THE COST OF DEMENTIA IN SOUTH AUSTRALIA 2012

PREPARED BY PHIL SAUNDERS
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The Cost of Dementia in South Australia 2012

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1800 100 500
(NDH is an Australian Government initiative)
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The Cost of Dementia 2012 Questionnaire

Alzheimer’s Australia SA asked people living with dementia, their carers and families about the impact of dementia on their financial and personal lives, the top issues they faced and what would help them.

The Questionnaire Opportunity

During the second half of 2012 dementia consumers – people living with dementia, their families and carers, were given a number of opportunities to complete the Cost of Dementia 2012 Questionnaire including:

- Get Your Voice Heard: Living with Dementia in Country SA project consultations held across rural South Australia from July to November 2012 (76 respondents).
- Have a Voice: The Cost of Dementia Consumers’ Forum at the Live.Love.Learn: Making the Connections Dementia Carers Conference on 19 September 2012 (7 respondents).
- The Cost of Dementia Consumers forum on 29 November 2012 (40 respondents).

123 forms were completed; 12 from respondents identifying as people living with dementia, with 106 identifying as family members (31) or carers (75).

Major findings

Dementia has more impact on people’s lives than on their finances.

The top three personal issues were concerns facing the carer, concerns about the limits of the person living with dementia and the emotional toll on both the person living with dementia and their families.

The top three financial issues were household costs, transport and income and finances.

Respondents were having more trouble meeting the personal impact than the financial costs.

Respondents wanted better information about the dementia and strategies to deal with the illness and the changing behaviours of the person living with dementia.

Carers wanted to be valued, understood and supported through respite, counselling and sharing experiences with other carers.

Respondents wanted greater financial support through increased rates of, and more flexible rules for, pensions, allowances and subsidies.
THE IMPACT OF DEMENTIA

What impact does living with dementia have on your financial situation / personal life?

Dementia has more impact on people’s lives than on their finances.

Less than a third (34%) of respondents said the financial impact of dementia was large to very large. However, nearly two thirds (63%) said the personal impact was large to very large, including several who wrote “huge” and “massive”.

“I gave up my life.”

“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

(as percentage)

Financial

Personal

Very Small Small Medium Large Very Large

112 respondents
TOP ISSUES: PERSONAL COSTS

What are the top three personal issues facing you?

The top three personal issues were: concerns facing the carer (42%); concerns about the limits of the person living with dementia (19%) and the emotional toll on both person living with dementia and their families (18%).

Concerns Facing The Carer

Self Time

Carers outlined the impact on their time, the “lack of freedom and opportunity to pursue my own interests”. They had “no life of my own”, “no more holidays”, “restricted activities” and a “lack of privacy and personal space”.

They gave up businesses and careers, changing their role “to caring from working”.

They were unable to “plan a future”, rather the future held “uncertainty” and “survival as a person in terms of my own health”.

“Life is lonely – Alzheimer’s has taken over.”

Social Isolation

Respondents were concerned that the social isolation and the loss of friends brought on by living with dementia reduced their ability to lead “a normal life”.

People living with dementia commented on the “isolation from activities I used to do” and for people with younger onset dementia “not being able to communicate with people my own age”.

For carers there was “a lack of ability to socialise, travel, visit my children interstate”, being “unable to attend cultural activities I used to enjoy”, “not being able to go out at night or weekends”. It was “not feasible to take my partner to social functions or to entertain at home”.
Responsibility

Respondents outlined having to take on the responsibility “for all decision making” when “we did it together before”. This included “thinking for two people” “without talking it over”, “making financial and lifestyle decisions for the person with dementia”, “dealing with the provision of total care of my wife” and being “totally responsible for living (meals, cleaning, maintenance of the house and garden)”. Taking on the role as ‘guardian’ “weighed heavily – making decisions about mum’s health and wellbeing” and “having to make the decision to put mum into full time care”.

Exhaustion

Carers outlined their exhaustion, brought about by “the extra responsibilities both physical and emotional”. There was “24 hour care” with a “lack of sleep and privacy”.

