GET YOUR VOICE HEARD: LIVING WITH DEMENTIA IN COUNTRY SA REPORT

PREPARED BY PHIL SAUNDERS
JUNE 2013
Get Your Voice Heard: Living with Dementia in Country SA Report

Prepared by
Phil Saunders
Policy Officer
Alzheimer's Australia SA

Published by
Alzheimer's Australia SA
27 Conyngham Street, Glenside SA 5065
Telephone: 08 8372 2100
www.alzheimers.org.au

© Alzheimer's Australia SA
ABN 36 236 331 877
ISBN 978-0-9872055-1-3

For information and advice contact
the National Dementia Hotline
1800 100 500
(NDH is an Australian Government initiative)
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FOREWORD</strong></td>
<td>5</td>
</tr>
<tr>
<td><strong>INTRODUCTION</strong></td>
<td>6</td>
</tr>
<tr>
<td><strong>KEY THEMES</strong></td>
<td>7</td>
</tr>
<tr>
<td><strong>GET YOUR VOICE HEARD: LIVING WITH DEMENTIA IN COUNTRY SA PROJECT</strong></td>
<td>8</td>
</tr>
<tr>
<td><strong>THE FORUMS</strong></td>
<td>9</td>
</tr>
<tr>
<td><strong>REGIONAL DESCRIPTIONS</strong></td>
<td>11</td>
</tr>
<tr>
<td><strong>GLOSSARY</strong></td>
<td>12</td>
</tr>
<tr>
<td><strong>DISCUSSION</strong></td>
<td>13</td>
</tr>
<tr>
<td><strong>TOP ISSUES AND KEY ACTIONS</strong></td>
<td>14</td>
</tr>
<tr>
<td><strong>DISCUSSION OF FINDINGS</strong></td>
<td>17</td>
</tr>
<tr>
<td><strong>THE COST OF DEMENTIA IN COUNTRY SA</strong></td>
<td>35</td>
</tr>
<tr>
<td><strong>SERVICE PROVIDER ACTION</strong></td>
<td>43</td>
</tr>
<tr>
<td><strong>WHAT IS YOUR MESSAGE TO ALZHEIMER’S AUSTRALIA-SA?</strong></td>
<td>47</td>
</tr>
<tr>
<td><strong>STORIES</strong></td>
<td>49</td>
</tr>
<tr>
<td><strong>PEOPLE LIVING WITH DEMENTIA</strong></td>
<td>49</td>
</tr>
<tr>
<td><strong>CARERS / FAMILY MEMBERS</strong></td>
<td>50</td>
</tr>
<tr>
<td><strong>SERVICE PROVIDERS</strong></td>
<td>58</td>
</tr>
<tr>
<td><strong>ADDENDUM</strong></td>
<td>59</td>
</tr>
<tr>
<td><strong>FORUMS HELD</strong></td>
<td>60</td>
</tr>
<tr>
<td><strong>AWARENESS OF SERVICES</strong></td>
<td>61</td>
</tr>
<tr>
<td><strong>SERVICE PROVIDER ORGANISATIONS</strong></td>
<td>67</td>
</tr>
<tr>
<td><strong>SERVICE PROVIDER ORGANISATION TYPE</strong></td>
<td>68</td>
</tr>
<tr>
<td><strong>ROLE OF SERVICE PROVIDERS</strong></td>
<td>69</td>
</tr>
<tr>
<td><strong>SERVICE PROVIDER INVOLVEMENT WITH PEOPLE LIVING WITH DEMENTIA, THEIR FAMILIES AND CARERS</strong></td>
<td>70</td>
</tr>
</tbody>
</table>
There are 7,100 people living with dementia across the rural and remote regions of South Australia.

This report is their story. It is a powerful reminder of the many challenges faced by them and their families and service providers. In giving them a voice, it shows their individual stories and explores the issues underpinning those stories.

From July to November 2012 Alzheimer’s Australia visited South Australia’s country regions, meeting with over 320 consumers and service providers in a series of forums. Others, unable to attend the forums, provided comments via email or phone.

Special consultations also took place with Aboriginal and Torres Strait Islander communities.

Alzheimer’s Australia SA staff were welcomed with warmth and openness by the participants who spoke freely, often emotionally, of their situations – their ‘lived experience’.

The forums and associated comments have provided Alzheimer’s Australia SA with valuable information for its representation of people living with dementia and their families from country South Australia; and as it explores possibilities for its own service initiatives.

I would like to thank the staff for their work on this project.

More particularly, I would like to thank all the participants for meeting with Alzheimer’s Australia SA and for their heartfelt contributions.

We can all make a difference in the lives of people living with dementia and their families across country regions by accepting and working toward the challenge that confronts us through this report. We need to consider and act upon these questions:

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

Kathryn Cunningham
CEO Alzheimer’s Australia SA
June 2013
INTRODUCTION

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.

Proposals for key actions, identified by the consumers to improve their lives, 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.

There are 25,100 people living with dementia in South Australia. Of these, 7,100 (28.3%) live in the state’s country regions.

The disease impacts many more people in these communities, including family members and 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 multi-disciplinary 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.

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

Separate sessions were held for consumers and service providers to ensure that they were equally included and heard.

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

The stories of the 162 consumers who participated put a human face on the issues, with a focus on both the personal and financial cost of dementia to them.

These consumers 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.

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

Commonalities in responses from both consumers and services providers, and from across the various regions, were observed, although some variations were expressed at the level of local experience.

1 Estimate based on ABS Population Projection 2006-2101 (Cat.No. 3222.0) using Access Economics prevalence data.
KEY THEMES

AWARENESS

Community awareness of dementia as a disease and the associated community support for people living with dementia were observed to be increasing. However stigma, particularly in small communities, remained a barrier to the timely diagnosis of dementia and the participation of people living with dementia in society.

An increased effort in raising community awareness and understanding of dementia through action at national and local levels was required.

TIMELY DIAGNOSIS

It took a long time to get a diagnosis of dementia, delaying access to appropriate support. The knowledge of consumers and medical professionals, the ability, readiness or reluctance of GPs to diagnose and access to specialists were critical factors.

POST DIAGNOSIS – EARLY INTERVENTION

It was important that information about services and assistance with access to them was provided at the time of diagnosis.

SUPPORT AND MANAGEMENT: COORDINATION AND CARE MANAGEMENT

Consumers, faced with various types, levels and availability of services needed help to get to the support they needed.

The assistance of Dementia Link Workers and service collaboration was required.

SUPPORT AND MANAGEMENT: COMMUNITY SERVICES

Services were limited in availability and scope.

Gaps included personal care for people living with dementia and programs that provided sufficient stimulation for them; support groups for both the people living with dementia and their family carers; flexible personalised respite options; and education and training for consumers on dementia and the caring role.

Greater flexibility in existing programs and increased resources for the development of support activity, improved infrastructure and greater service collaboration were required.

CONTINUING CARE, INCLUDING RESIDENTIAL AND HOSPITAL CARE

Improving the quality of life for people living with dementia in the later stages of dementia would require greater support for those living at home; improved transition between hospital and residential care including supporting the family carers; a greater number of local aged care beds; ongoing training of staff; specific dementia facilities and programs and sustaining local facilities and their community links.

END OF LIFE: PALLIATIVE CARE

Preparing for end of life and providing better support for families at that time, including palliative care for people living with dementia, required greater attention.

FUNDING

Participants wanted funding bodies to understand that rural outcomes would come at a higher cost than metropolitan outcomes. Additional allowances for rural and remote regions needed to be added to baseline funds.

There was recognition that complementary to any new monies, there was a need to find resources within existing budgets at government and agency level to meet the issues raised in this report and the actions outlined.
GET YOUR VOICE HEARD: LIVING WITH DEMENTIA IN COUNTRY SA PROJECT

PROJECT AIMS

The Living with Dementia in Country SA project will:

• Provide Alzheimer’s Australia SA with valuable information to inform its comment and representation on behalf of people living with dementia, their families and carers from country South Australia.
• Provide Alzheimer’s Australia SA with valuable information as it explores possibilities for its own service initiatives.
• Produce a summary of the discussions from each forum, provided to people participating in the consultations, which will assist the ongoing conversation in each region in meeting the needs of people living with dementia, their families and carers.

• Produce a comprehensive project report for use by Alzheimer’s Australia SA in its comment and representation as the leading advocate for people living with dementia, their families and carers in South Australia; and for wider distribution as appropriate.
• Increase Alzheimer’s Australia SA’s consumer and service provider base for future consultations.
• Provide Alzheimer’s Australia SA with a strong, authoritative voice on issues affecting consumers and service providers across rural and remote regions of South Australia as it develops state wide messages on behalf of consumers.
• Provide a range of partnership and networking opportunities at regional level.

THE FORUM OPPORTUNITY

Each forum will provide:

• Updates on recent activities of Alzheimer’s Australia SA, in particular comment and representation.
• An opportunity for personal networking amongst participants.
• An opportunity for participants to discuss particular topics and raise issues important to them.
• An opportunity for participants to offer practical solutions for service delivery and support, for Alzheimer’s Australia SA itself and across the wider service sector.
• A challenge to service providers about what their agencies could do.

Participant Comments

“Very helpful. It was the first time that I had met with people in the same boat. It answered questions that I had.”

“Everyone’s opinion was listened to and a general round table discussion ensued.”

“Very interactive workshop; everybody encouraged.”

“Thank you for the network session.”
THE FORUMS

THE IMPACT OF DEMENTIA

People affected by dementia include those living with dementia, their carers and other family members and the health, aged care and other professionals that provide services for them.

As outlined in this report, services do not match the need indicated by the numbers of people affected by the disease.

<table>
<thead>
<tr>
<th>Region</th>
<th>Subregion</th>
<th>Forum Location</th>
<th>Dementia Numbers</th>
<th>People Impacted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eyre And Far West</td>
<td>Eyre</td>
<td>Port Lincoln</td>
<td>430</td>
<td>1,614</td>
</tr>
<tr>
<td></td>
<td>Eyre</td>
<td>Whyalla</td>
<td>271</td>
<td>1,017</td>
</tr>
<tr>
<td></td>
<td>Far West</td>
<td>Ceduna</td>
<td>74</td>
<td>278</td>
</tr>
<tr>
<td>Far North</td>
<td>Far North</td>
<td>Pt Augusta</td>
<td>1,049</td>
<td>3,938</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Coober Pedy</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Quorn</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yorke and Mid North</td>
<td>Lower North</td>
<td>Clare</td>
<td>348</td>
<td>1,306</td>
</tr>
<tr>
<td></td>
<td>Yorke</td>
<td>Kadina</td>
<td>590</td>
<td>2,215</td>
</tr>
<tr>
<td>Fleurieu and Kangaroo Island</td>
<td>Fleurieu</td>
<td>Victor Harbor</td>
<td>1,020</td>
<td>3,829</td>
</tr>
<tr>
<td></td>
<td>Kangaroo Island</td>
<td>Kingscote</td>
<td>71</td>
<td>267</td>
</tr>
<tr>
<td>Murray and Mallee</td>
<td>Riverland</td>
<td>Berri</td>
<td>558</td>
<td>2,095</td>
</tr>
<tr>
<td></td>
<td>Murray Mallee</td>
<td>Murray Bridge</td>
<td>595</td>
<td>2,233</td>
</tr>
<tr>
<td>Limestone Coast</td>
<td>Lower Limestone Coast</td>
<td>Mt Gambier</td>
<td>626</td>
<td>2,350</td>
</tr>
<tr>
<td></td>
<td>Upper Limestone Coast</td>
<td>Bordertown</td>
<td>289</td>
<td>1,085</td>
</tr>
<tr>
<td>Barossa, Light and Lower North</td>
<td>Barossa</td>
<td>Nuriootpa</td>
<td>906</td>
<td>3,401</td>
</tr>
<tr>
<td>Adelaide Hills</td>
<td>Adelaide Hills</td>
<td>Mt Barker</td>
<td>562</td>
<td>2,110</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td></td>
<td><strong>7,118</strong></td>
<td><strong>26,719</strong></td>
</tr>
</tbody>
</table>

PROMOTING THE FORUMS

The forums were widely promoted at the regional level through various media including: direct mail of flyers and posters, emails, websites, carer support newsletters, e-bulletins, display advertisements in regional newspapers, several regional radio interviews and one regional television interview.

FORUMS HELD

366 consumers and service providers participated in the project from July through to November 2012. 145 consumers attended 17 forums and 176 service providers attended 15 forums.

A further 17 consumers and 28 service providers made comments outside of sessions.
METHODOLOGY

Alzheimer’s Australia SA used a focus group approach for its consultations. Open-ended questions were used to allow conversations within a core agenda. This resulted in a broad range of responses, often emotionally expressed, and strong interaction with extensive sharing of information and experience between participants.

Accompanying the conversations were Comment Sheets for the consumers and service providers and a Cost of Living With Dementia questionnaire.

Separate sessions were held for consumers and service providers.

Each session included:

**Round Table Introductions**
Participants outlined their personal or professional situations.

**Raising Awareness of Issues**
Participants provided an overview of their regions, explored the issues facing consumers and discussed whether available services met needs. This included highlighting what they saw as the Top Three Issues facing consumers in a Post-It note exercise.

**Meeting the Needs**
Participants explored what was needed to ‘fix the gaps’ in services for dementia consumers in their region. This included highlighting, in a Post-It note exercise, the Three Key Actions they considered should be provided in the region to assist consumers.

Service providers were challenged as to three key actions their agencies could undertake to assist consumers.

Participants were also invited to send a message to Alzheimer’s Australia SA.

**Comment Sheets**
Participants were provided with Living With Dementia in Country SA Comment sheets, giving them an opportunity to provide written responses complementary to the verbal conversations.

**Cost of Living With Dementia in Country South Australia 2012 Questionnaire**
Consumers were also given a questionnaire that explored the financial and emotional impact that dementia had on their lives.

Using a thematic approach, the information received through the conversations and written responses was analysed following 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
This region is struggling due to a downturn in horticulture production and the loss of vibrant businesses. Many younger families are leaving the area, leaving many older people without family support both physically and emotionally.

A one hour circle around the regional centre includes a large diverse “conservative” farming community, but soon becomes desert. It is a “great country to live in, everybody helps one another”. There are small communities; the largest with 2,600 people, with an aging population and a variety of cultural groups.

This rapidly growing region is close to Adelaide but is “neither one nor the other”, with pockets of isolation, boundary issues and a big growth in the older population.

“We live in the country: we are important too.”

There are two people/square kilometre. The regional centre is a township of 3,500, surrounded by a large number of small towns. One town is “fairly poor with lots of unemployment, lower education: a hide-away for people with mental illness and disability, but people support each other”. It is “fast becoming a region of people who come from Adelaide”.

This peninsula has “distance, a sparse population, minimal and diminishing services and is white, Anglo, agriculture, Christian and conservative”. The ‘retirement village’ population is increasing “but if one dies the other is left”.

This island has 4,500 in isolated pockets. It is a “caring community but not always aware of what is going on”: an aging population that “seems to fall just outside of everyone’s jurisdiction”.

This is a large friendly country town servicing farming communities with large distances between towns.

This area is “geographically isolated with coastal and inland towns”.

“Our voice is a little squeak when decisions are made metro centric.”

There is a growing rural city with a “small town culture” servicing small communities and farming areas. It is a low to middle socio-economic environment, poorly resourced.

These farming and fishing communities are widely dispersed across a wide geographical area, settled particularly along southern coastline.

This semi rural coastal holiday area is “a beautiful place to live with a strong community feel”. It has a high proportion of aging population, with a large increase in population during summer.

“Better than Adelaide”, with a “community feeling; protective of each other”.

This semi-arid remote region with a lower social economic, aging population is serviced by South Australia’s largest regional centre of 24,000. Most employed people work in industry, mainly mining, and services but there is high unemployment and a transient population. The culturally and linguistically diverse community is “in the age for an increased incidence in dementia” due to the surge in sponsored migration in the 1960’s – 70’s.

