



Supporting Family Carers
Number of carers who responded:

640

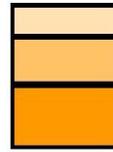
Snapshot of Findings Carers Survey 2015



77%
female



23%
male



14% under 45 years
42% 45-64 years
44% over 65 years

89% of carers put the needs of the person they are caring for before their own - either all or most of the time



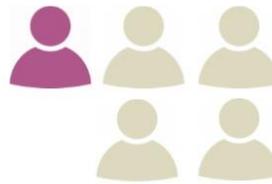
90% of carers have been in their long-term caring role for over 3 years (51% over 10 years)

97%

would recommend Carers SA on to another family carer— based on their experience with Carers SA

48%

main source of income is government income support payments



1 in 5 are either dissatisfied or very dissatisfied with their standard of living

27%

Stated their financial position is worse than last year

5% of carers have no support in their caring role

21% of carers have used websites specifically designed for carers

77% of carers of the elderly have not used the My Aged Care



17% are eligible for the NDIS

71% of carers would not feel confident around individual NDIS care plan development

The majority of carers have minimal 'me time' outside their caring role and household chores



17% of carers stated their health was poor

26% of carers have less than 1 hour of exercise per week



Our Carers – Our World

Carers SA Carers Survey 2015

Carers Survey Title: **“Our Carers – Our World”**

Date: October 2015

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Overview

Carers SA recognises that demand for carers is at an all-time high and will increase further into the future. Carers SA is committed to supporting unpaid family carers in their rewarding, but demanding role and we will continue our pledge to listen to the voices of carers.

The Carers SA Carers Survey 2015 is the most comprehensive and extensive survey that Carers SA has ever conducted. The survey collated statistics about the life of carers and asked South Australian unpaid family carers for their input and comments regarding their caring role, their health and wellbeing, issues around education, and employment, services and needs that carers use and require in their caring role, carers and the digital world, the NDIS and feedback on a range of other topics. This survey was supported by the outstanding support from South Australian carers. Carers SA received 640 responses to the 94-question survey from carers across South Australia, including metropolitan Adelaide, country and regional/remote areas. An additional 95 carers responded to the Carers SA Carer Survey Supplement regarding Financial Institutions released in August-September 2015. The information and feedback from the carer community will enable Carers SA to develop and maintain up-to-date understanding of current and topical carer needs, concerns and priorities and provide support and advocacy for carers as well as policy advice to Government on issues at the heart of unpaid family carers in South Australia.

Carers were able to participate in the survey online, or via hard-copy forms. This survey was distributed to and publicised through print and social media, carer and service networks, cultural groups, Aboriginal networks, businesses, Government and disability and health sector networks.

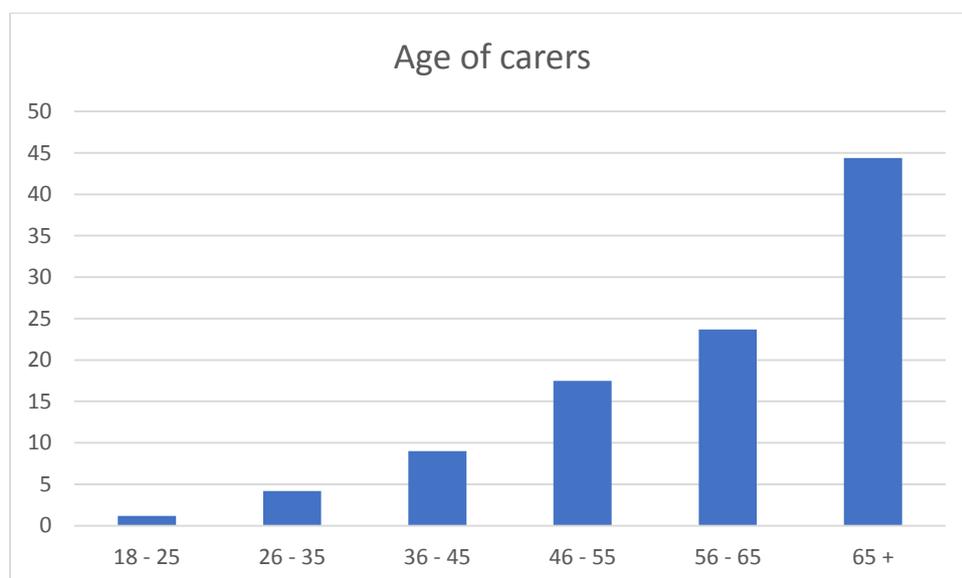
This overview of the 2015 survey provides an insight into the everyday life of South Australian carers and highlights the challenges carers face in the changing landscape of the disability and aged care sector.