As one carer explained, “he wanders and is extremely restless at night; up at least every two hours and sometimes takes an hour to settle. So I get very little sleep”.

Dementia Taking Over

Dementia had “taken over my life” with “so much to do” there was limited autonomy, privacy and freedom “to do what we like”.

Being Supported

Carers were interested in “getting more help”. They wanted “quality debriefing, not a cuppa, chat and pat on the head”.

<table>
<thead>
<tr>
<th>Carer Concerns</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self Time</td>
<td>30</td>
</tr>
<tr>
<td>Social Isolation</td>
<td>26</td>
</tr>
<tr>
<td>Responsibility</td>
<td>24</td>
</tr>
<tr>
<td>Exhaustion</td>
<td>13</td>
</tr>
<tr>
<td>Dementia Taking Over</td>
<td>5</td>
</tr>
<tr>
<td>Being Supported</td>
<td>2</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100</td>
</tr>
</tbody>
</table>

102 respondents

“You cannot change the illness; mainly just give it your full support.”

Limits of the Person Living With Dementia

Care Requirements

Carers outlined the time required “thinking how to keep my husband amused”, “keeping dad occupied on weekends and Fridays when there is no day activity”, “needing to follow his every action”.

They were “always home with him as he does not like going out”, or were “not able to leave him alone all”.

There were also medication, hygiene, food intake and behavioural management issues.

Behaviour

Carers noted the need to “understand what possible behaviours to expect”, to “understand her change in character”.

They wanted “the strength to have the skills, time, energy to enjoy your partner’s well moments and patiently, timely deal with the bad”.

Communication

Respondents detailed their communication problems, from “continual arguments, continual questioning” and “difficulty with compromising” to the loss of communication skills (“can’t read, can’t write”) with the person with dementia “not understanding what I say to them”, having trouble “remembering instructions, information verbally given” and the carer “not understanding what my husband is trying to say”.

There was an “incremental loss of companionship developed over 46 years of marriage”.

Deterioration

Respondents noted the deterioration in health, hygiene standards and mental capacity with an associated loss of confidence in the people living with dementia.

<table>
<thead>
<tr>
<th>Limits of the Person Living with Dementia</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care Requirements</td>
<td>36</td>
</tr>
<tr>
<td>Behaviour</td>
<td>26</td>
</tr>
<tr>
<td>Communication</td>
<td>21</td>
</tr>
<tr>
<td>Deterioration</td>
<td>17</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100</td>
</tr>
</tbody>
</table>

47 respondents
**Emotional Costs**

Respondents pointed to the stress, worry, frustration, guilt, grief, anger, sadness, uncertainty and loss of patience that impacted on their emotional and physical health.

They outlined their worries “about where grandmother will end up”, “providing emotional support to the person living with dementia”, “trying to understand behaviour and being tolerant”, “coping with the diagnosis of my husband”, “having the patience to accept change” and “trying to keep my spirits up”.

“Because of tiredness I find it hard to become motivated and get fed up with having to think about, organize and do everything.”

**Dealing With The Health And Aged Care Systems**

Respondents were concerned about 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” in a “very complex aged care system”.

They observed that “GP’s need to be more aware and informed about the disease”.

They experienced a lack of medical support and access, waiting “months to get into an appointment at the Memory Clinic” and wondering “what treatment is available?”

They had to deal with “paperwork, questionnaires, taking over the finances” and privacy and confidentiality issues with “the doctor saying the patient with dementia needs to authorise release of information to family members”.

Respondents observed that there was a need for “more training for staff in care facilities. Those people must be better paid! We need lots more staff too! ”

They had difficulty in finding “responsible and professional” people to look after the person with dementia.

**Family Dynamics**

Respondents detailed a reduction in social interactions with family by the person living with dementia due to distance, limited family support and understanding and family conflict.

Carers were concerned that they had to “deal with the anger of a family member”, that other family members “see the person for a short time and think that they are OK”, not being comfortable in leaving their partner in care of the family overnight and the impact of their caring responsibilities on their own family.

**Day To Day Living**

Respondents felt the impact of “not enough money for household expenses” for shopping, toiletries, electricity, cleaning, home maintenance and transport costs.