“If something happens to your partner you can survive better in the country.”
GLOSSARY

ACAT: Aged Care Assessment Team
ACFI: Aged Care Funding Instrument
Aricept (TM): ARICEPT® (Donepezil HCl) is a prescription medicine to treat mild, moderate, and severe Alzheimer’s disease
ATSI: Aboriginal and Torres Strait Islanders
B12: Vitamin B12, also called cobalamin, is a water-soluble vitamin with a key role in the normal functioning of the brain and nervous system and for the formation of blood
CACP: Community Aged Care Package
CALD: Culturally and Linguistically Diverse
CAPS: Continence Aids Payment Scheme
Care Workers: people who provide care support in a paid capacity
Carers: family members or close acquaintances who provide unpaid care and support to the person living with dementia.
CDRC: Consumer Directed Respite Care
CHAP: Country Home Advocacy Project Incorporated
CME: Continuing Medical Education
Consumers: people living with dementia, their families and carers
COPD: Chronic Obstructive Pulmonary Disease
DBMAS: Dementia Behaviour Management Advisory Service
DNR: Do Not Resuscitate
EACH: Extended Aged Care at Home
EACH-D: Extended Aged Care at Home-Dementia
EN: Enrolled Nurse
GEM team: Geriatric Evaluation and Management
GLBTI: Gay, Lesbian, Bisexual, Transgender, Intersex
GPs: General Practitioners
HACC: Home and Community Care
HLC: High Level Care
LLC: Low Level Care
MMEs: Mini-mental State (Status) Examination
MRI: Magnetic Resonance Imaging
NGO: Non-Government Organisation
NRCP: National Respite for Carers Program
OT: Occupational Therapist
Oxicodene (TM): An opioid pain medication used to treat moderate to severe pain through extended-release for around-the-clock treatment of pain
PATS: Passenger Assistance Transport Scheme
RAH: Royal Adelaide Hospital
RIBS: Remote Indigenous Broadcasting Service
RN: Registered Nurse
Service Providers: 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
Younger Onset Dementia: people under 65 living with dementia
DISCUSSION

An increasing awareness of dementia as a disease in the rural communities of South Australia was reducing stigma and encouraging people to seek diagnosis earlier than in the past.

However, problems with getting a timely diagnosis, limited services and barriers to getting to them, remained critical issues for people living with dementia and their families seeking support in country South Australia.

Providing more information to people living with dementia and their families, linking them to services and improving the services for them would require individual assistance and a mix of greater service provider collaboration at the local level, a re-arrangement of existing resources including greater flexibility in service delivery and additional funding.
TOP ISSUES AND KEY ACTIONS

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

RAISING AWARENESS OF ISSUES

TOP ISSUES

What are the top three issues facing people living with dementia, their families and carers in this region?

Consumers entered 245 Post-It note issues, whilst service providers entered 419 issues.

The top three issues for consumers were:
1. Support and Management: Community Services (36%)
2. Continuing Care (16%)
3. Support and Management: Coordination and Care Management (11%)

The top three issues for service providers were:
1. Support and Management: Community Services (49%)
2. Continuing Care (13%)
3. Awareness of Dementia and Assessment and Diagnosis (both 8%)

![Top Three Issues Graph](image-url)
MEETING THE NEEDS
KEY ACTIONS

What are the most important services that should be provided for people living with dementia, their families and carers in this region?

Highlight three key actions in this region that would assist people living with dementia, their families and carers.

Consumers entered 151 Post-It note key actions, whilst service providers entered 323 key actions.

The top three key actions groups for consumers were:
1. Support and Management: Community Services (32%)
2. Continuing Care (18%)
3. Support and Management: Coordination and Care Management (17%)

In comparison, the top three key actions groups for service providers were:
1. Support and Management: Community Services (49%)
2. Awareness of Dementia (11%)
3. Assessment and Diagnosis (11%)
TOP ISSUES AND ACTIONS
SUPPORT AND MANAGEMENT: COMMUNITY SERVICES

Further analysis of the Post-It note entries for the dementia journey stage Support and Management: Community Services was undertaken.

These entries were grouped under topics discussed during the forums, that is: Availability of Services, People Living with Dementia, Carers, Packages of Care in the Community and Respite.

Top Issues

Consumers entered 88 top issues identified in this stage, whilst service providers entered 204 top issues.

The top groups for the 'Top Issues: Support and Management: Community Services' for consumers were:
1. Carers (27%)
2. People With Dementia (25%)
3. Respite (23%)

In comparison the top groups for the 'Top Issues: Support and Management: Community Services' for service providers were:
1. Respite (23%)
2. Carers (20%)
3. People With Dementia (20%)
DISCUSSION OF FINDINGS

AWARENESS AND RISK REDUCTION

Community awareness of dementia as a disease and the associated community support for people living with dementia were observed to be increasing. However stigma, particularly in small communities, remained a barrier to the diagnosis of people living with dementia and their participation in society. An increased effort in raising community awareness and understanding of dementia through action at national and local levels was required.

STIGMA

Regardless of increasing community awareness and acceptance of dementia as a disease, social and emotional stigma, real or perceived, remained a huge issue, particularly in small communities, according to the participants.

In these communities where people knew each other there was “a feeling all the community knows your business”, where you had “larger chances of bumping into someone in hospital hallways” and where “people don’t talk about it”.

Denial by family members and social resistance by friends resulted in the disappearing of circles of friends and the support provided by them.

Service providers reported that engaging carers was very hard because families did not acknowledge their family member had dementia and did not seek services. They “don’t want packages even on their own deathbed”.

“These people are conservative. Reaching out is seen as a weakness.”

The issue is how to de-stigmatize dementia in small communities, to overcome the lack of awareness and understanding of dementia as an illness and to promote early diagnosis and associated intervention.

Participants, however, observed a reduction in the levels of stigma due to a greater awareness of the disease and acceptance of the individuals living with dementia.

“There is an open awareness of the person living with dementia. Even strangers in Woolies bring her back home.”

“More people are openly accepting the dementia; so we can help more.”

AWARENESS

Underpinning stigma was the lack or poor awareness of dementia in the community. There was a lack of understanding about dementia by consumers. Consumers said that they were not getting enough information or education about dementia and the signs to look for.

“Four years ago when we received the diagnosis I knew nothing about Alzheimer’s.”

Consumers were keen to make dementia “more obvious” to the community at large. They wanted an awareness of the illness and what to expect.

“Make Alzheimer’s top of mind for everyone. This information is vital.”

Service providers expressed their own concerns at the differing levels of knowledge of dementia amongst their own colleagues.
Consumers said that they 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.

“We are new to this. We want to know what to expect and how to handle the situation.”

“Ignorance is one of the problems.”

They wanted to know where to get the information and that the information was “getting to the right people”. “What can we do to get more information out?”

Participants called for an increased effort in raising community awareness and understanding of dementia. A large number of strategies for increasing community awareness of dementia were outlined, including:

- Up to date interactive website for information and counselling.
- Getting more information from the doctors when diagnosed.
- “More frequent and better” regional specific relevant dementia information sessions and open forums for families, the general community and health and other care professionals. “To ring up is a world away.”
- Visiting aged care people in their homes or aged care facilities.
- Regular visits from Alzheimer’s Australia SA for resources and information.
- A national awareness campaign; for example, advertising in country papers; “a decent TV explanation of the situation”.
- A national ‘recovering the stories’ project, including promoting positive role models of people with dementia.
- A ‘shop front’ dementia clinic in shopping centres for information (coffee shop format).
- Talks at Probus / Men’s Sheds etc to promote information sharing.
- A comprehensive step by step guide from diagnosis through to nursing homes: a poster flow chart, ‘Worried About Your Memory?’.
- Arts programs.
TIMELY DIAGNOSIS

It took a long time to get a diagnosis of dementia, delaying access to appropriate support. The knowledge of consumers and medical professionals; the ability, readiness or reluctance of GPs to diagnose and access to specialists were critical factors.

GETTING AN ASSESSMENT / DIAGNOSIS

Participants experienced getting a diagnosis of dementia as a long process. This worked against consumers receiving timely intervention including access to treatment and support for the family and carers and planning for the future at the earliest possible time.

“We need an earlier diagnosis and testing to check which stage the patient is at.”

“What about the under 65s? There is nothing for them.”

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

“We saw six to seven doctors. They come and go. Less than five have stayed long term.”

“What do you do if a good doctor moves away?”

Consumers expressed concerns about whether GPs had “to provide a service against best practice”. Suitable care by GPs should include a best practice medical treatment model; a framework to support the GPs in their treatment and diagnosis of dementia.

Consumers experienced difficulties in getting timely appointments due to GP workloads.

The time taken for a diagnosis caused considerable frustration and distress in many instances.

KNOWLEDGE / AWARENESS OF CONSUMERS

Participants reported that limited general community knowledge and awareness resulted in people not seeking help from medical professionals, in particular their GP, when symptoms of dementia initially appeared. This lead to diagnosis in mid and later stages of the disease.

More education to the wider community and to health and other care professionals was required, to enable a better understanding of what it meant to have a life with dementia; to know where to go to for information on dementia.

“The family goes to the doctor and says nothing because they feel they are ‘dobbing in’ a family member. If the doctor does not provide the information then they are lost.”

There was a role for a dementia clinic.

“We need a “Contact Person” to help the carer with the processes, support and reassurance that they are doing the right thing because assessment can be daunting.”
GP KNOWLEDGE / EDUCATION

Participants experienced varying degrees of GP knowledge and/or interest in dementia. Anecdotal evidence included GPs diagnosing depression rather than dementia, for example.

Consumers expressed the need for GPs to be more knowledgeable.

“What sort of training do doctors get?”

Carers wanted more education and training for GPs on dementia, so that the GPs had baseline information to better identify, diagnose and arrange a referral to specialists and to the support and links that were available regionally and as state-wide services.

“There needs to be more training for doctors including the supporting medication. They do not know enough. One loves to deliver babies, one loves bones, but no one loves to do dementia.”

GPs needed to have a better understanding of the impact into the dynamics of a family life with dementia, including culturally and linguistically diverse backgrounds, so that cultural beliefs were reflected in practice.

It was recognised, however, that GPs had to know a broad range of health issues and that if they had worked in a community for a long time they “got to know people”.

ATTITUDE OF GPs

Participants observed that whilst most doctors had a good reputation, being regarded as “very good”, nevertheless some were “not sensitive”.

Participants observed that GPs’ empathy, understanding and tactfulness was vital for families struggling with, and coming to terms with, a family member showing signs of dementia.

One GP practice was cited as having a policy of “in and out in 7 minutes” which raised the concern, “what about caring for patients’ feelings and emotions?”

READINESS BY THE GP TO DIAGNOSE DEMENTIA

Participants reported that a timely diagnosis relied heavily on the GP’s readiness or reluctance to diagnose; however there was a great deal of inconsistency in how the various GPs approached a dementia diagnosis referral.

“With the impending epidemic of dementia you would think that the GP was set up as the first port of call: this includes having longer appointments with the GP to discuss the possibility of dementia.”

“Here in the country, doctors know you well and say, “No it’s not that,” or words similar and you have to argue for a referral, etc.”

“I couldn’t get the GP to take serious notice about my husband’s memory, drinking ability and depression. In the end I wrote everything down and insisted it be dealt with. When diagnosed we went back to the GP who said, Yes it’s been coming on for a long time, but he never said anything.”

“Diagnosis in rural community? The long-term doctors pick it up because of community contact, for example at bowling. With the transient doctors, such as those trained overseas, there is no training on dementia.”

FOLLOW-UP INFORMATION FROM THE GP

Participants observed that following diagnosis the GP had an important role to play, indeed “a responsibility”, to be more responsive to their role as coordinator in assisting the person living with dementia and their families and carers in managing the disease and its affects and in providing information about available support services. This was particularly so in small communities where no other person fulfilled this role.

“The GP knows the personal history: must have contacts further up the line and referrals.”
OVERSEAS TRAINED DOCTORS

Participants observed that doctors trained 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 and dealing with people living with dementia. Getting out to the wider region beyond the country centres was also a challenge for them.

“Overseas doctors’ don’t know the background knowledge that someone here for twenty years knows.”

Participants recognised that overseas trained doctors needed more support “for the best outcome for residents”; including, for example, a briefing for them on arrival in the region.

SPECIALISTS

In rural areas a diagnosis took longer than in metropolitan Adelaide purely due to access to specialists - geriatricians, neurologists and psychiatrists. Nearly all were visiting, once a month, once a quarter: waiting times of four to six months were not uncommon. It invariably took more than one visit to get a diagnosis, resulting in further delays in intervention assistance.

A number of consumers identified concerns with getting the person living with dementia to a specialist, which was “frightening for them”.

One region expressed concern at the lack of planning in terms of the visiting geriatrician and related services.

“There is no succession plan for the visiting geriatrician who is elderly”.

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

POST DIAGNOSIS - EARLY INTERVENTION

It was important that information about, and assistance with access to, services was provided at the time of diagnosis.

Participants observed that early intervention undertaken immediately following the diagnosis needed to be “more than lip service”.

On diagnosis consumers wanted to be provided with information about the dementia and services, with associated referrals. Without this information they felt isolated. This was seen as a critical step in the support being provided to them.

“After diagnosis we were shown the door without any direction of how to cope.”

Consumers wanted a whole of family approach. They sought collaboration between doctors and dementia support agencies in the region; local partnerships to support early intervention and integrate people with dementia into a community based service.

Consumers wanted someone to speak to personally; to give them advice “face to face”.

Support groups actively assisting in providing information and sharing experiences could play an important role here.

“A phone call to an unknown person is often difficult.”
SUPPORT AND MANAGEMENT: COORDINATION AND CARE MANAGEMENT

Consumers, faced with various types, levels and availability of services needed help to get to the support they needed.

The assistance of Dementia Link Workers and service collaboration was required.

NAVIGATION

Participants expressed concern at the consumers’ capacity to “work through the maze of caring organisations”, in being able to access help and support easily; in navigating the pathways of support services across the continuum of care from diagnosis to end of life.

Consumers wanted pathways easily identified so they could see what support is available, who to contact for support and how to get the support.

“Knowledge – you never know what you need till you need it – where do they start?”

“What to expect? We found out about things through other people.”

Consumers expressed concern at either the lack of information about services or being “snowed under with information” but were “left to work it out on my own”.

Service providers recognised the difficulties consumers faced:

“People in rural areas don’t access the right care pathway. There is a fair share of people living with dementia. This is a challenge for us. We have to find a care worker or they have to find one.”

Recommendations for navigation support included:

• Providing one service directory that refers to, for example, Carelink, Medicare Locals.
• Giving correct information and direction to consumers.
• Providing a consistent community information service.
• A low-income landline phone helpline.

DEMENTIA LINK WORKER

“The carer needs a personal advocate to navigate the system and services to provide coordinated, timely intervention and support.”

Dementia Link Workers, dementia specialists who provided the “on the ground help” to “take people on the journey” were recognised as the most appropriate people to assist consumers to navigate the support system by providing advice, one on one support, getting access to help and linking consumers with appropriate services.

“Every region needs and should have one.”

The Dementia Link Worker could be placed at dementia clinics as part of allied health regional site office. A dementia clinic would provide:

“Access to help, advice, one on one support: A central place for people to access information on dementia; a shopfront; a memory cafe. If I have a problem and know where to go, where I know I can walk in, see someone or make appointment.”
COLLABORATION

"I'm ringing around my connections: that link is important."

Effective service collaboration was observed to vary from region to region.

Participants expressed concern about a lack of coordination between services such as the GP, service providers, the GEM team, the geriatrician, and mental health and ACAT teams where “the right hand doesn’t know what the left hand is doing”.

This 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.

“Lots of part-time staff had difficulty in networking. We are insular in what we do: do we share well – not really.”

Working well together through “Coordination, Collaboration, Communication of available activities for clients” included:

- Collaboration from a much earlier point.
- Stronger, more active relationships between service providers “to see how we can consolidate services to get more for the client”; sharing and supporting each other through collaborative projects and regional coordination:
  - “More than Adelaide services need to because in the country there are not as many resources as metropolitan Adelaide.”
- Progress in dementia working parties and community services forums.
- Creating a map of the services.
- A coordinated approach to information provision for dementia consumers.
- Regular liaison with Alzheimer’s Australia SA.
- Referrals by community health to Alzheimer’s Australia SA.
- Agencies advising each other about the services they offer so that they can impart this information to consumers.
  - “Talking to you, talking to ourselves about what we can do.”
SUPPORT AND MANAGEMENT: COMMUNITY SERVICES

Services were limited in availability and scope.

Gaps included personal care for people living with dementia and programs that provided sufficient stimulation for them; support groups for both the people living with dementia and their family carers; flexible personalised respite options and education and training for consumers on dementia and the caring role.

Greater flexibility in existing programs and increased resources for the development of support activity, improved infrastructure and greater service collaboration were required.

A REGIONAL PLEA

“As a team head how am I going to provide appropriate individual services to meet the growing need in the region knowing we are not getting increases in funding, people, infrastructure, aged care facilities. I feel it is a wish list but it is a fundamental need.

“The reality does not equate with what policy makers see or think they are going to do. What does it mean in practice? Programs do not hit where they are really needed. It needs a huge shift to make us more receptive and meeting needs. Service providers are well aware of what is going to happen. They are not being heard by decision makers. We are supposed to turn miracles. How are we going to do that?

“In our region we need $15 million on education on dementia for the community; $15 million for education to service providers in appropriate dementia care and $150 million for facilities to provide services for carers and clients.”