A carer is defined for the purpose of this survey as a person providing long term care (at least six months) for a parent, partner, child or other relative or friend who has a disability, is frail, aged or has a chronic mental or physical illness. In 2012, it was estimated that there are 2.7 million carers Australia wide, with approximately 29% of these identifying as primary carers (ABS 2012). South Australia has officially estimated that 213,700 (ABS 2009) carers are providing ongoing assistance to someone with a disability or an age-related frailty. The Deloitte Access Economics Report, 'The Economic Value of Informal Care in Australia 2015', details how the replacement value of the care provided by Australia's unpaid carers has increased to \$60.3 billion per year - over \$1 billion every week. Australian Bureau of Statistics' data from 2011 suggests that approximately 3% of carers are from a culturally or linguistically diverse background with limited English language skills, while a further 1.7% are Aboriginal family carers. Furthermore, participants in the Carers SA Carer Survey generally

reflect carer backgrounds, with 8% of respondents from culturally diverse backgrounds including 16 language groups and 1.8% identifying as Aboriginal family carers.

Carers participating in this survey:

- 51% of carers answering the survey have been in their caring role for more than 10 years.
- 68% of carers answering the survey are aged 56 years and older.
- 14% of carers answering the survey are aged under 45 years.

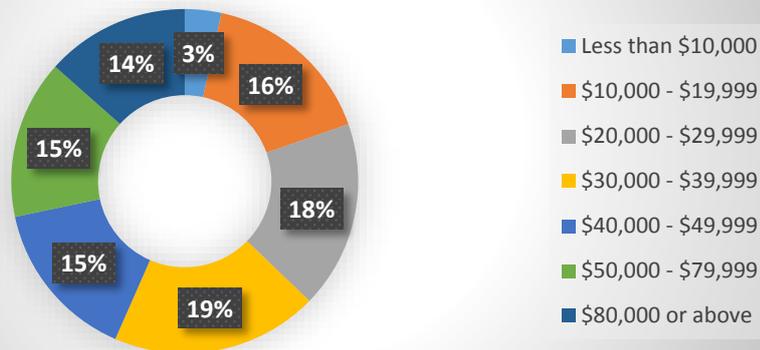


Carers and Finances

Carers and the person(s) they care for, especially couples are often operating joint finances or have shared resource arrangements.

More than half of the carers listed their household income as less than \$40,000 per year and 27% of carers reported that their financial situation was worse than the previous year. The Australian Council of Social Services (ACOSS) was quoted (Taylor 2014) to have calculated annual family household incomes below \$39,104 as reflecting the poverty line in Australia.

Total household income per year



The majority of carers indicated income support such as the pension or Centrelink as their main source of household income followed by carers who have some form of paid employment (18%), or receive payments as self-funded retirees or from superannuation (11%).

Utility and services costs have been rising substantially in recent years. Therefore, it is unsurprising that the most frequently claimed concession by carer households were related to energy (23%), followed by water/sewerage (18%) and Council rates and Emergency Services Levy (17%). Increasing numbers of carers are indicating that they are not eligible to claim concessions (6% in 2013 and 12% in 2015) and find it increasingly difficult to pay bills.

Carers SA asked respondents to expand further on living standards:

- Only 36 % of carers reported that they can always manage the needs of caring and living within their current budget. This reflects a 3% increase in carers indicating that they are under ongoing budget stress in comparison to the 2013 Carers SA survey.
- 24% of carers occasionally go without meals and 6% of carers frequently go without meals. This is an increase of 3% of carers forgoing meals to the previous 2013 Carers SA survey.
- 18% of carers indicated that they are only occasionally or never able to heat and cool their homes according to the weather (13% in 2013 Carers SA survey).
- 18% of responding carers reported that their standard of living is of concern.
- 67% of carers are never, or only occasionally able to afford a night away from their caring role.

