

Dementia-friendly communities: what consumers really want

“It’s a lonely and frustrating disease,” says David Anderson, a South Australian resident living with younger onset dementia. David was one of more than 130 people who attended a series of Dementia Friendly Communities Consumer Forums in Adelaide late last year, organised by Alzheimer’s Australia SA to allow people living with dementia, their families and carers to share experiences, discuss what is required to make communities more accessible to them, and offer a way forward.

David’s views and comments are typical of people living with dementia in any community: “People living with dementia and their carers talk about the challenges and difficulties they experience with technology, shop service, bank dealings and utilities service, post offices, using transport, going on holidays, maintaining social contact and enjoying hobbies and interests,” he says.

“These things are taken for granted by most people and form an everyday part of a person’s life until they are confronted with the deterioration in their abilities. A person living with dementia’s attitude, personal characteristics and behaviour are also often misinterpreted by society, thus adding to the challenges and difficulties. They can feel trapped and cut off from everyday life, feel let down by the community, feel like a burden, so they avoid getting involved with community life,” David says.

“Dementia-friendly communities would recognise that a person living with dementia lives in a slightly different world and that the speed of society and its processes is sometimes beyond

How can communities become more accessible and supportive for people living with dementia? A series of Dementia Friendly Communities Consumer Forums in Adelaide has generated plenty of suggestions from people with dementia, carers, family members and service providers. **Kathryn Cunningham** explains

that person’s comprehension and capabilities.

“A dementia-friendly community would show a high level of public awareness and understanding of the disease, be inclusive of the person living with dementia and assist the person living with dementia to have choice and control over their lives, to remain independent and to participate in activities that are meaningful to them.”

What we have learnt in these recent conversations about creating dementia-friendly communities is paramount to the way Alzheimer’s Australia SA will help to facilitate a whole-of-state change which will assist in tackling dementia issues head on. People living with dementia, their families and carers are integral in developing services that best meet their needs. Regular consumer forums like these provide a means for people to share their experiences with others and with Alzheimer’s Australia SA.

Drawing on experience

More than 130 people, including people living with dementia, carers, family members and a small number of service providers attended the Adelaide forums to discuss what is required to create dementia-friendly communities. The forums were structured in two parts, to gauge and understand the issues more clearly and provide

greater context. The first part focused on the experiences of living with dementia ‘out and about’ in the community, while the second was about gaining an understanding of living with dementia ‘at home’.

Through these conversations, people living with dementia, their families and carers discussed what was happening on a personal level and what can be done to support them. This provided Alzheimer’s Australia SA with the best picture possible of their lived experiences and their concerns.

The first part of the forums – ‘Out and about’ – revealed the difficulties people with dementia and carers experienced when they were out in the community. These included supermarket checkouts being “too fast and not helpful”; shop assistants becoming impatient; taxi drivers “cheating” and overcharging or being “very abusive”.

Consumers also described issues such as having to wait four to five hours in a hospital emergency department without being able to leave the person living with dementia to go to the toilet or buy food; the person with dementia becoming disoriented and getting lost in shopping precincts that were noisy and had confusing exit signs; and everyday obstacles like uneven footpaths and disability group homes “not geared toward dementia care”.

The second part of the forums – ‘At home’ – revealed there are even some negative experiences ‘at home’ including: the person living with dementia losing things such as mail and “important paperwork”; damaging household infrastructure because they no longer have handyman skills; not eating, drinking or taking medication; being vulnerable to buying from telemarketers, mail order catalogues, door-to-door salespeople and donating money to charity collectors; local council staff being unaware of available services; and the impact on carers and family.

Taking action

Consumers outlined a number of wide-ranging actions to help make their communities dementia friendly:

- Dementia education for key retail and service staff, particularly in banks, supermarkets and even smaller traders.
- One of the major concerns is the speed at which staff currently wish to deal with consumers. Consumers wanted staff to slow down and take time with the person living with dementia.
- A supervised care room in shopping centres would enable carers to get on with shopping and business without worry.
- The acceptance of companion dogs would be helpful in

shops, hospitals and other places.

- Education for taxi drivers and bus drivers would be a huge advantage.
- Day care centres need to be supported to have their own transport.
- Bus stop numbers should be provided for people travelling by bus.
- Parking drop-off zones at GP clinics and other medical facilities would enable the carer to take the person living with dementia safely inside, before parking the car.
- Service clubs could create street safety projects, for example, clearing gardens from footpaths and repairing broken paving to provide safer mobility.
- Living at home could be made easier through home assessments to reduce the possibility of harmful behaviour.
- Councils could provide more support for home maintenance and update building codes to provide for dementia-friendly houses.
- Health system

improvements sought by consumers included making people living with dementia a higher priority in emergency departments, including triage, and giving GPs greater access to specific dementia training.

- Technological assistance could include voice activation aids, equipment and appliances, developing a computer app to know where the person living with dementia is and assistance with IT in public places.

These terrific ideas and initiatives will act as a platform for discussion and form a solid base for Alzheimer's Australia SA's future decisions.

The consumers' forum opportunity

Alzheimer's Australia SA's consumer forums are designed to be as engaging as possible and start with a guest speaking of their story of living with dementia. Each forum provides information and real time updates on recent consumer engagement and the policy

advocacy activities of our organisation in SA.

Our consumers are provided an opportunity to network, discuss particular topics, raise issues important in their lives and offer practical solutions for service delivery across the wider service sector.

To date, forum topics have included people listing the most pressing issues facing them, charting the journey with dementia, the cost of living with dementia and living positively with dementia.

The benefits of the program to Alzheimer's Australia SA have been remarkable. Without doubt the forums are an excellent way to listen, learn and understand the needs of the community and form part of our ongoing consumer engagement which also includes reference, focus and working groups.

Already our online training resource *Is it dementia* has provided initial training to transport, emergency services, retail, fire, banking and correctional service workers, pushing us closer to achieving

greater understanding within the community. As we move forward we hope to see more industry groups, more services, more councils, and indeed the entire community become dementia friendly. ■

A full report of the conversations of the Dementia Friendly Consumer Forums is available on www.fightdementia.org.au/South-Australia.aspx



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