“Receiving the right support” included increasing the number of services so that there were no waiting periods, with a continuity of individualised patient-centred care from diagnosis to death. This included use of available and emerging technologies.

Service providers emphasised providing the service but were aware of the gaps, at both a systemic level and within their own agencies. They indicated a desire to develop appropriate locally based services.

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 because “it was too hard”; medication rounds and people living alone.

“Care at home; ageing in place. This needs individual care. Carers know best.”

Participants observed that the resources available for people living with younger onset dementia were often unsuitable for younger people.

Limited staff resulted in service providers asking, “How much time can I spend with each client?”

AVAILABILITY OF SERVICES

Participants reported a lack or limited amount of appropriate dementia specific services and resources across country South Australia. This was particularly so for people living with younger onset dementia.

Often services were “far away”.

Get Your Voice Heard: Living With Dementia in Country SA Report
Participants called for increased resources for the development of ‘shop-front’ centres where people living with dementia could go for activity, emotional and social support and community engagement, diversion therapies and for local support groups for consumers. Specific activities and programs for people living with younger onset dementia were particularly mentioned.

“Another person to talk to my wife for variety.”

“Activity that the carer and the person living with dementia can do together.”

“Someone to help the person living with dementia deal with stories, family postcards, etc who becomes aware of their needs/habits.”

CARERS

Similarly, providing the resources for the specific recognition and support of carers at a regional level was recognised as important for enabling people with dementia to live at home longer and for the maintenance of the carers’ own health and wellbeing.

Participants were particularly concerned about carer health. Many carers spoke about their depression, exhaustion and stress levels; their ability to make personal modifications and to deal with behavioural issues and their concern about the future. They had great difficulty in taking care of themselves, in saying, “I need help with...”. “Who cares for the carer? It is a lonely ride.”

Carers saw the value in education and training for themselves about dementia and their caring role, whether in a formal situation or in forums. They sought such support strategies as meeting places for family and friends; regular support groups where they could have guest speakers and share with each other their experiences; special groups for crisis care, for males and for carers whose family member had been placed in residential care; a “register of people who allow themselves to go forward to meet and chat with each other” and forums for information.

“Utilise the experience of those who have been through it before.”

“I can pop into carer support anytime, make a cup of tea and chat to someone.”

The use of technologies for getting people together and for other services was also explored.

PACKAGES

Care packages such as EACH-D, CACP and Consumer Directed Care were “giving the carer what helps most to keep the loved one at home”.

Comments centred on the extremely limited number, variety and elements of these packages. Often there was a mismatch between what the packages could provide and what they in fact provided, for example, respite instead of showering; “cleaners who will wash windows and clean shower recesses”.

“Hated this business of you can have 2 hours today, 2 hours tomorrow. Really needed a ‘9 to 4’ two times a week. Need to have a lot more consideration of the situation of the consumer.”

“What is the point of having the package if you can’t access respite beds in your own area?”

One carer outlined her needs as:

1. Cleaning my house properly.
2. Need two days respite, for example, a weekend is two whole days.
3. Someone to talk about it at the beginning.

What was required was an increase in the number of packages and in their flexibility: packages that met individual needs, with allowances for transport, high care needs and flexible time blocks.

“A person who can be booked up so that the carer knows who is coming (most times) and knows they can relate to the client; who can pop in for five minutes, not three hours, check my partner is OK and leave. If I have to go away for the day he needs either one or two five minutes checks in the day.”
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 difficulty 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.

“It is a juggle to find respite for the person living with dementia when the carer needs treatment. The person living with dementia had to go to hospital with the carer and stay in her room while she was being treated, because there was no-one to care for the person living with dementia.”

Meeting this respite need would involve greater resources through the significant development of infrastructure and greater service provider collaboration.

Service providers wanted to explore why people did not take up respite, whether this was country ‘stoicism’, or cultural or generational issues.

Participants sought flexible personalised respite options including overnight in the consumer’s home and residential care; respite for longer periods in own home; flexible outings; funded day centres; cottage facilities; short term respite including at short notice; an increase in access to various levels of respite; in home respite where both the person with dementia and the carer could stay at home when they wished; emergency care if the carer was suddenly hospitalized or sick and planned respite for high care needs.

One agency decided that 70% of the respite they would provide for the next year would go on groups. It was:

“Better that way because more people would come to that and carers could go shopping etc knowing the person living with dementia was cared for. One area has 20 people living with dementia but only two car workers.”

CARE WORKERS

Participants observed that the provision of services relied on quality staff in sufficient numbers.

Concerns about care workers included the lack of consistency in care worker personnel and a resultant lack of continuity of services; a lack of support to care workers by their agencies resulting in ‘burn-out’; a lack of information to care workers about their clients; services being confidential and respectful when giving emotional support and information; gender issues; workplace health and safety that had “gone too far” and debriefing options for those care workers working alone.

Participants wanted more funding and recruitment to allow workers to specialise in dementia care.

There was recognition that staff at all levels needed to improve and maintain their knowledge and skills to provide services for dementia consumers.

“There should be a course for everyone who deals with people living with dementia. We have to be better at what we do.”

Participants called for local specialist practical dementia workshops for staff across all levels including GPs, nurses, aged and other care workers, para-medical aides, volunteers and unregulated care workers.

There should be compulsory training for aged care and community support workers.

Barriers to providing staff training included lack of peer support for staff working alone and distances from Adelaide training providers.

“Access to education and training is difficult because of our regional location. The expense is quite significant; $7,000 to hold a training program.”

E-learning courses for care workers and support staff were also seen as useful.

Alzheimer’s Australia SA was recognised as a tertiary support resource.

“Would Alzheimer’s Australia SA have any scope to support a dementia champion?”
CONTINUING CARE, INCLUDING RESIDENTIAL AND HOSPITAL CARE

Improving the quality of life for people living with dementia in the later stages of dementia would require greater support for living at home; improved transition between hospital and residential care; greater number of local aged care beds; supporting carers with the transition from home to residential care; ongoing training of staff; specific dementia facilities and programs and sustaining local facilities and their community links.

STAY AT HOME

Participants wanted access to resources to enable the person living with dementia to stay at home longer. They recognised that this would require timely adequate 24 hour care support outside of the hospital setting.

This included the provision of ancillary services, regardless of when residential care stays took place.

“There must be a way of getting these people more help.”

HOSPITAL CARE / ACUTE CARE

Issues discussed about hospital care included small hospitals with dementia patients that had staff with a limited understanding of dementia care; patients having to go to hospitals a considerable distance from home, including Adelaide metropolitan ones; the importance of the carer being able to stay with the person living with dementia in some cases as a calming measure and the differences in attitudes and the 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.

“The staff know people before they come into the facility. They see them at the supermarket. They are smaller facilities, so they are community minded.”

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.

“As a carer I had lot of information that I shared with the facility but they were not interested; never took it on board.”

“It is less likely that elderly neighbours would be shut in if younger people were involved in helping them.”

Access

Participants reported that there were not enough aged care facilities in rural South Australia.

“They have to go out of town to get into residential care. Why? This is their home.”

“Provider can’t get approval from the council for a new facility. CRAZY!!”

Get Your Voice Heard: Living With Dementia in Country SA Report
Transition

With limited places and placements that occur 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 want to know "when to know" to put their family member into care; they needed to know about the facilities that had available places.

“When a person goes into care there is no information. People don’t know how to or what to ask. It would be useful to have an ‘expectation report’.”

“You are handing over your loved one. Aged care facilities could shake up a bit. Even a tick box report would be useful, particularly regarding aggression.”

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

Strategies for improving the transition process of moving from home to acute care 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.

Carer Role

Carers spoke about their grief, loss, sadness and guilt at placing a family member into residential care. In addition there was a reduction of financial support. They sought support.

“I felt very alone with no-one to call on.”

“I was looking after someone 24/7 for six years. It slowly deteriorated to the point where I couldn’t look after him anymore. I had to come to grips with him going into care. I felt terrible because I had made a promise not to put him into an aged care facility. At the end I felt not worth anything. I all but had a nervous breakdown after it.”

Support, either through one on one or in support groups during the transition period would be welcome. This included making decisions about residential care and in debriefing afterwards.

Carers stressed that even when the person went into full time care the caring role did not finish. They visited the aged care facility, often once or more a day, helping out or advocating on behalf of their family member, monitoring their care.

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 the appropriateness of the local facility in meeting the needs of people living with dementia included the lack of specific dementia wards and dementia activity programs; limited training of staff in particular in behaviour management; limited access to DBMAS due to resource limitations and people living with dementia on hospital beds due to a lack of beds in the dementia ward.

“The aged care facility doesn’t provide enough stimulation for people living with dementia and they withdraw. Weekends are the worst.”

“Nursing staff are busy with physical care. They are compassion rich but time poor.”

Participants sought the creation of more 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.

They wanted to see appropriate activities including music therapy; interactions with the community such as visits by school children; the use of dementia resources such as therapy dolls; social get togethers for the people living with dementia and their families and the engagement of people living with dementia in activities, for example food preparation that they were capable of performing.

“The word is CHOICES. Is the Commonwealth changing this?”
There was recognition that improving specific services for people living with dementia would require additional resources, or a re-arrangement of existing resources.

**Staffing**

Staffing levels, staffing attitude and training and staff pay all played a role in the quality of the care of the person living with dementia.

“As a nurse it impacts on me personally. I can only care as much as the employer cares for me.”

“Community nurses act over and above their mandate (country thing). If we don’t do it, no one else will.”

There was disappointment by participants at the different levels of understanding and knowledge of dementia amongst staff and care workers. Consumers sought staff with a good sense of humour, who would “walk in with smile”, who had patience and understanding and who wanted to work with dementia patients.

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 the consumers for a long time.

“Staff became family when no family is near by.”

Participants recognised the need for a greater emphasis in staff being trained in appropriate and consistent responses to dementia clients; for example, in the challenge to get care workers and nurses to manage behaviour rather than medicating residents.

“Resources for short term intensive support and education are not available (GEM type programs).”

Participants sought an increase in scholarships for aged care; funding to provide more specific training for all staff of aged care/dementia clients to improve delivery of care, including in complex and inappropriate behaviours, younger onset dementia, medication management, available services and how to contact services and new trends and treatments.

“Training is an event: change is a process.”

“Each site had a third year dementia champion who was a shining light to create ideas to make a big difference.”

**Sustainability**

The issue of the sustainability of the small facilities was discussed. Small town aged care facilities were finding 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:

“The aged care facility with 27 beds is little and unique. Big is better is not true.”
END OF LIFE: PALLIATIVE CARE

Preparing for end of life and providing better support for families at that time, including palliative care for people living with dementia required greater attention.

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; that is, advance care planning, in particular Enduring Power of Attorney and Guardianship.

Participants wanted greater encouragement of consumers on diagnosis to make pre-care arrangements before the person living with dementia lost their decision-making capacity.

Participants expressed concern at the situation in residential wings of small country hospitals where people living with dementia at the end of life were in beds side by side “in communal living” with people who did not have dementia. This was observed as confronting for families whose loved one did not have dementia and challenging in keeping staff “happy and safe”.

There was also concern that palliative care specialist services were lacking because dementia was not traditionally seen in the palliative care context. Nevertheless demand for a greater understanding of dementia consumers was increasing in this respect as people living with dementia stayed at home longer. “We are forgotten at the end of life.”

A difficulty with overseas trained doctors holding different beliefs and value systems regarding supporting families at the palliative care journey was also noted.
ACCESS AND EQUITY

The cultural barriers facing people from diverse communities, such as Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse communities are immense.

Participants observed that those with complex problems were the most marginalised.

“People with exceptional needs will not front up.”

ABORIGINAL AND TORRES STRAIT ISLANDERS

Special consultations took place with Aboriginal and Torres Strait Islander communities.

“You can’t turn your back on your family. There are not suitable places for our people in aged care facilities. You struggle with family. The family is wanting to make decisions but the white mob is making decisions for the blackfella.”

“We are needed for family support; for families to be responsible. Nursing homes neglect them anyway.”

Participants observed that the number of Aboriginal and Torres Strait Islander people living with dementia was grossly underreported. It was noted that dementia in remote Aboriginal people (Kimberley (KICA) Study) was five times the non-Indigenous rate at age 45 and three to four times the non-Indigenous rate at age 60².

Major issues included Vitamin B12 deficiency, the link between diabetes and dementia, infections and lifestyles.

Dementia Knowledge, Awareness and Acceptance

Workers with Aboriginal and Torres Strait Islander communities observed significant levels of denial, and the effects of cultural norms in which Aboriginal people do not identity as ‘carers’ and Elders don’t like the term ‘dementia’.

“They don’t want to know (don’t want to handle it).”

“The main carer is the youngest son. He doesn’t accept or admit that his 45 year old mother has dementia.”

Similar to the rest of the community there was a significant lack of knowledge of dementia and associated support for people looking after others living with dementia.

A strong desire for knowledge of dementia by the women in the community was noted. Participants wanted training about dementia and how to identify dementia from Alzheimer’s Australia SA.

Participants also expressed concern at the limited consumer awareness of services.

The Importance of Country: the Importance of Community

Participants discussed the importance of country, of encouraging people living with dementia and their families in country, of the need for help in country.

Currently specific facilities for Aboriginal and Torres Strait Islanders are “a long way from country”, leading to significant isolation from country.

“The aged care facility is the family. People come at 50 with alcohol dementia might live 20 years.”

“The whole mental thing is pulling them out of their home at Leigh Creek into an aged care facility at Port Augusta. If they live that long they deserve to do what they want.”

What was important was to communicate what people wanted; to meet needs through a community development approach, with full training for community and with community control. It was essential to consult the elders.

Specific Aboriginal Workers

Participants observed that there was a "desperate need for Aboriginal and Torres Strait Islander workers". Participants wanted intensive training for these workers, including in dementia.

Appropriate Facilities

Participants discussed the importance of specific facilities for Aboriginal and Torres Strait Islander people. "I prefer Wami Kata because it was set up specifically for Aboriginal and Torres Strait Islander people."

One facility had 50-60 residents, 80% of whom had alcohol related conditions, dementia, diabetes or head trauma. Over 20 needed care twenty four hours a day. It was noted that it "could have double the number", that these people had not been well looked after in community.

Participants recognised that even though this was an Aboriginal and Torres Strait Islander specific facility that staff needed more training, not only in dementia, but also in Aboriginal issues and cultural awareness.

Specific Aboriginal resources were in short supply.

Doctors

Participants expressed concern at the lack of cultural understanding and affiliation with communities by local GPs, in particular by overseas trained doctors.

Participants wanted suitable palliative care places in country “to go back”.

**CULTURALLY AND LINGUISTICALLY DIVERSE**

Due to limited resources this project focussed on Aboriginal and Torres Strait Islander communities. However, during the conversations a number of issues arose from participants from Culturally and Linguistically Diverse backgrounds.

Further exploration of their situations is required.

Participants discussed the issues of people from Culturally and Linguistically Diverse communities facing their own increases in dementia as the population ages, in particular those from the large migrations of the 1960’s and 1970’s.

Language and cultural norms and beliefs became increasingly important considerations for services working to meet the needs of these people and their communities.

Participants spoke about the challenges of service provision, both in the community and in ‘mainstream’ residential care.

Services needed an awareness of the dynamics in the small Culturally and Linguistically Diverse communities where people knew each other.

Services needed to be able to provide information “in the right way” so that it could be readily understood, to have “someone to speak to them” as people living with dementia reverted to original languages with the onset of dementia. They needed to be able to communicate to people living with dementia through the consumers’ children acting as interpreters but not necessarily with a comprehensive understanding of dementia.
FUNDING

“Providers pull in extra without funding. This is what country people do; help each other. But it is all underfunded.”

Participants discussed the role of increased funding and better resources combined with better targeting of existing funding in enabling the further development of services for consumers across country South Australia.

Participants wanted equitable funding between the rural and remote and Adelaide metropolitan areas. They sought allowances for transport costs across regions. They sought Commonwealth and State Government commitments to dementia action plans “to keep faith with people who give input into consultations”.

One consumer wanted to know what impact the $268 million dollars for dementia in the Living Longer. Living Better. Aged Care Reform package would have “on a local person with dementia”.

Participants wanted funding bodies to understand that rural outcomes would come at a higher cost than metropolitan outcomes. Additional allowances for rural and remote regions needed to be added to baseline funds.

There was a recognition that complementary to any new monies there was a need to find resources within existing budgets at government and agency level to meet the issues raised in this report and the actions outlined.

DISTANCE AND TRANSPORT

Participants reported that distance from services and support exacerbated rural isolation; not only distance from Adelaide metropolitan services, but also distance from regional centres.

“Getting services to the clients involved geography, distance, transport. Transport: it could be a long way to go to have a face-to-face consult.”