Support and Services

According to Deloitte Access Economics (2015), carers will provide 1.9 billion hours of unpaid care in 2015. This equates to carers providing between 40 and 104 hours of care to the person they care for depending on their medical condition (Mental Health Council of Australia and Carers Australia 2000).

As a community, we have an obligation to ensure carers receive adequate support in their caring role. 48% of carers report that they receive from their family or friends, of these 26% get less than 3 hours a fortnight. However, nearly half of carers in South Australia receive no support outside of their family.

5% of carers report that they receive no external support, from either formal or informal services.

It is therefore of concern that some carers reported a loss of services and supports over the last year. The most common support lost in the past 12 months was related to Centrelink payments (19%), followed by support services (17%) and respite (16%).

When seeking support for their caring role, carers generally turn to an organisation. The majority of the support services available focus on the care recipient and include disability support (25%) followed by health, ageing and mental health support services. Results indicate that 25% of services are delivered by the not for profit sector.

Carer inclusion

Carers were asked to comment on their perceived inclusion on decisions and choices regarding services available. The response indicates a mixed experience depending on available services and processes in place with service providers, individual family circumstances and needs, hence 19% of carers stated that they felt more included yet 8% stated that they felt less included.

Carers were also asked to indicate whether they believed their needs had been met. Over half (55%) indicated that their needs had only been partly met or had not been met at all. In a related question, 40% of carers indicated that they would like extra help in the coordination of services.

An alarming 60% of carers, of all ages represented, indicated that they were concerned, or sometimes concerned about finding long term independent accommodation for the person they care for.