**Respite**

Respondents noted a lack of dementia respite. The need for respite included “the need to find friends to visit her (German native language)” and “arranging care to continue working”.

**Community Attitude**

Dealing with stigma and a “lack of understanding from people” and gaining a “general acceptance of the illness in the community” continued to be difficult for respondents.
TOP ISSUES: FINANCIAL COSTS

What are the top three financial issues facing you?

The top three financial issues were: household costs (18%), transport (16%) and income and finances (16%).

Respondents were concerned about the following costs:

Utilities / Living Expenses

The increasing cost of household utilities on top of a greater use of electricity for washing, cleaning and heating and cooling; house and garden maintenance respondents were no longer able to undertake themselves; renovations for safety reasons and buying different foods.

Transport

The increasing costs of fuel and vehicle registration; travelling to access services including over long distances for country people in particular travelling to Adelaide for consultants and treatment and regular, often daily, visits to the person living with dementia in residential care.

Income and Finances

The loss of salaries because of the loss of work due to the onset of dementia, leaving work to take on a caring role; the “loss of personal health which affects work prospects” due to the caring role; followed by living on the limited fixed incomes of pensions.

Residential Care

Placing the person living with dementia in permanent care; the additional costs for activity materials, therapies and trips because “costs do not cease because your partner enters residential care”.

Medications

Taking medication, including alternative or supplementary medicines, for dementia.
Personal Care

Personal hygiene products, in particular incontinence aids; personal hygiene services; Meals on Wheels; cleaning; payments for personal care services and co-payments for government packages such as EACH and EACHD.

Respite

Paying for residential and community day care when not covered through government assistance.

Medical

Paying for appointments with doctors, specialists and for hospitalisations.

Diversional Therapies

Including services not supplied by residential care facilities.

Other

Gaining information and access to services; altering clothes; replacing lost items; paying for entertainment “as a relief from everyday life”; paying for “my husband’s ideas” and taking “frequent holidays to enjoy the time left together”.

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

Personal care at home, transport and utilities / living expenses were the most common items causing extra costs for people living with dementia.

43 respondents put a figure on their costs. The average extra cost for these respondents was $3,480 per year not including residential care.

187 items were listed. 93 of the items listed included the estimated cost per year.

In addition, six respondents noted the loss of or limited income they received.

“Everything costs money.”

<table>
<thead>
<tr>
<th>Extra Living Costs</th>
<th>No. Items Noted</th>
<th>% Items Noted</th>
<th>No. Items Costed</th>
<th>% Items Costed</th>
<th>Average Cost / Item / Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Care At Home</td>
<td>44</td>
<td>23</td>
<td>25</td>
<td>27</td>
<td>$1,858</td>
</tr>
<tr>
<td>Transport</td>
<td>33</td>
<td>18</td>
<td>20</td>
<td>22</td>
<td>$1,212</td>
</tr>
<tr>
<td>Utilities / Living Expenses</td>
<td>31</td>
<td>17</td>
<td>10</td>
<td>11</td>
<td>$1,635</td>
</tr>
<tr>
<td>Medication</td>
<td>26</td>
<td>14</td>
<td>11</td>
<td>12</td>
<td>$954</td>
</tr>
<tr>
<td>Respite / Day Care</td>
<td>17</td>
<td>9</td>
<td>15</td>
<td>16</td>
<td>$1,961</td>
</tr>
<tr>
<td>Medical</td>
<td>12</td>
<td>6</td>
<td>5</td>
<td>5</td>
<td>$854</td>
</tr>
<tr>
<td>Residential Care</td>
<td>7</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>n/a</td>
</tr>
<tr>
<td>Aids and Equipment</td>
<td>5</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>12</td>
<td>6</td>
<td>3</td>
<td>3</td>
<td>$1,033</td>
</tr>
<tr>
<td>TOTAL</td>
<td>187</td>
<td>100</td>
<td>93</td>
<td>100</td>
<td></td>
</tr>
</tbody>
</table>
MEETING THE COSTS

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

Respondents were having more trouble meeting the personal impact than the financial costs.