Distance and transport issues applied not only in the much larger regions but also in the more settled regions where there might not be a large regional centre but rather a collection of ‘scattered’ small towns.

For people without personal transport through limited funds or loss of the drivers licence this could be devastating. This could also include people living in regions next to the Adelaide metropolitan area.

Service providers wanted to be able to incorporate time to travel into funding criteria and outcomes for getting services to consumers or consumers to services. This might mean “less from the bucket for the next consumer, but people should not miss out because of distance”.

The loss of the drivers licence was a major issue for people living in country regions.

“If I see a doctor and lose my licence...but I’m the only one who drives and everyone in family relies on me.”

Consumers spoke about inconsistencies in the way people living with dementia lost their licence. This was often done in an ‘on the spot’, insensitive manner, leading to considerable distress for both the person living with dementia and their carer.

“When mum was diagnosed she got a letter advising her not to drive. She was expecting to do a driving test and was preparing herself to fail and accept that. Unfortunately it didn’t happen that way. It was so detrimental to her condition.”

“Doctors in small rural communities won’t take them off their licence because of the flack they would receive. They turn around to say, “That’s not my place”. There is no public transport so if someone loses their licence, the community does not rally, or there is no family, life virtually stops; and / or they drive without a licence.”
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.

“The nearest community car is 65 kilometres away. We have to get to that. How do you survive down on the leg of the Peninsula?”

“Transport for respite is a major issue. Workers don’t get funds for petrol. We have an Op-Shop to raise money for transport costs. A volunteer will get up at 7.30 and drive 45 minutes to the client to drive them somewhere.”

Kangaroo Island

“There are no cabs on KI. The ferry acknowledges the Companion Card but this does not cover the car. It should cover the car because of our low income. There are disability access issues regarding the boat anyway. Air transport is ridiculously expensive.”

“To get a client from the aged care facility to a funeral we had to hire a bus $60 to drive around the corner.”

“There is no public transport. People walk.”

“A significant subsidy for people to get to the mainland would make a huge difference. Make the ferry part of national highway in the same way as Bass Strait.”

Outer Urban

“Workers sometimes take people to the Alzheimer’s Resource Centre. Carers need an amount of time, but all day might be too long. It is great to have the Memory Van come to the region.”

Examples were provided where problems with distance resulted in an earlier admission to residential care than would otherwise have been expected.

EMOTIONAL IMPACT

The emotional impact on consumers included a sense of isolation and loneliness in the community from their peer group, friends and family; the person living with dementia’s acceptance of their condition and necessary changes in relationships; emotional stress and physical wear and tear on the carer; frustration for both the person with the disease and their loved ones; the fear or absolute terror people living with dementia go through of losing their self identity and being ‘pushed around’; the guilt and sadness of the carer when they place the person living with dementia in an aged care facility and the embarrassment and a growing feeling of powerless by the person living with dementia as they become increasingly unable to read and write.

FINANCIAL AND LEGAL IMPACT

Carers, in particular women, spoke about having to take on new financial responsibilities with the loss of capacity by their partners, in association with putting together the legal elements for advance care planning. In addition, living expenses had been increasing on top of the extra expenses of dementia medication, personal care and travel to medical appointments.

There was concern too about future planning in case something happened to the carer.

“Money – it all lands on me.”
THE COST OF DEMENTIA IN COUNTRY SA

CARER STORY

My name is Tracey Dickens. My husband Philip is 61 years old and was diagnosed with younger onset dementia in November 2010. We had been married for two years when Phil was diagnosed and my new role became that of a carer.

‘Carer’; such a small word, but one that carries immense love, strength and support.

FINANCIAL

We live in rural South Australia, a town called Millicent on the South East Coast about 420 kilometres from Adelaide. Our dilemma starts here because we don’t have any local specialists that deal with this illness. Visits to Adelaide for treatments and testings are both costly and time consuming.

We are fortunate enough now that we have a small car for travelling but it is still has to be remembered that the costs of running and maintaining a vehicle are never cheap.

With us no longer having a dual income you have to restructure your whole life to accommodate these changes. Budgeting becomes a priority but then we have to remember these are just early days.

What other costs are we expecting to incur in the future when the illness progresses?

Remember also if legal paperwork is not in order this can cause you an even greater headache both financially and emotionally.

EMOTIONAL

This category could also be included under financial issues too.

You feel like you are on a roller coaster ride some days, trying to keep your brain focused and dealing with what seems to be a hundred other things at the same time. There is no magic book to guide us but we do have some amazing strengths with the combined aid of Alzheimer’s Australia SA and their regional support for the Limestone Coast in Vicki Pickles; and the TQEH Memory Centre who monitor and advise on Phil’s condition and give valuable support.

This, again, I need to remind you, is Adelaide based, other than Vicki who visits us at home in Phil’s familiar surroundings.

There are days when you cry and days when you laugh, you can feel so alone but then you have to remember that the illness is here to stay so just enjoy what you can while you can and take each new day as an adventure.

A beautiful honest lady once told me “It is going to be hard for you”. Ironically it comforted me to know that I am not alone in this, many other people have and are experiencing this journey and even though it is a drain on your emotions you as a carer do come out the other side. We do have to remember carers need support.
PHYSICAL

What training is available for me in rural SA; how do I know where to go to get the information to make these contacts? What costs will we incur? We live on a two acre property. I realise this is not the norm but it takes work to maintain it.

Phil is able at the moment but when the time comes he cannot do it anymore this responsibility will fall on my shoulders along with everything else.

Yes, we are copping out early and we do have our home on the market so we can move back to the city, then the facilities and resources will be at our doorstep. With the economic climate we are experiencing we don’t hold out much hope to sell soon.

MENTAL

You do feel alone at times, and although all your family and friends are there for you, you don’t want to burden them with daily issues.

Thankfully with the Alzheimer’s Australia Helpline and the regular visits from Vicki Pickles support is at hand. I have also found friendship and comfort from other carers that I have been blessed to meet through Alzheimer’s Australia SA.

You don’t know how comforting it is to hear that something you might consider to be a silly or bizarre question is actually one that has been asked a hundred times before and they always have a common sense reply for you.

These services along with many more like them are as important in all areas but especially in the rural areas where we already feel so isolated.

SUPPORT / FRIENDSHIP

Telling people Phil had been diagnosed with dementia always prompted the response, “Oh I forget things too”. Man, I wish I had a dollar for every time someone tells me that.

Sadly people don’t know enough about the illness and their lack of knowledge of it sees them distancing themselves from us.

I have found people don’t listen to me when I try to tell them to be patient with Phil when in conversation with him; don’t confuse him with multiple conversations and always feel free to speak to him openly and if you say something that you feel is ‘foot in mouth’ disease just laugh. Phil still has a sense of humour and enjoys a giggle.

Millicent has us fairly isolated though. My sister lives in Melbourne and our family and friends live in Adelaide’s surrounding suburbs.

The closest support and friendship we have are friends 50 kilometres away in Mt Gambier. She is someone who is amazing and is someone who is always open and honest with me.

Our other friends live on a farm some 70 kilometres from us. Again, another great couple who always keep in touch and we are always visiting each other’s homes. Phil feels very useful on the farm helping them out.

We don’t have any other support locally so there is no ‘pop in for a coffee’ options available.

When it is bundled up in one neat package my story comes to highlight the disadvantages we face in rural SA. It is so important to this area and areas with similar dynamics the need for specialists, advisors, support, respite and carer support networks and 100 other things.

Don’t forget: we are all here to Fight Dementia together.

Tracey Dickens
Presentation to Cost of Dementia Consumers Forum, Alzheimer’s Australia SA, 29 November 2012.
Tracey Dickens is a member of the Alzheimer’s Consumers Alliance SA.
COST OF DEMENTIA QUESTIONNAIRE

As part of the Get Your Voice Heard: Living with Dementia in Country SA project, consumer participants were invited to complete a Cost of Dementia in Country South Australia 2012 questionnaire.

75 forms were returned; seven from respondents identifying as people living with dementia, with 68 from those identifying as family members (41) or carers (27).

Respondents were asked about the impact of dementia on their financial and personal lives, the top issues they faced and what would help them.

THE IMPACT OF DEMENTIA

Whilst less than one third (29%) of respondents indicated that the financial impact of dementia was large to very large, over a half (56%) stated that the personal impact was large to very large.

“It’s often really hard to convince people that I’m having trouble coping and that my partner actually requires the care that they do.”

![The Impact of Dementia](chart.png)
TOP ISSUES: FINANCIAL COSTS

The top three financial issues facing you.

Respondents listed 98 financial issues. The top three were Residential Care (20%), Transport (17%) and Household Costs and Income and Finances (both 14%).

In listing their concerns respondents outlined the costs of:

- **Residential care**: placement into permanent residential care, as well as supplementing activity materials, therapies and trips.
- **Transport**: travelling to access services, visits to the person living with dementia in residential care and travelling to Adelaide for consultants and treatment.
- **Income and finances**: loss of salary with the onset of dementia, or leaving work to take on the caring role and then living on limited fixed incomes.
- **Household costs**: the growing expense of household utilities on top of increased use of electricity for washing and cleaning; renovations for safety and buying different foods.
- **Medications**: for the dementia and aids such as for incontinence.
- **Respite**: care when not covered through government assistance.
- **Medical**: paying for specialists.
- **Personal care**: co-contributions to personal care services.

- **Other**: gaining information and access to services, altering clothes and paying for "my husband’s ideas".

What extra living costs do you have because you are living with dementia?

Respondents were asked to itemise their extra living costs due to living with dementia. A total of 96 items were listed, including 50 with an estimated expense per year. The 24 respondents who had estimated their expenses outlined amounts averaging $3,123, not including residential care.

Medical expenses, personal ‘home care’ and transport costs were the most common items listed.

### Extra living costs

<table>
<thead>
<tr>
<th>Item</th>
<th>%</th>
<th>Average Expense/Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aids and Equipment</td>
<td>8</td>
<td>$3,200</td>
</tr>
<tr>
<td>Transport</td>
<td>18</td>
<td>$1,515</td>
</tr>
<tr>
<td>Medical</td>
<td>25</td>
<td>$705</td>
</tr>
<tr>
<td>Home Care</td>
<td>19</td>
<td>$967</td>
</tr>
<tr>
<td>Residential Care</td>
<td>4</td>
<td>n/a</td>
</tr>
<tr>
<td>Respite</td>
<td>7</td>
<td>$2,462</td>
</tr>
<tr>
<td>Living Expenses</td>
<td>13</td>
<td>$1,800</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>n/a</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>100</td>
<td></td>
</tr>
</tbody>
</table>

96 items: Averages are based on small sample sizes of 2 to 13.
TOP ISSUES: PERSONAL COSTS

The top three personal issues facing you.

Respondents listed 139 personal issues. The top three were concerns about the carer (38%); concerns about the person living with dementia (20%) and the emotional toll (16%).

In listing their concerns respondents outlined:

- **Concerns for the carer**: having to “think for two people”, taking on the responsibility “for all decision making”, including the financial, lifestyle and social responsibility for the person living with dementia; no ‘self’ time for the carer with the “loss of freedom” and “no life of my own”; the social isolation faced by both the person living with dementia and the carer; carer exhaustion; the dementia taking over “our whole lives” and the carer wanting “quality debriefing, not a cuppa, chat and pat on the head”.

- **Concerns for the person living with dementia**: understanding the changes in character and behaviour to know “what to expect”; increasing difficulties in communication with someone who has difficulty in “remembering instructions” to who “can’t write, can’t read, can’t walk”; the deterioration in health, hygiene standards and mentally and the associated care requirements.

- **Emotional costs**: of grief at “losing the person I love”, frustration, anger, loneliness, isolation, guilt, boredom; “trying to keep my spirits up” and “providing emotional support to the person living with dementia”.

- **Family dynamics**: decreased social interaction with family due to distance and caring responsibilities and limited family support and understanding.

- **Day to day living**: shopping, cleaning, “checking food intake” and coping with household expenses.

- **Dealing with the health and aged care systems**: getting information “to know in advance what help there is”, “how to access the support when I need it” and “coping with questions that I don’t know the answer to”.

- **Respite**: getting a break.

- **Community attitude**: dealing with the stigma and the “lack of understanding from people” and gaining a “general acceptance of the illness in the community”.

<table>
<thead>
<tr>
<th>Carer Concerns</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self Time</td>
<td>32</td>
</tr>
<tr>
<td>Responsibility</td>
<td>26</td>
</tr>
<tr>
<td>Social Isolation</td>
<td>25</td>
</tr>
<tr>
<td>Exhaustion</td>
<td>9</td>
</tr>
<tr>
<td>Dementia Taking Over</td>
<td>6</td>
</tr>
<tr>
<td>Being Supported</td>
<td>2</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100</td>
</tr>
</tbody>
</table>

53 respondents

<table>
<thead>
<tr>
<th>Person Living with Dementia Concerns</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behaviour</td>
<td>32</td>
</tr>
<tr>
<td>Deterioration</td>
<td>29</td>
</tr>
<tr>
<td>Communication</td>
<td>25</td>
</tr>
<tr>
<td>Care Requirements</td>
<td>14</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100</td>
</tr>
</tbody>
</table>

28 respondents
MEETING THE COSTS

Are you having trouble meeting these extra costs / dealing with these personal costs?

Whilst less than a third (30%) of respondents indicated that they were having trouble meeting the financial costs of dementia, nearly double this number (53%) indicated concerns in meeting the personal costs.

Financial 47 respondents: personal 58 respondents

In commenting on meeting costs, respondents outlined the impact of “just not enough income to stretch”; personal sacrifices, “putting costs for (the person living with dementia) ahead of or ignoring own needs”; the difficulties in coping “especially when all bills come at the same time, ambulance, electricity, car registration, new tyres in two weeks” and limited family support and re-iterated the emotional toll and their concerns about the limitations caused by dementia.

Do you receive any assistance to meet these extra costs?

Respondents outlined financial assistance through government pensions and allowances and subsidies for utilities, personal and household care, residential care, aids and equipment and assistance with travel.

<table>
<thead>
<tr>
<th>Assistance with Finances</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Income</td>
<td>44</td>
</tr>
<tr>
<td>Subsidies</td>
<td>40</td>
</tr>
<tr>
<td>Travel</td>
<td>16</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100</td>
</tr>
</tbody>
</table>

25 respondents

Do you receive any help to deal with the personal impact of living with dementia?

Respondents outlined help with the personal impact of living with dementia through carer support with social interactions, counselling and help lines; “understanding” family and friends; respite care including regular respite and when “I have my moments and call on respite at these times”; packages of home care; medical support by the GEM team and health services and by receiving income support.

<table>
<thead>
<tr>
<th>Help with Personal Impact</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer Support</td>
<td>28</td>
</tr>
<tr>
<td>Family and Friends</td>
<td>22</td>
</tr>
<tr>
<td>Respite</td>
<td>18</td>
</tr>
<tr>
<td>Home Care</td>
<td>16</td>
</tr>
<tr>
<td>Medical Support</td>
<td>12</td>
</tr>
<tr>
<td>Income Support</td>
<td>4</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100</td>
</tr>
</tbody>
</table>

50 respondents
WHAT WOULD HELP?

What is one thing that would help you meet the financial costs of living with dementia?

Over half (58%) of the 24 respondents who indicated one thing that would help financially sought more income support, with nearly one fifth (17%) seeking additional household assistance.

They wanted the pension and allowances and subsidies for utilities, transport and medical costs increased, a "quick mainstream financial injection" and more flexible rules for income support.

What is one thing that would help you deal with the personal impact of living with dementia?

Over one third (37%) of the 49 respondents who indicated the one thing that would help them deal with the personal impact of dementia sought carer support through more respite (25%) or sharing experiences (12%) with a similar number (35%) seeking information; either information on dementia (23%) or information on services (12%).

In seeking information on dementia respondents wanted:

- Strategies for coping with behaviour, "knowing that I was doing the right thing to help and try to improve my husband's state of mind".
- Better information regarding the stages of the disease.
- Understanding "simple activities for daily living", "that my forgetfulness is not intentional".