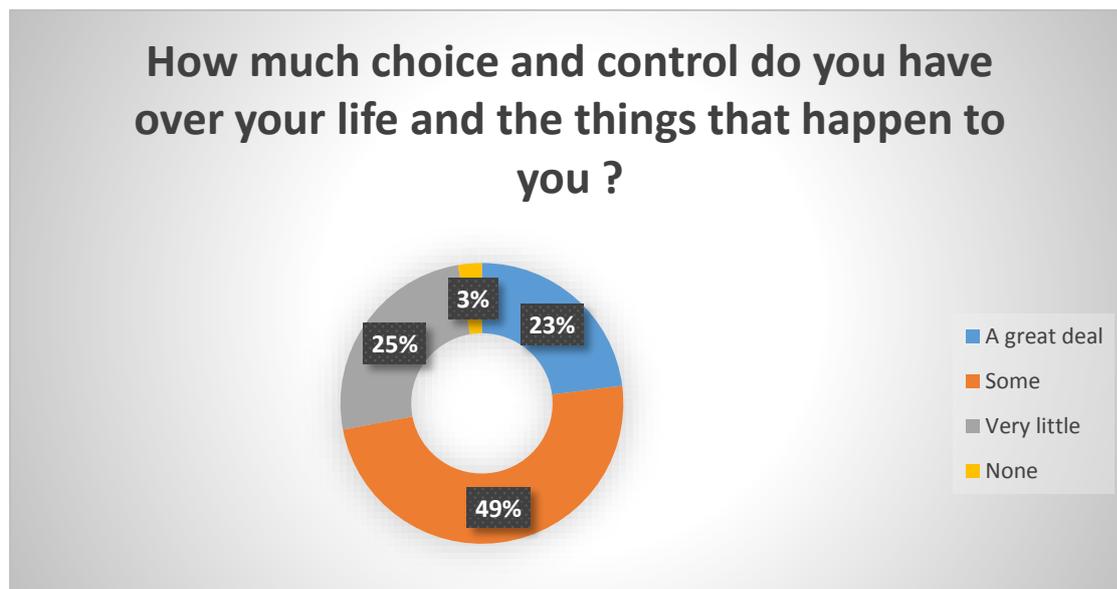


Carers Health and Wellbeing

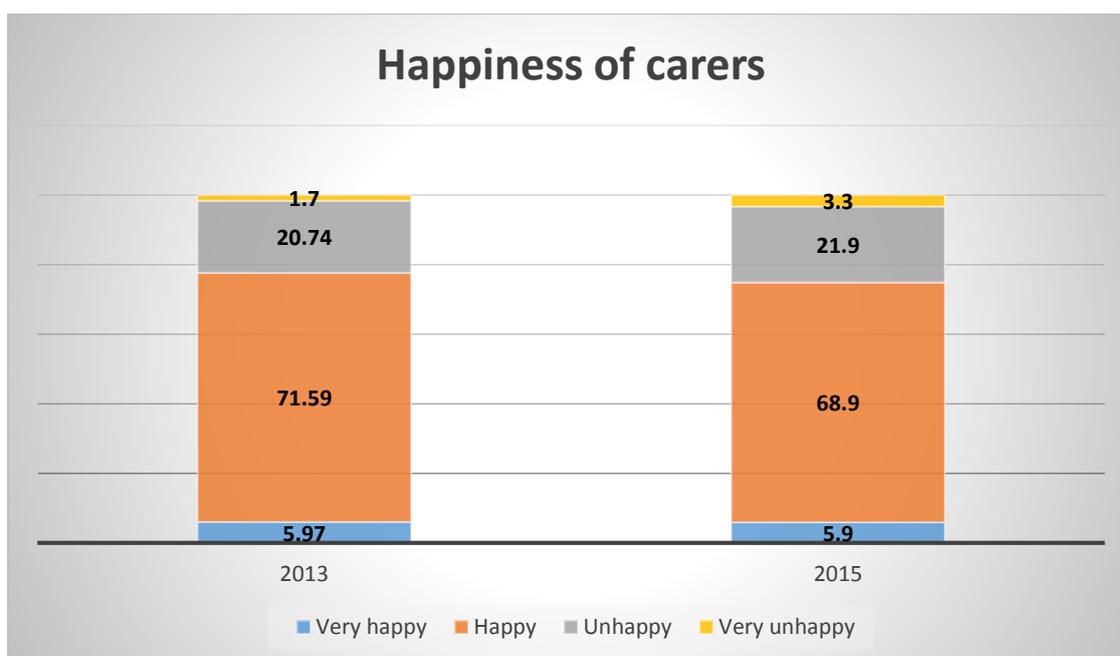
Although carers reported that they consider their health generally as “ok”, a closer examination of responses, indicates a negative trend in comparison to the 2013 Carers SA survey:

- An overall decline in general carer health (59% in 2015 - 63% in 2013).
- 30% of carers reported their health as being worse than during the previous year.
- 13% of carers are not exercising and 26% are doing less than 1 hour of exercise per week.
- 17% (2013; 15%) of carers indicated that their health was poor.
- Carers indicated that they have less than 5 hours per week of ‘me time’. ‘Me time’ activities listed by carers included essential activities and household chores as well as group activities such as socialising and spending time with family and friends (66%), exercise and sport (19%), volunteering (8%) and cooking/baking (6%).

89% of carers reported that they put the needs of the person they are caring for before their own often, or all the time. Further, 22% of carers reported feeling generally unhappy and 25% believe that they have very little choice and control over their life and the things that happen to them.



Nearly 50% of carers believe they have some control over the life this is a 15% increase in carers’ belief from 2013. A further 23% believe that they have a great deal of choice and control over life; this is a very positive increase of 7% on the 2013 survey.



When asked about their overall state of happiness, the majority of carers reported being happy. However, 25% are either unhappy or very unhappy. This compares similarly to 2013 results, with a minimum increase (4%) in carers' overall unhappiness.

Digital Literacy – Carers Online

Our community is seeing a shift in the provision of information to online platforms. In particular, these changes have occurred in the disability sector, aged care services, official distribution of Government information, banking, shopping and social engagement. Digital literacy skills are becoming the forefront of carer concerns and will become vital to support carers in negotiating the online environment effectively. In response to perceptions of concern over digital literacy, Carers SA asked carers about their use of digital devices and their online activity.

Somewhat contradictory results emerged from the survey. Firstly, about half of the carers who use electronic devices such as mobile phones and email, have also reported that they generally do not access websites. Secondly, although 22% of carers indicated that they consider the Internet as an effective source of information, 51% indicated that they preferred to ask a professional/service provider and would actively seek or prefer person to person contact.

These results are echoed through comments left by carers stating that the internet *“is so impersonal and caused so much stress to the already stressed out carer! Many older people do not have access or the ability”* and that *“Speaking with people in person can often save me hours of time, as opposed to searching online over multiple websites”*.

