

# South Australian Home and Community Care (HACC)

## Carers Project Report

Presented to the Department for Communities and  
Social Inclusion, South Australia

*HOKJOK*

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Amanda McInness undertook the consultations with the Aboriginal and Torres Strait Islander communities and assisted with some data entry. Administrative input was provided by Stephanie Rogers.

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## GLOSSARY OF TERMS

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ACAT	Aged Care Assessment Team
ATSI	Aboriginal and Torres Strait Islander people
CALD	Culturally and Linguistically Diverse people
CACP	Community Aged Care Packages
Care Recipient	Person receiving care sometimes known as caree
Carers SA	Carers Association of SA Inc.
Carer Support Network SA	<p>The Carers Support Network is comprised of seven organisations which use the Carer Support Model unique to South Australia:</p> <ul style="list-style-type: none"><li>- Carers' Link: Barossa &amp; Districts</li><li>- Carers' Link: Lower North</li><li>- Carers' Link: Yorke Peninsula</li><li>- Carer Wellness Centre Adelaide Hills and Strathalbyn</li><li>- South Coast Carer Support: Southern Fleurieu Peninsula</li><li>- Northern Carers Network: Northern Suburbs</li><li>- Carer Support and Respite Centre: Southern &amp; Eastern Suburbs</li></ul>
Current carers	Carers responding to the survey who self-identified as a current carer (10 % of these were caring for someone in formal care)
DoHA	Department of Health and Ageing
EACH	Extended Aged Care at Home
EACHD	Extended Aged Care at Home, Dementia
FaHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs
HACC	Home and Community Care
HACC eligible carers	Carers of those frail older people and younger people with a disability who meet HACC eligibility criteria (See section 2.1)

MDS	Minimum Data Set
Past carers	The term past carers refers to bereaved carers and carers who identify as past carers
Past HACC carers	Former HACC eligible carers, i.e. the people they care for are no longer eligible for HACC services, e.g. have moved into residential care, being provided with a higher level package
HACC Carer Support Agency	Agencies which support HACC eligible carers
NB	Nota Bene (special attention should be paid to this)
OHS	Occupational Health and Safety
RDNS	Royal District Nursing Service
SATSS	South Australian Transport Subsidy Scheme

## DISCLAIMER

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This paper has been prepared as described in the methodology section of the report. The findings in this paper are based on a qualitative study and quantitative study and the results reported reflect the perceptions and self-reported impacts and needs of the Department for Communities and Social Inclusion's approved sample of stakeholders.

Whilst the carer stakeholder sample is over 500 people any projection to the wider population of stakeholders is subject to the extent of representation of that broader population among the stakeholders included.

No warranty of completeness, accuracy or reliability is given in relation to the statements and representations made by, and the information and documentation provided by stakeholders consulted as part of the process, and the Department for Communities and Social Inclusion (formerly the Department for Families and Communities).

HOKJOK has indicated the sources of the information provided with the following exceptions: identifying details of survey respondents from either HACC carer support agencies or current and past carers are not provided. HOKJOK is under no obligation in any circumstance to update this paper, in either oral or written form, for events occurring after the paper has been issued in final form.

The views in this paper have been formed on the above basis.

This report is solely for the purpose set out in the Project outline and for the Department for Communities and Social Inclusion's information. This report has been prepared at the request of the Department for Communities and Social Inclusion in accordance with the terms of HOKJOK's engagement contract. Other than our responsibility to Disability Ageing and Carers, Department for Communities and Social Inclusion, neither HOKJOK nor any member or employee of HOKJOK undertakes responsibility arising in any way from reliance placed by a third party on this paper. Any reliance placed is that party's sole responsibility.

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## 1 EXECUTIVE SUMMARY

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The current Home and Community Care (HACC) program is a joint Australian Government, State and Territory initiative to provide low level support to:

a) the ‘target population’—people in the Australian community who, without basic maintenance and support services provided under the scope of the National Program, would be at risk of premature or inappropriate long term residential care, including—

- (i) older and frail people with moderate, severe or profound disabilities;
- (ii) younger people with moderate, severe or profound disabilities; and
- (iii) such other classes of people as are agreed upon, from time to time, by the Commonwealth Minister and the State Minister; and

b) the unpaid carers of people assessed as being within the National Program’s ‘target population’ . (Commonwealth of Australia 2007, National Program Guidelines for the Home and Community Care Program).

