CACP, were “giving the carer what helps most to keep the loved one at home” but were extremely limited in number, variety and components. Often there was a mismatch between what the packages could provide and what they in fact provided.

What was required was an increase in the number of packages and in their flexibility: packages that met individual needs, in particular high care needs, with an allowance for transport and more flexible hours.

**Respite**

Everyone recognised that the most important need of carers was respite: appropriate, quality, sufficient and flexible respite, close to home. Common issues included long waiting times; the lack of places in respite houses and residential care facilities, in particular locally; getting limited value from short hours; the difficult in organising respite care; crisis respite in emergencies or carer illness; places only being available in a hospital setting; places unable to meet high care needs; meeting the needs of people living with younger onset dementia and the reticence of the person living with dementia.

Meeting respite needs through much greater flexible personalised respite options would involve greater resources through the significant development of infrastructure, greater service provider collaboration and improved flexibility in criteria.

Service providers wanted research into why people often said “no”, to explore the barriers whether country 'stoicism' or cultural or generational issues.

**Care workers**

Provision of service relied on quality staff in sufficient numbers. Concerns raised about care workers included lack of continuity of services due to the lack of consistency in care worker personnel; a lack of support to care workers by agencies; a lack of information to care workers about their clients; debriefing options for those care workers working alone; services being confidential and respectful when giving emotional support and information; OH&S that had “gone too far” and gender issues.

There was recognition of the need for improving and maintaining the knowledge of health and other care staff in dementia and the skills in providing services for consumers. Service providers recognised the need for ongoing training across all staff levels “to be better at what we do.” Practical dementia workshops for staff would include volunteers and unregulated care workers. Compulsory training for aged care and community support workers was recommended. Alzheimer’s Australia SA was recognised as a tertiary support resource. E-learning courses were also seen as useful.

Barriers to providing staff training included the lack of peer support when working alone and the costs and distance from Adelaide dementia training providers.

**Continuing care, including residential and hospital care**

**Hospital care/acute care**

Issues discussed on hospital care included small hospitals that included dementia patients but with staff that had limited understanding of dementia care; patients having to go to hospitals a considerable distance from home; the importance of the carer being able to stay with the person living with dementia as a calmative measure and the differences in attitude and time required between general nursing and ageing/dementia nursing care.
Residential care

Liaison with community
Participants discussed the value in rural communities of community involvement in the local aged care facilities; how staff “knew people before they came into the facility; they saw them at the supermarket.” Consumers sought special days in aged care facilities for families, the involvement by local students as a means of raising awareness and reducing stigma and for the facilities to listen to the carers’ information about their family member.

Access
There were not enough aged care facilities, such that consumers expressed concern about waiting lists; when it “came to the point of needing care but finding that care was difficult” with loved ones having “to go out of town to get into residential care: why: this is their home.”

Transition
With limited places and placements that occurred through crisis rather than good planning, participants agreed that the transition from home to aged care facilities could be an “all or nothing” traumatic event. Carers wanted to know “when to know” to put their family member into care; they needed to know about the facilities that had available places.

Carers were concerned about the impact of placement costs on farm finances within the context of generational assets.

Improving the transition process from home to residential care included dementia ‘brokers’ for those looking for a placement; special days by the facilities to make families feel wanted and carer support after the person living with dementia had been placed in permanent care.

Carers role
Carers spoke about their grief, loss, sadness and guilt at placing a family member into residential care and a reduction of financial support. They sought support during the transition period, either through one on one or in support groups, in making decisions about residential care and in de-briefing afterwards.

Carers stressed that even when the person went into fulltime care the caring role did not finish. They visited the aged care facility, often on a daily basis, helping out or advocating on behalf of their family member.

Dementia specific
Dementia care in residential facilities, in particular in smaller communities where the hospital and the aged care facility were co-located, was regarded as a balancing act between competing demands. Concerns about local facilities meeting the needs of people living with dementia included the lack of specific dementia wards and programs; limited training of staff in particular in behaviour management and the use of hospital beds due to the lack of beds in dementia wards.

Participants sought the creation of specific areas for people living with dementia in the smaller mixed facilities as well as the building of dementia specific facilities. They urged facilities to make use of dementia behaviour management consultants such as the Dementia Behaviour Management Advisory Service (DBMAS). They wanted to see appropriate activities including music therapy; interaction with the community; the use of dementia resources such as therapy dolls; social get togethers for the people living with dementia and their families and work classes where appropriate. There was recognition that this too would require additional resources, or a re-arrangement of existing resources.
Staffing
Staffing levels, attitude, training and wages all played a role in the quality of the care of the person living with dementia.

There was disappointment at the various level of understanding of dementia. Consumers wanted staff with a good sense of humour, patience and understanding and who wanted to work with people living with dementia.

Service providers spoke about being only marginally younger than the residents and the emotional effect of this on them; of “loyalty in the country” with staff prepared to do extra because of their awareness of budget constraints and through having known people for a long time.

They recognised the need for a greater emphasis in training in appropriate and consistent responses to people living with dementia, for example, in the challenge to appropriately manage behaviour. They sought an increase in scholarships for aged care and funding to provide more specific training for all staff in dementia care, accessing the wider services and new trends and treatments.

Sustainability
The issue of the sustainability of the smaller facilities was explored. Smaller town facilities found it hard to get staff. There were economies of scale and benefits of co-location when the aged care facility was attached to the hospital; keeping both hospital and aged care facility “alive”. There was considerable loyalty to maintaining smaller facilities; “big is better is not true.”

End of life: palliative care
Limited discussion took place about end of life issues. There were concerns that too many people did not concern themselves with the financial and legal implications of a diagnosis; ie advance care planning. Participants wanted greater encouragement to people to make pre-care arrangements before the person living with dementia lost their decision making capacity.

Consumers were concerned that “we are forgotten at the end of life,” that palliative care specialist services were lacking because dementia was not traditionally seen as ‘palliative care’ but that demand was increasing as people living with dementia stayed at home longer.

Miscellaneous

Funding
Participants sought increased funding and better resources combined with improved targeting of existing funding; equitable funding between rural and remote and metropolitan areas; allowances for transport costs across regions and government financial commitments to dementia action plans, to enable the further development of services for consumers across country South Australia.

Distance and transport
Distance from services and support exacerbated rural isolation and the difficulties in both provision and receipt of services. This applied with the distance from Adelaide services, distance from regional centres, in regions where there might not be a large regional centre but rather a collection of ‘scattered’ smaller towns and in regions adjacent to the metropolitan area. For people without personal transport this could be devastating, including an earlier admission to residential care than would otherwise have been expected.

Community transport too, differed from region to region. Issues included the use of volunteers, increasing costs of fuel, availability and getting to and from the community transport routes.
Agency action
Service providers were challenged to highlight “three key actions that your agency could do to assist people living with dementia, their families and carers.” Actions outlined reflected the discussions and indicated a commitment by participants to dementia consumers and to further develop services for them.

The challenge, then, in further supporting and building services for people living with dementia and their families across country regions, is for all of us to consider:

- What are you doing now for dementia consumers?
- What can you do better?
- What else can you do?

Recommendation
That rural health services take up the Dementia Challenge to identify three key actions they can do to assist dementia consumers in their region.