These comments reinforce responses indicating that 67% of carers who are online have not used websites specifically designed for carers and an additional 12% of carers were uncertain if they had used websites specifically designed for carers. My Aged Care, a website designed to simplify the process of negotiating the aged care system and information, had not been used by 77% of respondents who are carers of the elderly.

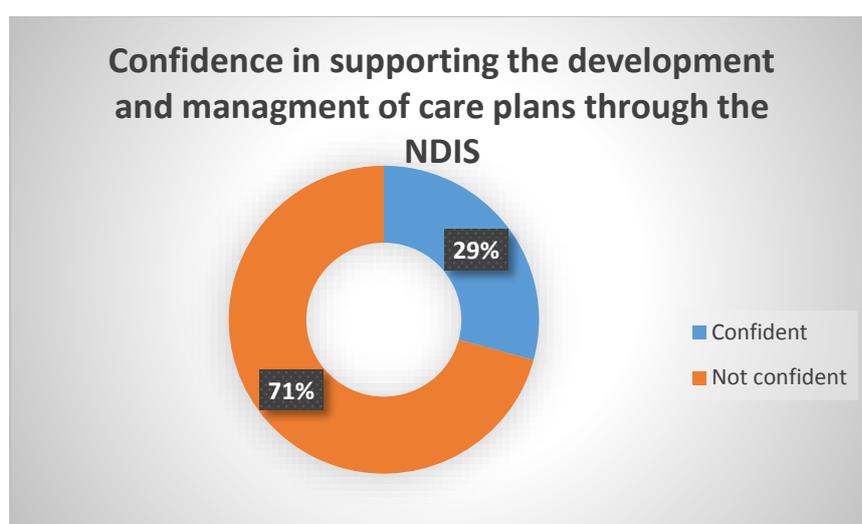
However, there is a small group of carers who have successfully made the shift to digital technology and use the Internet to access information and services. These carers reported that they successfully search for services and use the internet extensively to access email accounts, download and/or print off articles, manuals or instructions and search for contact information on provider/services websites. Further, some carers use the internet for online banking, shopping, social media and entertainment. However, very few carers use web-chat purposes facilities to ask questions.

National Disability Insurance Scheme - NDIS¹

The National Disability Insurance Scheme (NDIS) has been operating over a number of trial sites across Australia since July 2013². The trials will be implemented over a three year period and in South Australia involves children from birth to 14 years. The NDIS is based on individualised funding to enable people with disability to exercise choice and control in the selection and use of the support they require.

Family carers are the cornerstone of support for many people with disability.

Over half (54%) of carers are unsure whether they, as a family are eligible for the NDIS. Nearly three quarters of carers do not have confidence in the development and management of care plans through the NDIS.



¹ NDIS Homepage: <http://www.ndis.gov.au/>

² NDIS sites: <http://www.ndis.gov.au/about-us/our-sites>

Carers SA Consumer Feedback

Carers strongly endorsed Carers SA services.

- 97% of carers who have had contact with Carers SA would recommend the organisation to another family carer.
- 95% of carers stated that they felt understood, respected and listened to when talking to Carers SA.
- A 79% of respondents who had contact with Carers SA, indicated they gained access to services or support that was appropriate to their needs and family situation.

Carers were asked to indicate the type of services and support from Carers SA they had access to and/or would like to see extended. The most popular answers included support in accessing respite and information related to financial support and payments. The second tier of popular services carers indicated they prefer Carers SA to provide (more of) included good

“Carer SA staff were great. I didn’t feel so isolated anymore, knowing they are there and able to offer support and understanding.”

Survey respondent, 2015.

practice workshops for carers in their roles as carers, general information relevant to carers, training courses and carer events, computer/tablet training and specialist counselling for carers.

Most carers prefer the personal contact – a personal touch - in service delivery

and information sharing. Carers generally became aware of Carers SA through a carer they knew (36%), followed by recommendations from a service provider (14%), an Internet search (12%) Commonwealth Respite and Carelink Centre (11%) and other advertisements (9%).

Carers SA will certainly continue its commitment to be the voice of carers, represent carers and provide support for family carers in South Australia. Carers SA appreciates feedback and suggestions and will continue to expand its supports and engagement with carers.

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