At present there are two types of HACC supports for carers: ‘Respite’ and ‘Counselling, Support, Information & Advocacy (Carer)’. Over the years it has become clear that some carers need different or additional support as their caring role changes or increases. It has also become clear that some carers would benefit from knowing what support is available when the person they are caring for passes on or moves to residential care.

Disability, Ageing and Carers, part of the South Australian Department for Communities and Social Inclusion commissioned the HOKJOK consultancy to undertake the HACC Carers Project. The HACC Carers Project explores ways to respond to the needs and choices of HACC eligible carers and how the HACC Program can support carers’ to: maintain and strengthen the friendships, networks and community connections that carers already have, and successfully manage transitions in their caring role.

The project aims to:

- find out how the HACC Program can help support carers to stay connected to their communities and prepare them for changes in their caring role
- identify what can be done within the HACC Program to help carers:
  - live their own lives
  - stay connected to their communities
  - maintain their interests and employment
  - maintain a sense of worth and what is important to them
  - maintain and strengthen what they already have e.g. friendships, social networks
  - understand HACC and purpose of HACC carer supports
  - prepare for the time when they are no longer eligible for HACC support.
- develop a framework of practice about how the HACC Program could maintain and strengthen carers' existing networks and supports.

The project methodology is based on a community development model which empowers people to effect change in their community and had strong carer participation with more than 500 carers participating either by attending meetings and/or completing the carer survey. The methodology included a literature survey, the establishment of an Advisory committee, face to face consultations and two surveys (one by current and past carers and one by Agencies).

The project findings are based on large samples of both qualitative and quantitative data with over 196 current and past HACC carers participating in 23 community meetings and 434 people responding to the Current and Past HACC Carers survey. While some survey sample sizes were comparatively smaller i.e. for males, employed respondents and the CALD community they were still larger than the previous qualitative studies on transition issues reported on in the literature survey. Large samples of both current and past carers responded as did carers from both metropolitan Adelaide and Regional South Australia. The 23 meetings aimed to cover a representative group of carers in terms of age, gender, geographic location, illness or disability of the care recipient and caring status.

Of the current and past carers surveyed 47% indicated that they received details of their eligibility for HACC and 52% believed that they understood the HACC program and the purpose of HACC carer supports. Given that HACC support is entry level support for care recipients this number is relatively low and indicates that there could be additional promotion of HACC services both for care recipients and carers.

Two thirds of the people who responded to the survey were caring for people aged 65 or over with 29% caring for someone aged 80 or over.

Over 60% of survey respondents are or have been caring for over 40 hours a week and nearly 60% of both current and past carer respondents provided care for more than six years. Long term caring was higher amongst current carers with 33% of current carer respondents indicating that they have spent more than ten years caring at this point in time versus 26% for those identifying as past carers.

Of the 299 respondents who identified as being in a current caring role, 62% said they spend more than 40 hours a week providing care however, only 11% indicated that the person they were caring for was receiving a higher care package (i.e. CACP, EACH or EACHD).

One third identified that their care recipient received support from HACC, 33% said that the person they cared for was not receiving any assistance and 12% were unsure where the care recipient was getting assistance from.

Carers save the Australian government and taxpayers \$40.5 billion p.a. (Access Economics 2010). It is therefore important they are not penalised, but supported for the escalating level of caring they provide. According to the Australian Bureau of Statistics Survey of Disability, Ageing and Carers (2009), 38% of primary carers in South Australia provide more than 40 hours of care per week. This matches the survey findings with more than 60% of respondents indicating they provide more than 40 hours a week of care.

These findings indicate there were a number of carers who responded to the survey are caring for people who have needs greater than the low level HACC program and thus the carers would strictly not be eligible for HACC. Carers often accessed HACC services late in their caring role and require greater assistance but only are able to receive HACC support which is low level. Carers with higher needs appear to have been accessing the HACC Program but their higher needs have been hidden within this Program and are not addressed by funding and other programs. This report highlights that HACC low level services do not reflect the care levels provided by vast number of carers and their need for support.