Other support would include more help around the house, more help from family including "having my children live closer"; the "ability to take my wife, who is confined to a wheelchair, for a drive in the countryside" and "a magic wand".
### ABOUT YOU

#### I live in

<table>
<thead>
<tr>
<th>Location</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>A major country centre</td>
<td>36</td>
</tr>
<tr>
<td>A country town</td>
<td>57</td>
</tr>
<tr>
<td>Not in a major centre or town</td>
<td>7</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

#### Age of respondents

<table>
<thead>
<tr>
<th>Age</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 50</td>
<td>10</td>
</tr>
<tr>
<td>51 - 64</td>
<td>31</td>
</tr>
<tr>
<td>65 - 69</td>
<td>13</td>
</tr>
<tr>
<td>70 - 79</td>
<td>29</td>
</tr>
<tr>
<td>Over 80</td>
<td>17</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

#### Gender of respondent

<table>
<thead>
<tr>
<th>Gender</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>29</td>
</tr>
<tr>
<td>Female</td>
<td>71</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

#### Age of person with dementia

<table>
<thead>
<tr>
<th>Age</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 65</td>
<td>12</td>
</tr>
<tr>
<td>66 - 69</td>
<td>5</td>
</tr>
<tr>
<td>70 - 79</td>
<td>41</td>
</tr>
<tr>
<td>80 -89</td>
<td>40</td>
</tr>
<tr>
<td>Over 90</td>
<td>2</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

#### Do you live with the person with dementia?

<table>
<thead>
<tr>
<th>Status</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>62</td>
</tr>
<tr>
<td>No</td>
<td>38</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

#### Is the person with dementia in residential care?

<table>
<thead>
<tr>
<th></th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>22</td>
</tr>
<tr>
<td>No</td>
<td>78</td>
</tr>
</tbody>
</table>

#### Number of hours caring each week

46 respondents put a figure on their hours of caring each week for an average of 116 hours (16.6 hours per day). Nearly two thirds (61%) were caring “24/7” (168 hours per week).

#### Household income

<table>
<thead>
<tr>
<th>Source</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment</td>
<td>7</td>
</tr>
<tr>
<td>Pension</td>
<td>57</td>
</tr>
<tr>
<td>Self Funded Retiree / Superannuation</td>
<td>34</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

#### Household income per year

<table>
<thead>
<tr>
<th>Amount</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $10,000</td>
<td>2</td>
</tr>
<tr>
<td>$10,000 - $19,000</td>
<td>20</td>
</tr>
<tr>
<td>$20,000 - $29,000</td>
<td>16</td>
</tr>
<tr>
<td>$30,000 - $39,000</td>
<td>36</td>
</tr>
<tr>
<td>$40,000 - $49,000</td>
<td>8</td>
</tr>
<tr>
<td>$50,000 - $59,000</td>
<td>10</td>
</tr>
<tr>
<td>$60,000 - $69,000</td>
<td>6</td>
</tr>
<tr>
<td>$70,000 - $79,000</td>
<td>2</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Ten respondents identified as from Culturally and Linguistically Diverse backgrounds (13%).

Two respondents indentified as from Aboriginal and Torres Strait Islander backgrounds (3%).
When challenged to highlight key actions that their agency could do to assist people living with dementia, their families and carers, service providers outlined a wide range of actions that reflected the forum discussions, indicating their commitment to dementia consumers and to further developing services for them.

Highlight 3 key actions that your agency could do to assist people living with dementia, their families and carers.

Service providers, in emphasising aspects of service delivery, were aware of gaps in services, both at a systemic level but also within their own agencies. There was an openness amongst the participating service providers to the task of caring for, and ‘looking out for’ the people living with dementia, their families and carers.

There was a strong desire by the service providers to see the delivery of appropriate and adequate services at a regional level, whether by themselves, by others or in collaboration with each other.

Awareness and Risk Reduction

Awareness and Understanding

• Promoting dementia more through media
• Access to information for carers to understand how dementia is affecting their care recipient
• Provide information to our workers about the Alzheimer’s Australia Dementia Helpline to increase awareness in community and to increase support for families and carers whom they come in contact with
• Promote community awareness of dementia: bring it out into the open

Community Education

• Include a ‘healthy aging’ focus in the regional community services forum
• Training for Telecross volunteers regarding dementia
• Offer family and carer education across the region
• Have information days, education at groups / advertising
• Community education of some type
• Local education for care workers, GPs, etc
• Invite families to an information session: have brochures available
• Continue education programs with dementia focus
Assessment and Diagnosis

Diagnosis
- Early diagnosis assistance
- Provide a diagnosis for dementia sufferers

Specialists
- We are currently working towards securing the much needed specialist services

GPs
- Include dementia education specific for GPs for timely diagnosis, particularly now it is recognised as a national health priority

Support and Management: Coordination and Care Management

Navigation
- Provision of information and support to help carers through the processes
- Direct families to appropriate resources and support
- Assist carers how to access services within their region
- Case management
- Assist the community with the referral pathway

Dementia Link Workers
- Recruit a Dementia Link Worker
- Have a Dementia Care Coordinator

Information
- Provide information to families or put them in contact with Alzheimer's Australia
- Provide information and advocacy
- Provide carers with extra information on support groups locally
- Inform families of dementia focussed support
- Improve resources for case managers and coordinators to ensure knowledge of specialist services available

- Complete gap analysis of dementia services and/ supports in the region
- Local service registry
- Promote dementia services locally
- Have broad knowledge of services available

Collaboration
- Stop fighting over who should be seeing clients who are in 'grey' boundary areas
- Work with other services, agencies and GPs in the area to further facilitate clear communication and referral channels
- Develop community partnerships to support the integration of people in existing community activities
- Work with the local carer support agency to refer clients and carers

Support and Management: Community Services

Availability of Services
- Have more care workers
- Provide care support
- More dementia specialised workers
- Increased support services

Support Required
- Provide more time
- Train volunteers to better understand and support those who need our service
- Engage with carers and care recipients from the Gay Lesbian Bisexual Transsexual Intersex community who are facing or living with dementia
- Provide better support
- Provide counselling and support

Training Staff
- Access E-learning packages
- Ability, time, staff and funding to properly educate team
- Train staff: encourage knowledge building
People Living With Dementia

- Provide person centred care for people living with dementia
- Provide social support to assist people living with dementia to get to support groups and appointments

Support Group

- Provide access to guest speakers for support groups
- Start up ‘healthy mind club’ (training provided by Alzheimer’s Australia SA)
- Set up a ‘diners club’ to go out monthly over a meal for social interaction

Activities / Socialisation

- Provision of specialised dementia care, for example day care, residential aged care or in home services
- Provide more activities of interest to the individual
- Day care: onsite physiotherapy for day care, respite bed: with more funding more could be done
- Extend ‘the club’ day to include ‘medium level care’ dementia clients
- Community programs
- Increase availability to day care

Medication

- Offer medication management support

Carers

- Provide phone and home visits to support carers
- Have a trained staff member working closely with carers of people with dementia
- Be there for families

Support Group

- Provide support to assist carers to get to support groups and appointments
- Arrange a twilight program
- Help form a support group, network

Health

- Assistance and counselling for stressed out carers

Education and Training

- Provide dementia specific carer education

Packages of Care

- Trialling Consumer Directed Respite Care package: have more dementia packages
- We should provide more services for people under 65
- Provide extra funds to assist people to live in their homes comfortably (if needs assessed)
- Continue to apply for more community care packages as they become available
- Apply for Consumer Directed Care packages

Respite

- Explore case management approach for respite

Availability

- Offer respite as able and provide education and listen to concerns
- Apply for more respite care for families
- Fund extra respite support
- Expand partnerships with local providers to increase respite services

Options

- Provide overnight and short term respite support for carers
- Offer flexible respite options
- Access funding to provide more in home and overnight respite

Continuing Care, Including Residential and Hospital Care

- Improve facilities to engage better with residents
- Provide high level care facilities
- Improve safety of patients with dementia
- Provide open and caring environment

Stay At Home

- Provide a service of some kind to assist people to stay at home
Transition to Residential Care
- Support carers after admission by the person living with dementia into residential care
- Providing transitional care between hospital care and nursing home care
- Be more sensitive to the families when an intake is done

Dementia Specific
- We are building a new facility that is dementia specific
- Convert an existing area of the facility for dementia specific care
- Increase designated dementia care workers
- Increase staff hours to care for respite clients

Activities
- Provide activities for people living with dementia in acute care

Staffing
- Recruit more staff: train and up skill existing staff
- Improvement of recruitment (better incentives for skilled workers to come)
- Become more aware of best practice care for clients with dementia

Staff Training
- Ensure students have respect for the person living with dementia
- Ensure the dementia training we provide is sufficient and thorough
- Develop training to industry not just students
- Increase staff awareness of the special care needs of people living with dementia
- Provide more regular training for staff

• Education of staff (RN’s, EN’s, care workers and ancillary)
• Provide training money
• Education to include care staff, all staff, families
• Continue to work on developing a workforce that delivers quality dementia care in residential aged care facilities
• Provide education to residential aged care facilities regarding behavioural and psychological symptoms of dementia

Other
- Keep accurate records, statistics on numbers etc (if required)
- Conduct community consultations for carers, care recipients and the community in 2013 as part of the Dementia Working Party strategy

Funding
- Seek more funding from government

Distance and Transport
- Promote our transport service
- Volunteer driver and companion awareness

End Note
This is a selection to indicate the range of service provider actions outlined.

There were no entries for Post Diagnostic Support: Early Intervention or End of Life: Palliative Care.
WHAT IS YOUR MESSAGE TO ALZHEIMER’S AUSTRALIA SA?

CONSUMERS

Service Innovation and Delivery

Dementia and Service Support Awareness
- Keep informing the public: the more we know the better for everyone
- Hold more information meetings in country areas
- Would like to have an open forum so that the committee can become more involved and see the needs of people living with dementia and what they may need to look for
- More information out to the public — similar to the ‘shock’ ads in the newspapers, such as the smoking and drinking ones: asking families to help the carers
- Make people more aware in communities of what dementia is, how to try to cope with relatives who have dementia and what is available for them to assist them
- Is it possible to have a flow chart outlining the stages of Alzheimer’s from beginning to end?
- There are approximately 100 different dementias not just Alzheimer’s: focus more broadly than Alzheimer’s disease
- Focus on younger onset and publicity for very young people

Education and Training
- Training for the carer
- Can the ‘living with memory loss workshop’ be held here?

Consumer Support / Services
- Get out in the country more
- The telephone help line is fantastic
- More care for the carers required. If the carer’s health isn’t good they won’t be able to look after the person with dementia

• Encourage the doctors to listen when a partner says there is something wrong and make a referral to help afterwards: consumers should not to be left to their own devices

Consumer Engagement / Policy and Advocacy

Consumer Engagement
- Keep up the good work in going out to country areas to keep people up to date
- Great: the increased presence and delivering information and listening to responses

Policy Positions / Advocacy
- More research
- Find a cure

Representation / Lobbying
- Please lobby state and federal governments for responsible expenditure relating to community health
- More money for all the supported
- Keep up the pressure on governments, both state and national to cover all the help possible

Organisational Positioning
- Keep Ita Buttrose as Patron of Alzheimer’s Australia.
- Keep up the good work!!! Handy to know about you guys
- A wonderful organisation that is keeping people human
- How can we help you, so you can help us?
- You are seeking extra ways to help
- I have found Alzheimer’s in Adelaide VERY helpful
SERVICE PROVIDERS

Service Innovation and Delivery

Dementia and Service Support Awareness
- Continue community awareness to make the public aware of this major issue for the future: to fight for further funding
- Providing better access to information is essential
- Get the word out: increase education, decrease the stigma
- Make the community more aware about dementia increasing everyone’s knowledge
- Make sure that your national adverts do get out to rural and remote areas

Education and Training
- Keep educating the community and staff, especially doctors on dementia care, research updates and future directions
- Support and education is the key for getting people to understand and to be able to cope with situations
- Provide more training for health professionals in regional areas
- To more frequently provide education sessions relevant to country areas

Consumer Support / Services
- Provide hub offices so travel to isolated areas is not so far
- Empower carers
- To inform your family carers caring for someone with dementia to access services at a local level
- Could you provide us with training to enable us to run a ‘healthy minds club’ in our region? Or present a program here!! Let’s not reinvent the wheel
- More support needed in rural areas
- We need more services, hours, funding

Professional Support
- More help at every aged care facility: regular information, assessments and reviews
- We like the idea of a behaviour team member and educator in our region
- Behaviour, in particular aggressive behaviour, seminars including problem solving

Liaison and Networking
- Continue to have a presence in rural regions to enhance partnerships, information sharing and resources
- Develop partnerships to build capacity in rural services to deliver early intervention
- Continue to expand support in rural areas
- Continue with forums like this: excellent
- More collaboration and networking between our organisations in our region

Consumer Engagement / Policy and Advocacy

Consumer Engagement
- Thankyou for coming here and asking us for our views, thoughts and ideas
- Keep up the community engagement!! Very important messages need to be continually conveyed

Representation / Lobbying
- Continue to lobby for services in the regions
- For more research, training, funding, assistance, opportunities
- Regarding needs and providing advice, information and training to help meet future demands: a tsunami is coming

Organisational Positioning
- Without your support, who would we go to for advice and help?
- Thankyou for prompting some robust discussion
- Impressed with Alzheimer’s Australia making themselves known to the community
- Be proactive
- Keep on doing what you are doing
- Visit us more often!

End Note
This is a selection to indicate the range of messages provided.

Messages have been sorted using the Key Priorities Areas of the Alzheimer’s Australia SA Living with Dementia Strategic Plan 2014.
At the beginning of each forum session the participants were given the opportunity, as an introduction to each other and to the conversation, to tell their personal stories. A number of stories were also provided by people who made comment outside of forum sessions.

Who do they tell their stories to in normal circumstances? At the forums they indicated a strong desire to tell their stories, to outline their personal situations; to get the support they require.

It is the stories that are important: they put a human face onto the issues that the consumers raised, translating the knowledge about their experiences to focus on both the personal and financial cost of living with dementia across the rural and remote regions of South Australia.
PEOPLE LIVING WITH DEMENTIA

“It is embarrassing that I can’t remember and it is not a pleasant place to be.”

Things multiplied and I may have had dementia before that. I have been diagnosed with dementia. Physically I don’t feel sick. I’ve been forgetful but a lot of oldies are like this.

I have been a farmer all my life. Everybody thinks the job was taxing my brain. My ‘forgetery’ was improving. It has been a slow onset. When my son took over the farm I didn’t have to keep my brain working in the same way. Now it is embarrassing and not pleasant for my wife and children.

There are times when I am on top of things but suddenly there is stuff I can’t remember. I don’t know whether it was I didn’t continue with the complexity of farming. I don’t know why it went wrong. A lot of time it is embarrassing that I can’t remember and it is not a pleasant place to be. It took twelve months to get a diagnosis.

I am still trying to work out what is going on. I am not sure. I was in Africa where I had no trouble organising things. I’m going back to Africa. For me it is confusion. I’ve been quite upfront. I can’t bluff my way out of forgetting; I have to admit I can’t remember. People around here have been gracious. It is frustrating.

CARERS / FAMILY MEMBERS

“That’s what you do. I can’t chuck them away. You do it until you can’t do it anymore.”

When my grandmother got dementia I didn’t know where to go. You learn as you go. We don’t want to accept it. A stroke triggered the dementia.

My wife sees a specialist in Adelaide who always gives information on Alzheimer’s Australia including contacts. We moved here 12 months ago. We were referred to Carers SA.

I got sick and spent two weeks in the Royal Adelaide Hospital. My husband who has dementia was in respite. I was in the RAH trying to sort out respite. He ended up in hospital for the two weeks. I was readmitted at the regional hospital. He came too as there was no available respite. He then had a turn, but they revived him even with a DNR. I went home a week later and my husband died in hospital the next morning of viral pneumonia.

My mum had dementia 30 years ago. At that time there was no information and we battled along. There has been a lot of progress since.
You don’t think it will happen to you so you don’t worry about it. My husband’s diagnosis was ‘brain shrinkage’. The doctor put him on medication. I didn’t think it necessary to see a neurologist, but he ended up with extreme dementia. His medication is working. I have to push myself.

Grandad tried to gas himself to get grandma home. Granny developed early onset. Everyone was in denial. You did not feel safe there. We wanted to put her in the local retirement hostel next to the hospital. They were living 35 kilometres out of town, with a drug addict helping to ‘run’ the farm.

My husband was diagnosed twelve months ago at 73. He suffers depression. We were managing, but a number of problems tripped him over the edge. He is now on Aricept which has got him on an even keel. How aware is he? He was in hospital and went outside. He did not know where he was and he was suicidal. He was weeks in hospital before we got an appointment in Adelaide.

We had a couple of trips on the Passenger Assistance Transport Scheme but PATS have tightened up. We are fortunate we have family in Adelaide so do not pay for accommodation. We still need a letter from our private cover.

“I love doing it; but...”

My husband is in a local aged care facility. He did not have a brain scan. He has Parkinson’s related disorder. He has been in the aged care facility for 10 years. You can see him progressing into the dementia. He saw a neurologist for the Parkinson’s. The neurologist got him on medication. He has not seen the neurologist for two years.

Dad can come to the farm to visit. He is not allowed to touch anything but feels at home. The farm is thirty kilometres out from the town. If I go in and pick him up and take him to the farm, which he loves, this is 120 km in a day. I only really have two hours and I love doing it, but...