Just over a third (35%) of respondents said they had trouble meeting the financial costs of dementia. However, over half (67%) had concerns about meeting the personal costs.

[Graph: Trouble Dealing with Costs? (as percentage)]

Financial 89 respondents: personal 100 respondents

Carer respondents noted the personal sacrifices they made “putting the 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”, not being able to afford extras in the residential care facility and using up superannuation.

In commenting on the trouble they had in dealing with the personal costs respondents re-iterated the emotional toll “dealing with the changes in our life” and “feeling overwhelmed by the impact of the changes” and outlined the increasing isolation “from friends, family and activity”, the decline in fitness and physical health, the need for information and learning “to accept these things”.

“All I can do is try to manage time and stress effectively.”

In commenting on the trouble they had in meeting the financial costs, respondents outlined the impact of “just not enough income to stretch”; meeting all the expenses from “my residual income which previously were met by joint income”.

Do you receive any assistance to meet these extra costs / help to deal with the personal impact of living with dementia?

Respondents outlined the help they received with the personal impact of living with dementia from carer support social interactions, counselling, publications, workshops and telephone help lines.

They noted the “understanding” and “graciousness” of family and friends; regular respite and when “I have my moments and call on respite at these times”; home care packages; medical support from the GEM team and other health services, help from residential care staff and by receiving income support.

[Table: Help with Personal Impact]

Help with Personal Impact | %
--- | ---
Carer Support | 40
Family and Friends | 17
Home Care | 15
Respite | 13
Medical Support | 11
Income Support | 3
Residential Facility | 1
TOTAL | 100

92 respondents

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

[Table: Assistance with Finances]

Assistance with Finances | %
--- | ---
Income | 56
Subsidies | 36
Travel | 8
TOTAL | 100

48 respondents
**WHAT WOULD HELP?**

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

Nearly a third (31%) of the respondents who named one thing that would help them personally wanted carer support through more respite (22%) or sharing experiences (9%).

A quarter (25%) wanted more information, either information on dementia (16%) or information on services (9%).

A significant number (13%) of carers wanted more time for themselves.

Carers sought support “to keep people suffering with dementia out of residential care”.

Respondents sought more help from family; for example: “The need for the daughters to understand the person with dementia’s limitations eg they need to stay only one to one half hours to realise that he is OK; if habits are followed eg bed times; that he cannot cope with lots of noise, conversation or alcoholic drinks.”

“It’s very important and much better for the person with dementia to be in their own surroundings.”

Respondents wanted strategies for dealing with the illness and coping with behaviour and, “knowing that I was doing the right thing to help and try to improve my husband’s state of mind”. They wanted help from their specialists along the lines of “You are not alone; this is what is happening; this is what will happen next” and much more.

They wanted better information regarding the stages of the disease, to “know the other person’s knowledge” and to understand the “simple activities for daily living”, “that my forgetfulness is not intentional”.

Carers wanted to be valued and understood “for what we contribute”. They wanted time for themselves to “feel like a whole person”, particularly through more respite options “so I can also have a life”. Also helpful would be regular counselling and support from other carers, “hearing that you are not alone and that it is OK to have very mixed emotions”.

Other support required included more help around the house, more help from family such as “having my children live closer”; the “ability to take my wife, who is confined to a wheelchair, for a drive in the countryside”, “more government funding for finding a cure” and “a magic wand”.

![Personal Help Needed](image-url)

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

Over two thirds (69%) of the respondents who named one thing that would help financially wanted more income support.

Respondents wanted the various pensions and the Carers Allowance increased “in recognition of the struggles of keeping a person with dementia at home for as long as possible and the absolute sacrifice”.

They observed that the “Carers Allowance barely covers our costs just for medication – let alone anything else. The cost of caring in a facility is huge. The cost of a carer at $114 per fortnight is an insult.”.

They wanted Centrelink “to have a separate department totally dedicated with compassion and understanding and support of all carers (not just dementia)”.

