Living with dementia in country South Australia

Phil Saunders

1Alzheimer’s Australia SA

There are over 7100 people living with dementia in South Australia’s country regions. This group of consumers experience particular challenges that 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 the health and other professionals providing services for them. These numbers are expected to triple by the middle of the century, placing enormous burdens on the health and aged care sectors in particular.

There are few dementia-specific services outside of metropolitan Adelaide with most agencies providing a multidisciplinary response across a range of social issues, diseases and disabilities. These country service providers encounter a number of challenges given the diversity of their service delivery and lack of access to affordable, timely and effective dementia training.

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 October 2012, the project offered a series of focus group consultations providing people living with dementia, their families and carers, and agencies that provide services for them, an opportunity to discuss issues affecting the lived experience of dementia consumers and to explore practical ways of improving their situations.

Over 300 consumers and service providers across country South Australia participated in the consultations.

The stories of the 140 consumers who participated put a human face on the issues, translating the knowledge about their experiences with a focus on both the personal and financial cost to them of dementia. They spoke of their isolation; the lack of or limited support structures; access to health and other professionals and the differences between country and metropolitan support and services. Proposals for key actions required to improve their lived experiences centred around a greater presence by dementia-specific organisations, services and support and significant dementia awareness and education programs for the general community and in particular for health and aged care professionals.

Service providers examined their current dementia service provision and explored how to improve delivery within their existing programs and build new initiatives.

The research poses serious questions for all levels of government and for government and non-government providers in further supporting and building services for people living with dementia and their families across country regions.