“I am aware I have to be on call.”

Something about dementia I did not expect was the personality change in the person living with dementia. Mother was the backbone of the family; you couldn’t have asked for a better mother. Her personality has changed. She was diagnosed seven years ago. Dad died two and half years before that and we reckon he was covering for it.

“It is very confronting at times. You need to confront it, not avoid it.”

I have a mother with Alzheimer’s living in a regional centre. I am seeking information. In my job I see many families with people with dementia. They have great difficulties. Mum and Dad are OK because they can still sign things.

The GP said that there was “nothing wrong with her”, when clearly something was wrong and referral was difficult.

At a personal level Mum and Dad were not wanting to confront the issue. Mum did not want her children to know. There was a very rapid decline after a couple of years.

The geriatrician said that she did not have vascular dementia. We were disappointed at the nursing staff level of understanding of dementia; the mixed knowledge amongst staff and working care staff.

Mum looks fine. She is on medication because she was getting aggressive. The aged care facility doesn’t provide enough stimulation for people living with dementia and they withdraw. This comes down to money at aged care facilities.

Mum is in an aged care facility. She is terrific for ambos to pick up. The other children are interstate and had no idea until she sold the house. She is well cared for but doesn’t know where she is. She loves singing. She can’t do anything. She did like painting, reading.

“We were going to have a beautiful life but it has been taken away from us.”
I am in it for Mum. She has no other relations.
Four years ago when the diagnosis was made I knew nothing about Alzheimer’s. I went to Alzheimer’s Australia SA and got lots of brochures. I am a member of the Alzheimer’s Australia SA Resource Centre. I learnt a lot and mother went into an aged care facility in the northern suburbs.
Then she went to an aged care facility in the mid north. She is left to her own devices; there is nothing up there. I have used the internet to download lots of music.
She doesn’t remember her children, her past or the morning. She remembers me because I see her three times a week; but she remembers the music. I get her to diversional therapy occasionally. It’s all about funding.
The biggest thing up here is that her cancer is not being treated. We would have to go to Adelaide, but are just letting her go.

“You put your life on hold don’t you? Well I had.”

I am an only child. Mum died eleven and half years ago. I did not realise dad had symptoms of dementia. After an ACAT assessment we got a bed locally. For nine and half years I was coming to visit some distance. Two and half years ago I sold up and stopped working to be close to him. It is very difficult.
I have not been able to get help. He was receiving HACC support. He is now bed ridden. He knows who I am. His family is in Queensland so I’m the only one. A lot of people say he is depressed after visiting him. He is hanging on. I can’t take him out anymore. Just being aware of the next phase of what will happen.
At one time I was told to get father to Adelaide but this was not seen as appropriate. He is not a walking man so it is all downhill. It is just a sad fact. They don’t know if he is in pain because he can’t verbalise it. I have to rely on staff, to be a cog in the way things are done. They are doing all they can. I am aware I have to be on call.

“If I wasn’t looking after my partner, I should be in an aged care facility myself.”

I have a partner with fronto-temporal dementia. It is quite difficult because he forgets and is becoming more and more childlike, with overt behaviour. I have a T-shirt with “I have dementia, what is your excuse”.

This community has good safety. The dementia return bracelet works well. We are lucky with the small community that all the police know him. My children don’t see me because I am “not the same dad”. They are missing out.
If I was “heartless” I would “wack her into a home”. The children say dementia does not exist so they don’t have to deal with it.
The person living with dementia has got co-morbidities. I am 80. I have been driving people around for fifteen years because they won’t do it. If I wasn’t looking after my partner, I should be in aged care facility myself.

We live in small community. After a health scare it took nine and a half months to have the dementia recognised as an issue and I have a health background.
This is safe environment for him. I believe in forward planning. I have to fight for him. I am moving to be closer to support services; the community care bus and community health. We need some funding to keep that happening.
Yorke Peninsula has one of the best community transport scheme services in SA. A lot of people don’t know about it. We are fighting to keep it running. You can’t put people living with dementia, particularly in later stages, on a bus. You can’t be out in public so how to get to health services and help? They need community transport.
“Now I have got to do everything.”

My partner and I have known each other for twenty years. After our respective partners had passed away I had rung my now partner to ask her what she was eating. I started calling her over to my place, a couple of miles away. I got to see that she lost interest in her life.

Not long after that my partner had an accident getting the mail, but she didn’t know what happened. Things got worse. After lunch that day she did not look well. Sitting down she said, “Who are you?” This rang alarm bells. Now I have got to do everything.

The nearest community car is 65 kilometres away. We have to get to that. How do you survive down on the leg of the Peninsula? I’d like to see more of the community car. Down in the southern area there are a lot of people with dementia that don’t have a diagnosis and haven’t chased it up. We need more awareness through GPs.

There are helpers down there. My partner goes to a group four hours a week. It is very confronting at times. You need to confront it, not avoid it.

We met about eight years ago. We had started a little group of people who were on their own and that’s where we met each other. We are together on a daily basis. We live between two major centres.

We used the community bus to go to Adelaide. It was wonderful but we had to drive to a major centre to get to it. The expense of the car is a financial burden.

Both our families are interstate. They are all supportive and talk about it openly because it is better that way.

People living with dementia need dignity and consideration. If need be I will move in with the person living with dementia. We have a very good doctor in one town further away. We had an altercation with the local GP.

At times when he says he “feels confused” this might be dehydration. He knows he has a back up with me so is conscious of looking for signs. He is also using vitamins for memory.

One incident was when we went to Kangaroo Island. He was alright but he thought he was going to the car but he was going to a cliff.

In seven half years we have had eight GPs!! I have trained the person living with dementia to go to different people. As we go through the whole thing with new doctors I should put it on tape.

I am sort of hoping that when the person living with dementia needs to be hospitalised he can go to the town where he has his own GP.

“The whole journey was pretty horrible.”

My husband was diagnosed two years ago. This was a man doing everything to now not able to read much. He has got to be doing something. He plays bowls. He is losing his outgoing nature. We cope. We have been offered lots of help from friends, neighbours and the local health centre. We don’t need help now, but that time will come. I’m his security blanket. As long as he’s alright I’m alright.

“She was very active but now virtually does nothing. It’s just very sad.”

The people here are my community. I am involved in the auxiliary and hospital board. A few weeks ago I was doing something to help people living with dementia at an aged care facility. I went to nurses at the aged care facility and asked, “Can we get a conference, get people to come today”. People need to know what to do. My friend’s dad lived with it for ages but didn’t know other people had it.

Mum lived alone for a long time. She was incredibly deceptive at covering her dementia. She lived with us for five years prior to moving into the aged care facility. I communicate with her by singing songs.

I was unaware of the assistance available and what all the help I had been giving her had done to me. I had to get them to reassess her to prevent her going into low level care: she needed high care. This was very hard to do. A lot of ACAT questions are yes/no and are easy to cover. It was awful to have to say, “No, mum needs high care”. I felt I was undermining her.
My partner was diagnosed with dementia. My partner’s journey has been long. He would like to maintain his integrity. We now have care workers and assistance in the house.

We have had difficulties with services particularly with the health centre and GEM team assessment. We attended a local carers meeting but this was a disaster. We have issues with respite when attending programs.

The Alzheimer’s Australia SA Living With Memory Loss program was very helpful as it informed us about programs and services. A Link Worker in the hills would be invaluable.

“I am tired; it is like having a newborn.”

My husband has been on Aricept. I have attended workshops run by Alzheimer’s Australia and have received plenty of information and help.

My husband and I live in walking distance of a care centre, the local hospital and x-ray centre, our GP and the after care surgery, so consider ourselves very fortunate to be close to these facilities.

My husband is willing to attend the community garden at the Health Centre on Tuesday morning, day care Wednesday and Friday and the men’s health group Thursday morning. We have a care worker two hours three days of the week and four hours Thursday so at this time as a carer I do have respite.

I attended a fitness group run by the Health Centre for twelve years. I do not attend now as I volunteer days my husband goes to day care. I attend support groups for carers of people with dementia which I find very supportive.

I’m giving you all this information to let you know how much help the Health Centre has been to my husband and I. I do realise this help is because I have had contact with the Health Centre for a long time and received lots of information.

My husband and I consider the help we get financially at this time very helpful as my husband’s social activities are more than they used to be and of course this will continue as long as he is able to attend them. Also the discounts we get through the government.

“Sorrow is a significant emotion.”

My husband had a fronto-temporal lobe dementia diagnosis. He keeps active with activities (model trains, photography, paints, etc). He used to be actively engaged with Alzheimer’s Australia SA. There is a life after diagnosis! The main issue is distance. We live in a town away from the main centres and transport is a problem.

“I was unaware of the assistance available and what all the help I had been giving her had done to me.”

I am tired; it is like having a newborn. I am stressed. I have frustration, anger and difficulty in modulating emotional reactions to situations with person living with dementia.

He does not have a diagnosis – this is a source of frustration. No-one is brave enough to call it dementia. The doctors call it ‘memory loss’ and ‘depression’. You almost wish things would progress so you don’t hurt the person with disability. I feel guilt about his condition, wanting things to get worse.

He had a knee replacement a few years ago and the anaesthetic really knocked him around mentally and physically. A second operation was worse than the first in terms of recovery.

I am very stressed about my own health issues, the upkeep of the household and I am not sure what would happen with the person living with dementia. He has no awareness of dementia and the situation. He is getting through mini-mentals so they are no help.

I got in touch with the local carer support. They were saviours. I linked in with people to talk to: support groups and respite. This was very helpful.

There was a very quick diagnostic process with the GP for my husband. My husband has insight and is happy to attend functions. I attended an event with my husband which was very good and it was great that it was local. We get good support through the Health Care Service.
My husband is in residential care because we were not able to get respite services. He was diagnosed nine years ago. He was treated for a number of other conditions before the diagnosis of dementia. He had a scan ten years before the diagnosis but it was not recognised then.

He is totally dependent. The nursing home does a good job but you need to check up on them.

“A good thing is that every day is a new day! There are no grudges. I can yell my heart out and it is forgotten the next day.”

I have a consumer directed care package. I knew I had a procedure coming up so I booked the person living with dementia into respite. The only respite she could get was an hour’s drive away. This involved a lot of preparation and organisation.

The person living with dementia had issues with his eyes (I was not aware he was taking contacts out constantly) which caused many problems. I had a breakdown. I got in touch with the local dementia link worker who organised emergency respite but once again this was too far away. What is the point of having the package if you can’t access respite beds in your own area?

With my own health issues it is a juggle to find respite for the person living with dementia when I am unwell and need treatments. I have to arrange for others to support me at this time. I arranged an episode of respite in the person living with dementia’s home, but this resulted in an overdose as he forgets what he has taken. So I had to install a locked cupboard in the house.

I get some help from the council as well as care package entitlements.

I went on a carers retreat which was good. I had time to reflect and think.

I want to travel in the future but I am not sure who will look after the person living with dementia.

“I’m his security blanket. As long as he’s alright I’m alright.”

“I go to bed early and the person living with dementia goes to bed late. I tell him the incorrect time of night: ‘loving deception’. I say, “Look at the time, it’s 12 o’clock” when actually it is 9 o’clock. I also use this technique in terms of driving. I hide the keys so that he won’t drive.

I have my own health issues. I needed to call an ambulance but there was no-one to care for the person living with dementia. He had to go to hospital with me and stay in my room while I was being treated. He was very agitated in the hospital. This is a gap in the system. He was very agitated because I was sick.

A good option would be having respite at home for the person living with dementia. I have had respite through the GP when I have been sick in the past. My big worry is that I will get sick in the future and that this will have a great impact on the person living with dementia.

We have respite through an EACH package. It is hard because you are not sure about how much you are entitled to. This is difficult.

The EACH-D package would not be useful because the assistance is Adelaide based.

“We are looking after each other. If I get up in the morning and we are alive, we live the day out.”

I am concerned for the person living with dementia’s reputation in the town. He was a pillar of society. I want to protect this and not let people see his demise.

We are ‘shut in’ with limited social contacts.

We had a family conference which was very valuable. The family has seen the person living with dementia deteriorate. The doctor spelt out what the future might hold. You need to prepare for the future. The family conference provided a witness and put everybody in the picture. The family asked many questions. Intellectually they understood dementia but they didn’t really understand what it meant in practical terms.

It is difficult to plan the future; for example, should my daughter move in for twelve months next year to help out?
“I now need to make all decisions. I am not frightened to make ‘executive decisions’.”

The person living with dementia resigned as a piano teacher because of the dementia. We got the diagnosis after hammering the GP who said he was OK. There were lots of things we noticed. We started going to the GP, who said, “Ah well, we can do a cat-scan and maybe an MRI” then discovered quite a few things out of place.

We moved to an independent living unit in the Barossa. We received lots of support in the Barossa from Carers Link.

He is in high care respite but should be in low care. The Lutheran home is brilliant. It was wonderful to get the respite. There is not enough funding for respite, not really enough respite beds locally.

We are worried because of the funds needed to keep people in their own home. What happens when I can’t look after them? You get so tired and the dementia is only low care yet. I have got all this information. What worries me is the practicalities of care in the home when it becomes inadequate and he really needs a residential care place.

Mum had dementia. She was diagnosed in 2004. We changed specialists in 2011 and the diagnosis was formalised.

We are struggling to work around the maze to get support. This is not like cancer. How do you get to people living with dementia to make their journey easier for everyone? We have a good relationship with the GP. We couldn’t fault the ACAT assessment person.

The government has a role to play in particular in seeing country regions have beds. Care packages are only bandaid. You do not get the psychological support needed through packages.

“It is useful to talk through things. I do need someone to talk things through with.”

My sister has younger onset dementia at 56. My dad had younger onset dementia so I have seen it before. There is very little for younger onset dementia. We do not need residential care. The only place nearby is in the Adelaide metropolitan area an hour’s drive away. I don’t think there is anything specific for younger onset dementia. I am a member of the Alzheimer’s Australia SA Connexus program.

We have family support. There is a lack of special support. This missing link is a social worker working alongside the GP.

Following diagnosis the GP asked us back. The first thing he did was immediately cancelled my partner’s licence, saying, “You are not allowed”. I hadn’t driven for 40 years.

My partner goes to day care Monday and Tuesday morning; there is ‘carers coffee’ at Nuriootpa on Wednesday and Men’s Shed Thursday.

I am getting to the stage where I do not like being on my own.

“Mum declined rapidly. It was a rude awakening.”

He was an absolute leader but now can’t trust himself. He is so physical and gets on his bike; but there is no credible escape.

I moved to the regional centre to look after mum, who received the diagnosis twelve months ago. I am here to learn as much as possible about the disease; how to help mum. She knows it is a problem for her.

We are flying by the seat of our pants. It is important to talk to other people and learn about the stages of dementia. What can you say, or not say to avoid upsetting? This is a learning phase. Mum does not talk about her journey because she is a proud person.

When she received the diagnosis she lost her drivers licence (could have been done differently) and lost her independence. We are learning how to make her life bit happier. There has been an impact on us dovetailing into her routines.
“I am hungry for knowledge to keep mentally on the ball.”

My husband started with short term memory loss and progressed. We are starting on patches because the original medication affected him. His licence went following a negative response to the question, “Do you feel safe with him?” He has got back into gardening. There are a lot of things he has forgotten; arithmetic, his signature. I have long moments on my own wondering how I would cope. I have to stop what I’m doing to look after and monitor the person with dementia.

How useful a position dedicated to helping diagnosed people through the local services would be. When my partner was originally diagnosed we were living in country New South Wales. The Health Service had a team of two, a social worker and a registered nurse who provided such a service to all people diagnosed with Alzheimer’s in a large area. We were referred to them by the hospital before a diagnosis was confirmed.

The social worker and registered nurse were excellent in discussing the situation, giving me information, telling me about local services, good doctors, specialists, Centrelink everything. They were able to undertake MME’s and other memory tests on behalf of GPs and specialists and were known to the visiting Sydney specialists. They came to visit us at our home several times and were available for advice and help throughout the whole ‘journey’.

They also helped other people with arranging regular care, emergency respite and eventually placement in nursing homes. I had their mobile number for emergencies and their email addresses and it certainly helped ease the stress immensely.

He got sick two years ago last Monday. He had got lost around the river. He went gathering rocks and lost his way. It was downhill from there. He had never had a day sick in his life. We found it terribly hard to accept at first. When he got lost at Berri the first thing I thought about was that at 46 a clairvoyant told me I would be a carer and it would be very unhappy for me.

“I work in aged care and know the processes so if I am frustrated with the system then I cannot imagine what a community member goes through.”