They wanted more flexible rules for the income support, a “quick mainstream financial injection”, “more money to live like other people” and more financial support for the cost of utilities, transport, respite care and medical treatment and medications such as “access to discounts available to seniors”.

“Recognition of the financial and personal impacts of dementia by government.”

The Cost of Dementia in South Australia 2012

13
### ABOUT YOU

#### I live in

<table>
<thead>
<tr>
<th>Location</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>A major country centre</td>
<td>22</td>
</tr>
<tr>
<td>A country town</td>
<td>38</td>
</tr>
<tr>
<td>Not in a major centre or town</td>
<td>5</td>
</tr>
<tr>
<td>Adelaide metro</td>
<td>35</td>
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<tr>
<td>TOTAL</td>
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112 respondents

#### Age of respondents

<table>
<thead>
<tr>
<th>Age</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td>Under 65</td>
<td>38</td>
</tr>
<tr>
<td>66 - 69</td>
<td>12</td>
</tr>
<tr>
<td>70 - 79</td>
<td>33</td>
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<tr>
<td>Over 80</td>
<td>17</td>
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<tr>
<td>TOTAL</td>
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</table>

98 respondents

#### Gender of respondent

<table>
<thead>
<tr>
<th>Gender</th>
<th>%</th>
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<tr>
<td>Male</td>
<td>29</td>
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<tr>
<td>Female</td>
<td>71</td>
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<tr>
<td>TOTAL</td>
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98 respondents

#### Age of person with dementia

<table>
<thead>
<tr>
<th>Age</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 65</td>
<td>10</td>
</tr>
<tr>
<td>66 - 69</td>
<td>6</td>
</tr>
<tr>
<td>70 - 79</td>
<td>35</td>
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<td>80 - 89</td>
<td>44</td>
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<tr>
<td>Over 90</td>
<td>5</td>
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<tr>
<td>TOTAL</td>
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</table>

96 respondents

#### 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>TOTAL</td>
<td>100</td>
</tr>
</tbody>
</table>

96 respondents

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

<table>
<thead>
<tr>
<th>Status</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>25</td>
</tr>
<tr>
<td>No</td>
<td>75</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100</td>
</tr>
</tbody>
</table>

95 respondents

### Number of hours caring each week

75 respondents put a figure on their hours of caring each week for an average of 112 hours (16 hours per day). Over half (56%) were caring “24/7” (168 hours per week).

![Number of hours caring each week](image)

### Household income

#### Source

<table>
<thead>
<tr>
<th>Source</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment</td>
<td>7</td>
</tr>
<tr>
<td>Pension</td>
<td>59</td>
</tr>
<tr>
<td>Self Funded Retiree / Superannuation</td>
<td>31</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
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<tr>
<td>TOTAL</td>
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</table>

### Household income per year

<table>
<thead>
<tr>
<th>Amount</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $10,000</td>
<td>1</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>
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<td>$80,000 - $89,000</td>
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</table>

84 respondents

### Social and cultural diversity

<table>
<thead>
<tr>
<th>Community</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Culturally and Linguistically Diverse</td>
<td>15</td>
</tr>
<tr>
<td>Aboriginal and Torres Strait Islander</td>
<td>2</td>
</tr>
<tr>
<td>Lesbian Gay Bisexual Transgender Intersex</td>
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</tr>
</tbody>
</table>

22 respondents
The costs of living with dementia across country South Australia were outlined in the Get Your Voice Heard: Living With Dementia In Country SA Report of June 2013. This report discussed the issues arising from a series of consultations with 366 consumers and service providers that took place from July to November 2012.

Major findings included:

- There is increasing awareness of dementia as a disease but reducing stigma remains important.
- Getting a timely diagnosis then the proper care and attention remains difficult.
- There are a limited number of services and difficulty in getting them; particularly respite and health specialists.
- The tyranny of distance is a significant barrier to getting services: including limited transport options for people living with dementia and their families.
- The cost of dementia, financially and personally, remains high.
- Continuing care both in the home and in residential facilities requires ongoing staff development, more programs and infrastructure.
- Funding bodies need to understand that rural outcomes cost more: additional allowances for rural and remote regions should be added to baseline funds.