I am a carer of both my parents in a small country town. My father is 80 with dementia. My mother is 76 with multiple health issues. They believe that you keep things private. They:

- Are reluctant to get support
- Don’t want to make a fuss
- Keep battling on
- Are worried they will be put in a home if they say they can’t cope
- Have depression and anxiety
- Have a lack of sleep
- Are on the Carer Payment
- Are scared

Doctors need to be more aware of dementia and offer more support for the carer; look at the well being of the carer and make decisions; tell the person that this is what needs to happen and start helping to get respite, home support, ACAT and the Carer Payment.

We need a ‘Contact Person’ in the region, who helps the carer with the processes, support and reassurance that they are doing the right thing.

Nursing staff need to have more understanding of what is available for a dementia client in hospital, including training in how to best deal with dementia (agression, delusion, confusion), getting help to help care for the dementia client.

I find as a family member there is only so much you can do as I am working, with family commitments and health issues.

I have dealt with situations when my father has been in hospital including:

- The hospital ringing at four in the morning to come and get dad as they can’t control him
- Staff wondering if he is a drinker
- Nurses crying when he has verbally abused them
- Nurses who can’t control his agitation
- Staff expecting family to look after him while he is in hospital
- Rudeness to my father and family
- Staff not informing our family what is going on with his care
“I am so flat with no energy for anything. I am getting to the stage where I do not like being on my own.”

I am sorry I got rid of my licence. I cope with great difficulty because my husband is not able to drive. Some days it is easy to manage but others it is not. He cannot come into shops.

My sister helps but this is limited as well. She is 75 with a licence. The man in the next street helps with shopping and the paper. We went to school together.

She was quite the horse woman. She was the first female strapper in West Australia. She rode a horse and cart from South Australia to West Australia and she taught art. We are very happy. There are lots of people ringing up to see how we are. I was offered respite and full time care but turned them down. It takes about three quarters of an hour to feed my wife.

“It was a mine field to work everything out. Carers need help.”

**SERVICE PROVIDERS**

“As an example of rural people knowing rural issues, there was a gent ‘running riot’ in the dementia unit. He wanted to milk cows. I went in with wellies and told him that the milking had been done. He settled straight away.”

I am unofficially an acute care link nurse for the local area because of my experience. GPs would ring me. We need a uniform or specific role in every acute hospital to help people find places, for example, EACH places when the time comes; an awareness of the options. Families come in and say, “Help us to know what to do”.

Memory loss is a concern. I have friends with memory loss. Many people are on their own with memory loss. You make an offer of assistance but the family says, “We don’t need help right now”; “as long as I’m with him it’s OK”.

I am undertaking Cert 3 Aged Care to be a better ambo. There are psychological impacts of answering a call from people living with dementia. I could do better. Dementia is not something we focus on as an ambo but I am learning about dementia to be more effective. As an ambo I go into someone’s house. The couple will compensate as a couple. They are really upset, then, if you separate them to transfer one to hospital. What happens to the one left behind, either the person living with dementia or the carer?
366 consumers and service providers participated in the project from July through to November 2012. 145 consumers attended 17 forums and 176 service providers attended 15 forums. A further 17 consumers and 28 service providers made comments outside of sessions.

<table>
<thead>
<tr>
<th>Region</th>
<th>Date</th>
<th>Town</th>
<th>Consumers Attend / Comment</th>
<th>Service Providers Attend / Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lower North</td>
<td>31 July</td>
<td>Clare</td>
<td>2 / 1</td>
<td>11 / 1</td>
</tr>
<tr>
<td>Yorke</td>
<td>1 August</td>
<td>Kadina</td>
<td>6 / 2</td>
<td>6 / -</td>
</tr>
<tr>
<td>Far West</td>
<td>14 August</td>
<td>Ceduna</td>
<td>4 / -</td>
<td>1 / -</td>
</tr>
<tr>
<td>Eyre</td>
<td>15 August</td>
<td>Port Lincoln</td>
<td>11 / 1</td>
<td>8 / 1</td>
</tr>
<tr>
<td>Eyre</td>
<td>16 August</td>
<td>Wudinna</td>
<td>-</td>
<td>15 / -</td>
</tr>
<tr>
<td>Eyre</td>
<td>21 August</td>
<td>Whyalla</td>
<td>5 / -</td>
<td>19 / -</td>
</tr>
<tr>
<td>Far North</td>
<td>22 August</td>
<td>Port Augusta</td>
<td>- / 1</td>
<td>6 / 6</td>
</tr>
<tr>
<td>Fleurieu</td>
<td>28 August</td>
<td>Victor Harbor</td>
<td>22 / -</td>
<td>10 / 10</td>
</tr>
<tr>
<td>Kangaroo Island</td>
<td>30 August</td>
<td>Kingscote</td>
<td>13 / -</td>
<td>7 / -</td>
</tr>
<tr>
<td>Limestone Coast</td>
<td>6 September</td>
<td>Mt Gambier</td>
<td>13 / 4</td>
<td>23 / 2</td>
</tr>
<tr>
<td></td>
<td>7 September</td>
<td>Bordertown</td>
<td>13 / 4</td>
<td>8 / -</td>
</tr>
<tr>
<td>Murray Mallee</td>
<td>13 September</td>
<td>Murray Bridge</td>
<td>2 / -</td>
<td>10 / 5</td>
</tr>
<tr>
<td>Iron Triangle:</td>
<td>24 September</td>
<td>Port Pirie</td>
<td>3 / -</td>
<td>1 / -</td>
</tr>
<tr>
<td>Aboriginal And Torres Strait Islanders</td>
<td>25 September</td>
<td>Whyalla</td>
<td>6 / -</td>
<td>3 / -</td>
</tr>
<tr>
<td></td>
<td>25 September</td>
<td>Port Augusta</td>
<td>-</td>
<td>1 / -</td>
</tr>
<tr>
<td></td>
<td>26 September</td>
<td>Port Augusta</td>
<td>-</td>
<td>1 / -</td>
</tr>
<tr>
<td></td>
<td>26 September</td>
<td>Port Augusta</td>
<td>7 / -</td>
<td>2 / -</td>
</tr>
<tr>
<td>Barossa, Light and Lower North</td>
<td>2 October</td>
<td>Nuriootpa</td>
<td>8 / 1</td>
<td>6 / 1</td>
</tr>
<tr>
<td>Riverland</td>
<td>4 October</td>
<td>Berri</td>
<td>3 / 2</td>
<td>5 / -</td>
</tr>
<tr>
<td>Adelaide Hills</td>
<td>9 October</td>
<td>Mt Barker</td>
<td>11 / 4</td>
<td>12 / 1</td>
</tr>
<tr>
<td>Far North</td>
<td>7 November</td>
<td>Quorn</td>
<td>3 / -</td>
<td>2 / -</td>
</tr>
<tr>
<td>Statewide:</td>
<td>8 November</td>
<td>Leigh Creek</td>
<td>13 / -</td>
<td>1 / -</td>
</tr>
<tr>
<td>Aboriginal And Torres Strait Islanders</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Statewide</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Greater Adelaide:</td>
<td>13 November</td>
<td>Bowden</td>
<td>-</td>
<td>18 / -</td>
</tr>
<tr>
<td>Aboriginal Metro Mob</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sub - totals</td>
<td></td>
<td></td>
<td>145 / 17</td>
<td>176 / 28</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td>366</td>
<td>162</td>
</tr>
</tbody>
</table>

Notes:
- Wudinna: West Coast Community Services Forum.
- Aboriginal and Torres Strait Islanders Port Augusta included interviews with staff of Northern Country Carers and Wami Kata Old Folks Home.
- Leigh Creek included discussions with the Full Council of Aboriginal Elders of SA.
- This chart shows numbers at each location rather than by session because there was some crossover of carers and service providers, identified where possible. In Ceduna, Quorn and Leigh Creek there was a consumer session only: in Wudinna, Pt Augusta (22 Aug) and Bowden there was a service providers session only.
# AWARENESS OF SERVICES

What services are there in this region for people living with dementia, their families and carers?

<table>
<thead>
<tr>
<th>REGION</th>
<th>CONSUMERS</th>
<th>SERVICE PROVIDERS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>RIVERLAND</strong></td>
<td>• Hospital bus</td>
<td>• Carer support groups including specific dementia group</td>
</tr>
<tr>
<td>Berri</td>
<td>• CAPS 4 hours</td>
<td>• National Respite Care Program</td>
</tr>
<tr>
<td></td>
<td>• EACH-D 12 hours</td>
<td>• North South Dementia Action Plan</td>
</tr>
<tr>
<td></td>
<td>• HACC group at Barmera Community health</td>
<td>• Dementia Working Party</td>
</tr>
<tr>
<td></td>
<td>• Carers SA: courses covering stress and ways to deal with dementia; carer retreats</td>
<td>• Specific dementia units at Bonney Lodge</td>
</tr>
<tr>
<td></td>
<td>• Information included a list of geriatricians</td>
<td>• Small group respite program for carers</td>
</tr>
<tr>
<td></td>
<td>• Day activity</td>
<td>• Once diagnosed linked more specifically to GEM team: GEM team with a geriatrician attached: all visiting: clinics once a month: GEM team do a lot of falls work</td>
</tr>
<tr>
<td></td>
<td>• Home assistance: laundry, cleaning, showering, ironing</td>
<td>• Counselling</td>
</tr>
<tr>
<td></td>
<td>• Meals on Wheels</td>
<td>• Aged care services including HACC, CACP, activities, Men’s Shed</td>
</tr>
<tr>
<td></td>
<td>• Alzheimer’s Australia SA Living With Memory Loss training</td>
<td>• Loxton community health para-health aid – support people at home with illness; support the carers – medication checks, meals and eating checks, continuum of care, falls risk monitoring</td>
</tr>
<tr>
<td></td>
<td>• Parkinson’s group</td>
<td>• Boandik</td>
</tr>
<tr>
<td></td>
<td>• Cancer group</td>
<td>• Commonwealth Respite and Carelink Centre: care co-ordination through service providers: emergency, planned respite</td>
</tr>
<tr>
<td></td>
<td>• Dementia Helpline</td>
<td>• Carer house for respite available</td>
</tr>
<tr>
<td></td>
<td>• Companion Card</td>
<td>• Carers SA: carer retreats; carers education team re: dealing with stress; working carer retreats; carers counselling</td>
</tr>
<tr>
<td></td>
<td>• Toilet map</td>
<td>• Committed staff</td>
</tr>
<tr>
<td></td>
<td>• In home support up to high care packages: contacting local community services</td>
<td>• Community home care services, CAPS, EACH, EACH-D, CACP</td>
</tr>
<tr>
<td>LOWER LIMESTONE COAST</td>
<td>• Boandik community services, including extended care, care for people in their home</td>
<td>• Community respite house Naracoorte</td>
</tr>
<tr>
<td>Mount Gambier</td>
<td>• Community aged care packages</td>
<td>• Day Care Centres: Sundowners Group, Boandik. Day programs at Mt Gambier Millicent, Penola, Boandik, Naracoorte, Bordertown, Keith</td>
</tr>
<tr>
<td></td>
<td>• High care extended aged care package at home 22 hours per week (podiatry, physio, incontinence)</td>
<td>• GEM team, limited access to geriatrician: teleconference facilities for specialist team</td>
</tr>
<tr>
<td></td>
<td>• GP: contact for services available for sufferer</td>
<td>• Lifeline daily telephone service</td>
</tr>
<tr>
<td></td>
<td>• Community Health care services</td>
<td>• Lot of services, but scant on the ground</td>
</tr>
<tr>
<td></td>
<td>• Single flyer with all local contacts and numbers available for assistance and support</td>
<td>• National Respite for Carers Program: up to 3 hours per week: planned in home, out of home respite</td>
</tr>
<tr>
<td></td>
<td>• Resthaven home care</td>
<td>• Nursing care</td>
</tr>
<tr>
<td></td>
<td>• I am still trying to get information and support. Early days for me</td>
<td>• Dementia Project Officer available for advice to Resthaven staff</td>
</tr>
<tr>
<td></td>
<td>• Alzheimer’s Australia: Vicki Pickles</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Day centre at aged care facilities</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Aged care facilities</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Information services (limited)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Respite care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Supported care and accommodation</td>
<td></td>
</tr>
</tbody>
</table>
| UPPER LIMESTONE COAST | • Red Cross transport  
|                      | • Residential care  
|                      | • Residential respite – permanent, short term  
|                      | • Resthaven  
|                      | • Remote Indigenous Broadcasting Service  
|                      | • South East Regional Community Health Service  
|                      | • Social Support Services  
|                      | • Specialist from Mt Gambier going to Bordertown to set up telelink with GPs  
|                      | • Telecross  
| Bordertown           | • South East Carers: retreats  
|                      | • Community Health  
|                      | • Activities  
|                      | • Community bus  
|                      | • ‘Blokes’ day out’, ‘women’s day in’ activity centre  
|                      | • Respite services  
|                      | • Quite a few people are in hospital and we have a lock up area for wanderers  
|                      | • Resthaven  
|                      | • ACAT  
|                      | • CACP, EACH, EACH-D  
|                      | • Day activity centre  
|                      | • GEM  
|                      | • Social work  
|                      | • Home help  
|                      | • Community health services, government and private  
|                      | • Meals On Wheels  
|                      | • Low care residential respite  
|                      | • Four local GPs  
|                      | • Palliative care team  
|                      | • Community Health services  
|                      | • Passionate people who care about their fellow person  
|                      | • Aged care providers (residential, hospital and community)  
|                      | • Boandik Lodge  
|                      | • South East Regional Community Health Service  
|                      | • Carers SA: carer support group; guest speakers; carer retreats: social, stress management, legal stuff: Bordertown group shortly  
|                      | • Consultant psychiatrist  
|                      | • Community support services  
|                      | • DBMAS  
|                      | • Respite House in Naracoorte (emergency only)  
|                      | • Advanced Care Planning  
|                      | • Bordertown a hub  
|                      | • Commonwealth Respite and Carelink Centre  
|                      | • Teleconference service with specialist care; mental health videoconferencing  
| FAR WEST             | • The Pines – Elliston Hospital  
| Ceduna               | • Elliston has a 15 bed residential care facility. 80% have dementia.  
|                      | • Community Nurse  
|                      | • Carers SA: Eyre Carers for support for the person (family) who lives with the sufferer  
|                      | • UnitingCare Wesley  
|                      | • Residential aged care facilities  
|                      | • Community packages – a few in a large area  

### MID NORTH

**Clare**
- Cara House
- Some of local hospitals have beds run by local health
- Mix of providers
- None that I know of
- Respite house at Clare
- Helping Hand at Port Pirie and Clare well regarded aged care facilities
- St Joseph’s in Port Pirie

### YORKE PENINSULA

**Kadina**
- I am not aware of any services in my region. Possibly there is a carers group which I intend to follow up on
- Alzheimer’s Australia SA has family oriented program
- Community bus to Adelaide
- HACC car
- Support group four hours a week
- Community care bus and community health
- Community transport scheme
- Carers Link Yorke Peninsula: being encouraged to use them as a de-briefer
- General Practice doctors
- Community care
- Community car
- Respite care
- Unknown
- Carers Link and CHAP
- UnitingCare Wesley Respite Carelink

### KANGAROO ISLAND

**Kingscote**
- Regular information sessions
- Respite for relatives
- Hi - Lo dependents aged care and allied health
- Don’t know – but now have discovered where to find out thanks to this forum
- None that I am aware of!!!
- Neighbours
- Friends
- American River Meals On Wheels
- Social groups
- Aged care facilities at Carnarvon (low dependency)
- Anchusa (high dependency) hostel
- Cook Centre: dementia group: bus picks people up for activities: referrals: information: advance planning: social worker: extra psych workers
- Carers SA Commonwealth Respite and Carelink Centre
- Carer Support KI: three day event recently; Carers and ex carers group; guest speakers
- Visiting specialist once a month
- Repat Memory Clinic
- Dementia Helpline
- No individual counselling
- Lions Club

### Additional Services

- Limited respite care
- Limited transport to appointments
- Day Care
- At home care – EACH packages, etc
- Carers Link
- Community support
- Independent living units next to aged care facilities
- Country North Community Services (now SA Country Carers)
- Helping Hand
- Residential aged care, dementia specific units

- Fragmented
- Some but not enough and not knowing how or where to access the services
- Carer respite
- Direct service activities
- Transport assistance
- Yorke Peninsula Community Transport
- EACH, EACH-D, residential places
- Op Shop as fund raiser
- ACAT: team takes on extra roles, particularly education
- Community Transport provides information
- Aged care facility and community nurses take on extra roles
- Referrals from southern end
- All facilities will do respite if there is an empty bed
- UnitingCare Wesley

- Respite – residential and at home
- Day activity programs
- Personal care social support
- Delivered meals
- Carers SA
- KI Health Services
<table>
<thead>
<tr>
<th>ADELAIDE HILLS</th>
<th>MURRAY MALLEE</th>
<th>BAROSSA, LIGHT AND LOWER NORTH</th>
<th>FAR NORTH</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mount Barker</strong></td>
<td><strong>Murray Bridge</strong></td>
<td><strong>Nuriootpa</strong></td>
<td><strong>Port Augusta</strong></td>
</tr>
<tr>
<td>• Alzheimer’s Australia SA support</td>
<td>• A fair bit</td>
<td>• Carers Link</td>
<td>• Some respite but very limited</td>
</tr>
<tr>
<td>• Adelaide Hills Health Service: dementia support group</td>
<td>• Respite (limited)</td>
<td>• Local gym</td>
<td>• Low and high care facilities</td>
</tr>
<tr>
<td>• GEM team assessment</td>
<td>• ‘Continue the flow’ program</td>
<td>• GP Management Plan</td>
<td>• Hospital</td>
</tr>
<tr>
<td>• EACH-D</td>
<td>• Council</td>
<td>• Connexus (Alzheimer’s Australia SA)</td>
<td>• Visiting specialists</td>
</tr>
<tr>
<td>• Alzheimer’s Australia SA Living With Memory Loss, Dementia Care Essentials</td>
<td>• Package entitlement</td>
<td>• UnitingCare Wesley</td>
<td>• Respite – activity group once a week for over 65 care recipients including dementia</td>
</tr>
<tr>
<td>• Carer Wellness Centre</td>
<td>• Art therapy</td>
<td>• GEM geriatrician</td>
<td>• Northern Country Carers</td>
</tr>
<tr>
<td>• Community Health</td>
<td>• Buddy system</td>
<td>• Barossa Village</td>
<td>• Calvary Silver Service: CACP, EACH-D, HACC</td>
</tr>
<tr>
<td>• HACC service at Hills Council</td>
<td>• Dementia Link Worker</td>
<td>• Tanunda Lutheran Homes</td>
<td>• Dementia based day care one day a week</td>
</tr>
<tr>
<td>• Exercise group</td>
<td>• Resthaven: EACH program</td>
<td>• Two respite beds at Tanunda; two at Barossa Village</td>
<td>• Home based service through community health</td>
</tr>
<tr>
<td>• The Hut</td>
<td>• Murray Mallee Carers</td>
<td>• Day care</td>
<td>• Aged care facility for Aboriginal and Torres Strait Islander people</td>
</tr>
<tr>
<td>• Community garden</td>
<td>• GP</td>
<td>• Men’s Health Group</td>
<td>• Council assistance</td>
</tr>
<tr>
<td>• Day Care</td>
<td>• Care workers</td>
<td>• Care</td>
<td>• HACC services</td>
</tr>
<tr>
<td>• Men’s Health Group</td>
<td>• Adelaide Hills Positive Ageing Task Force</td>
<td>• Adelaide Hills Carers</td>
<td>• Day Care</td>
</tr>
<tr>
<td>• Care workers</td>
<td>• Kaleidoscope</td>
<td>• Carers assistance</td>
<td>• Limited respite</td>
</tr>
<tr>
<td>• Adelaide Hills Positive Ageing Task Force</td>
<td>• Respite</td>
<td>• Council assistance</td>
<td>• Adelaide Hills Community Health Service provides social groups, carers assistance and support, OT, transport, etc</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Carer assistance</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Transport</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• CACP</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• EACH</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• EACH-D</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• National Respite for Carers Program</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Residential care</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Minimal respite</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Carer support groups</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Group for people living with dementia and carers for outings</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Respite</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Caring coffee club for people who don’t necessarily want to go to day care</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Country North Medicare Local 5 regions, 5 people: works with services</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Tanunda Lutheran Care</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Northern Carers Network starting service in Gawler</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Carer Link Barossa includes carers of people living with dementia and memory loss: help through maze of referrals</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Day care at Gawler Health Service</td>
</tr>
</tbody>
</table>
### EYRE
**Port Lincoln**
- Three geriatricians from Adelaide
- ACAT
- GEM intensive program but for over 65s
- Lot of information for over 65s but not seen anything for under 65s
- Not a lot of services to cater for CALD
- Post war immigrants: Baby Boomers falling into that
- HACC minimal: 4 hours week for home help
- CACP has assessment for 5-10 hours per week
- EACH 10-20 hrs. Quite a few EACH-D
- Commonwealth Respite and Carerlink Centre

### FLEURIEU
**Victor Harbor**
- Don’t know
- Railway Cottage day time respite a life saver
- South Coast Carer Support Centre: an invaluable support for our problems and emotional needs: wonderful carers
- Southern Fleurieu Health Service
- Medical
- Transport
- Carer Wellness Centre
- Alexandrina Centre for Aging
- Southern Cross Buddy Program
- Palliative Care (including volunteers who help with respite)
- ACAT medication
- Living With Memory Loss program Alzheimer’s Australia SA
- Ross Robertson dementia respite
- Calvary Silver Circle

---

### Respite
- Information from Alzheimer’s Australia worker
- UnitingCare Wesley
- Memory Lane Cafe
- Eyre Carers: retreats, respite, support for carers
- Telecross
- Transport, social, medical, visiting sick member in hospital

### Respite services: overnight, residential
- Carer support groups
- Free counselling via Health Service
- Country hospital in Victor Harbor
- Numerous doctors for choice and experience
- EACH, EACH-D, CACPS, etc
- Day respite – Railway Cottage, Ross Robbie (ECH)
- Memory Support and Education
- One to one counselling
- ACAT
- HACC
- Allied Health Services for older people including people with dementia
- Commonwealth Respite and Carerlink Centre
- Railway Cottage early intervention
- National Respite for Carers Program: day respite
- Residential aged care services
- Buddy program in home for behaviours: six hours per client
- Primary health care
- Early identification of people concerned with memory four week program
- Education specific
- Retired geriatrician doing profiling of consumers: some joint visits
- ACH. Dementia project coordinator. Residential and dementia champions in each residential area. Twelve month intensive training in dementia problems and learning modules. Everyday Good Life program
- Norman House Bunnings Program
**EYRE**

**Whyalla**

- Doctor visits
- Day Care
- Domiciliary Care
- Whyalla Aged Care
- Calvary Silver Circle
- Whyalla Hospital
- Commonwealth Respite and Carelink Centre
- Carers SA Northern Country Carers; Eyre Carers.
- Coffee morning; Retreats
- ACAT
- EACH-D, CACP packages
- Aged care facilities
- GEM Rehab
- Helping Hand
- Dementia support group
- Respite day 8am – 5:30pm
- Oranga Day Centre
- Sunshine Club
- Whyalla Home Care home support
- Visiting geriatrician

- ACAT
- Aged care
- Alzheimer’s Helpline
- Alzheimer’s Australia SA Link Person
- Amaroo Lodge
- Calvary Silvery Circle
- Centacare
- Centrelink
- Church support
- CACP, EACH-D
- Community packages
- Day care (Sunshine Club)
- Dementia care
- Dementia clients’ respite
- Dementia education
- Dementia support group
- Domiciliary Care
- Extended family
- Family
- GEM Team
- GPs
- Guide Dogs
- Home support
- In-house respite
- Palliative care
- Introduction pre care arrangements prior to dementia taking hold: forward planning
- Library
- Meals on Wheels
- Mission Australia
- Numerous bodies within Whyalla Hospital
- Nursing homes
- Oranga Day Centre
- Pastoral social support
- Practical support, for example Meals On Wheels, general counselling
- Psycho-geriatricians
- Red Cross
- Respite care for carers and clients through community organisations and aged care facilities
- Salvo’s
- Sunshine Club
- UnitingCare Wesley (Commonwealth Respite and Carelink Centre)
- Visiting Geriatrician
- Whyalla Aged Care: High Level Care and Low Level Care Packages; home support care workers; residential care dementia specific
- Whyalla Hospital
SERVICE PROVIDER ORGANISATIONS

• ACH Group
• Adelaide Hills Community Health Service
• Adelaide Hills Division of General Practice
• Adelaide Hills Mental Health Team
• Anchusa Nursing Home
• Australian Red Cross
• Balaklava Mill Court Homes
• Boandik Lodge
• Bordertown Aged Care
• Bordertown Hospital
• Carer Support Kangaroo Island
• Carers Link Yorke Peninsula
• Carers SA: Northern Country Carers; Eyre Carers; South East Carers
• CHAP
• Charla Lodge Aged Care
• Commonwealth Respite and Carelink Centre: North and West Country; South and East Country
• Community Support Inc
• Cook Centre
• Country Health Local Health Network,
• Country Health SA
• Country North Community Services
• Country North SA Medicare Local
• Disability SA
• Domiciliary Care
• Eastern Eyre Health Aged Care
• ECH Ross Robertson Memorial Care Centre
• Eldercare
• Elliston Hospital
• Families SA
• Gilbert Valley Senior Citizen Home
• Hamley Bridge Memorial Hospital
• Helping Hand
• Home Support
• Homecare
• Kangaroo Island Community Health Service
• Maitland Hospital
• McCracken Views
• Mid West Health Service
• Murray Mallee Aging Taskforce
• Murray Mallee Community Health Service
• Nalya Lodge
• Naracoorte Community Health
• Northern Community Transport
• Peninsula Residential Care Centre
• Peterborough Health Service
• Port Augusta Community Health
• Port Augusta Hospital
• Resthaven
• Riverland Community Health Service
• Riverland Regional Health Service
• Rural City Murray Bridge
• Sandpiper Southern Cross
• South East Regional Community Health Service
• Southern Cross Care
• Southern Cross Care
• Southern Fleurieu Health Service
• Star of the Sea Home for the Aged
• TAFESA Regional
• Tanunda Lutheran Home
• Tumby Bay Hospital
• UnitingCare Wesley
• Wami Kata Aboriginal Old Folks Home
• Whyalla Aged Care
• Whyalla Hospital
• Willow Fern Cottage
• Yorke Peninsula Community Transport
SERVICE PROVIDER ORGANISATION TYPE

- Acute care
- Acute community and aged care
- Aged care
- Aged Care Assessment Team
- Aged care housing
- Aged care in community
- Aged care residential
- Ageing in place
- Care worker
- Carer support / information / counselling and advocacy
- Continuing Medical Education Administrator
- Community care: personal care, domestic assistance, home maintenance, social support, transport, respite
- Community health
- Community services
- Community services home support
- Day respite and residential care
- Dementia respite support
- Education
- GP care health assessments
- HACC

- Health
- Health care
- Healthy Aging Team
- Home support
- Home support aged care
- In home support
- Independent living program
- Mental health
- Older persons mental health
- Public sector
- Residential aged care
- Residential aged care / private hospital
- Residential care
- Respite
- Respite / information / training
- Social Work
- Telecross
- Telecross and Emergency Services
- Transport and Telecross
- Transport information and provision
- Women’s health
ROLE OF SERVICE PROVIDERS

- ACAT Assessor
- ACAT Coordinator
- Aged Care Manager
- Aged Care Team Leader
- Aged Care Worker
- Assessment and Liaison Worker
- Assessor
- Care Coordinator
- Care Worker
- Carer Support Coordinator
- Carer Support Worker
- Clinical Development Manager
- Clinical Manager
- Clinical Nurse
- Clinical Nurse Consultant
- Clinical Nurse Manager
- Clinical Nurse, GEM Team
- Clinical Services Coordinator
- Community Care Worker
- Community Care Worker / Home Support Worker
- Community Health Manager
- Community Service Nurse
- Community Services Director
- Coordinator
- Coordinator of Lifestyle and Day Respite Program
- Dementia Coordinator
- Dementia Para Medical Aide
- Dementia Programs Manager
- Dementia Project Worker
- Director of Care
- Director of Nursing
- Educator
- Enrolled Nurse
- Executive Officer / Director of Nursing
- Health Assessment Nurse

- Healthy Aging Program Manager
- Home Assessment Nurse
- Home Support Community Worker
- Home Support Coordinator
- Home Support Manager
- Home Support Worker
- Lecturer
- Lifestyle Coordinator
- Local Area Network Officer
- Manager Community Services / RN
- Occupational Therapist
- Occupational Therapist In GEM Team
- Occupational Therapist (Rural Generalist / ACAT)
- Older Persons Mental Health Clinician
- Para Medical Aide
- Program Manager Home Support Services
- Regional Coordinator
- Regional Manager
- Regional Telecross Officer
- Registered Coordinator Red Cross
- Registered Nurse
- Registered Nurse Acute and Aged Care
- Residential Care Manager
- Respite Coordinator
- Rural Social Worker
- Senior Coordinator
- Social Work Student
- Social Worker
- Social Worker – Hospital
- Social Worker – Rural Generalist and Palliative Care
- Social Worker Coordinator
- Support Service Coordinator
- Team Head Community Health
- Team Leader
- Team Manager
- Women’s Emotional Health and Wellbeing Worker
SERVICE PROVIDER INVOLVEMENT WITH PEOPLE LIVING WITH DEMENTIA, THEIR FAMILIES AND CARERS

- 70% of the people I work with daily have been diagnosed with dementia
- Aged Care and Acute Nurse
- Aged Care Cert 3
- Aged care management
- As a member of team providing services and conducting medication support for people living with dementia and family and carers
- As care worker, caring for them in their homes. As Team Leader: organise care, assess care needs
- Assess clients
- Assessing eligibility for service; observing diagnosis; linking people in post diagnosis
- Assessment and consultation with psychiatrists: referral to appropriate services
- Assessment and referral to services
- Assist with activities for daily living, personal care, medication administration assessment, annual reassessments, referrals to other services
- Assisting with personal care, social care, shopping; whatever is needed to be done to assist clients with dementia
- Basic support, pick up if not quite right, then refer, link
- CAPS Coordinator and one client with dementia
- Care Worker
- Carer and supporting people with dementia through care provided
- Carer education
- Carer respite
- Caring for people with dementia in the facility
- Case Manager
- Clinical and administrative support via CACPs
- Coordinate care; implement services; referrals
- Coordinate daily activities for those who attend the lifestyle club
- Coordinate multiple projects to improve life and wellbeing for residents living with dementia
- Coordinate support groups, retreats, education respite for carers
- Counselling support for carers
- Daily involvement with residents; lots of involvement with families
- Day activity club for people living with dementia; giving partners respite
- Dementia Link Worker
- Developing and completing ACFIs for each resident, care plan reviews, staff education
- Discharge planning
- Education and advocacy to get services into homes; provide solid support
- Education, information, counselling and advocacy
- Facilitating care and awareness
- HACC funded dementia care, social and respite support, carer support, link to other services, carer support group
- Home assessments
- Home health assessments on people aged 75 years and over
- Home Support Worker
- Manage home support, ACAT, Geriatric Education Management Team and Dementia Support Program
- Manage various community care programs and special support, dementia specific groups
- Managed programs that have a direct link; ie HACC, CACP, NRCP, Lifestyle Clubs
- Managing residential care focussed on the end of the dementia journey
- Managing services (respite and residential) for people living with dementia and their families
- Many of my clients have dementia both diagnosed and undiagnosed
Many of my clients or their carers have dementia. I support them to live in the community and provide them with OT services.

Most of my OT clients have a level of dementia.

Offer and coordinate support groups, retreats, education, respite for carers.

Ongoing respite and activity group programs.

Overall manager of all health services.

Part of a multidisciplinary team, aimed at preventing early functional decline and diagnosis of dementia.

Professionally and socially.

Provide care for people living with dementia, support for families.

Provide personal hygiene, medication supervision, shopping (when no family support available), liaise with ACAT, GEM: Home Support Coordinator.

Provide residential care.

Provide social and emotional support and advocacy.

Providing carer support to family carers through information, support, counselling and advocacy.

Providing clients living at home with services, respite to carers, meeting social needs.

Providing in home care.

Providing information, referrals to family carers.

Providing our clients with domestic assistance, social support, home maintenance, and personal care to ensure they can stay at home and live as independent as possible.

Providing respite for carers.

Putting in place behaviour management strategies for residents with dementia.

Recruit and train Telecross volunteer callers and recruit clients.

Refer to organisations for support.

Register carers who care for people living with dementia and when needed we can supply respite.

Respite coordinator.

Respite coordinator for the whole of the region: speak to lot of carers with dementia.

Running day activity / respite program for people with dementia.

Service delivery in the home.

Supporting carers to access respite short and long term.

Supporting families and carers, coordinating access to services.

Through patient / carer admissions.

To keep clients living at home with dementia for as long as possible.

Transport: in events and disasters at evacuation centres or daily calls.

Usual first port of call when families are either at crisis point (acute admissions) or carer fatigue / health issues.

Visits, provide advice.

We support carers to link them into appropriate services to their needs and to increase their social networks.

Work in hospital in aged care facility.

Work is carer focussed.

Working alongside family carers to link them into appropriate services, for example: respite.

Working in a special care unit; twelve bed secure unit.