Therefore findings and recommendations contained in this report are not solely relevant for the HACC Program as it is clear they would be significant to other State and Commonwealth government programs, policies, planning and funding. The changing, and often increasing needs of carers should be included in the development of a HACC and disability levels of service approach.

## IMPACT OF CARING

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It is clear that there is no single impact of caring. The impacts vary from person to person depending on a range of circumstances.

For some carers, caring has been an inner personal journey and they said they had grown as a person, developing patience, calmness, understanding, compassion and tolerance. A number of carers said caring had made them a stronger and more independent person and an advocate for their family. Improving self care skills and focusing on the positives assisted some carers to change how they viewed life as a carer. Many carers said they had developed a stronger relationship with the person they were caring for and some carers said that the whole family was strengthened by caring.

Carers were appreciative of the support of workers who helped them. Many carers valued the friends they had gained through carers support groups and retreats. As well as friendship and companionship support group members were seen as a useful source of advice they could relate well to because of their common shared experiences as carers.

The majority of carers spoke of changes in their lifestyle because of their caring role.

The negative impacts of caring and the challenges of caring far outweighed the positive comments in the survey responses and at the various meetings by a ratio of about 20 to 1. There was a strong theme of loss and restrictions in current and past carers comments. For many carers the person they were caring for took priority over their own needs and well being. Lack of time for the carer's own needs impacted negatively on their life in a variety of ways.

Carers with other work and family responsibilities found it hard to find sufficient time to undertake all the tasks associated with caring. Some carers retired early or left work because of the difficulty of balancing the caring role and work.

There are primarily two negative financial impacts on carers. The first is a decreased income and the second an increase in unavoidable additional expenses. Carers said that financially they struggled to meet the extra costs associated with caring. A lack of funds prevented some carers from undertaking activities or socialising. Carers also expressed concern about the high cost of respite and the cost of accommodation bonds and entry to low care residential accommodation.

Carers reported that caring was a significant physical and emotional commitment and for some carers this led to negative health outcomes. The loss of time to exercise was seen as a cause of physical deterioration.

Carers spoke of feelings of helplessness, loneliness, guilt and grief. A few current and past carers were unable to find anything positive in the caring role. They said it was too hard, devastating, challenging and tiring. Some people shared that they felt suicidal or had thought of suicide /murder. A number spoke of having been treated for depression.

Carers caring for someone with behavioral issues faced difficulty coping with moodiness, personality changes, aggression, mood swings, memory loss and anger. Grandparents said caring impacted on their health and family life. Carers of both young and adult children with disabilities found it time consuming particularly, if there was a need to maintain constant supervision. A major concern for many of these carers was what would happen to the care recipient when they became ill, unable to care or died.

## YOUNG CARERS

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Many young carers indicated they felt older than their years with some undertaking adult responsibilities. Young carers both male and female between the ages of 10-17 years predominately worried about friendships and schooling. Carers in years 11 and 12 found schooling difficult and they struggled to balance their caring role and school needs.

The young adult carers aged between 18-25 years who were interviewed were struggling more in their caring role than the very young carers. They indicated that they felt 'cheated' of their youth and in many instances had been thrown into the caring role without being asked. There was a pattern in those interviewed of older children leaving home and the youngest left to care. They were provided with limited supports and struggled to find the balance between their caring role and developing a life for themselves. Their greatest fear was what was going to happen to them once their caring role ended in 10 to 20 years time. Many relied on the internet as their source of communication.

Young adult carers were concerned about their:

- lack of work
- lack of opportunities
- non-existent career path
- lack of qualifications
- lack of long-term savings
- lack of money on a regular basis
- lack of emotional support
- transport difficulties
- lack of a license
- limited or non-existent friendship group
- lack of a social life
- lack of a significant relationship with the opposite sex
- lack of family support
- the potential of not having children.

Younger carers need more research and a specific program of support developed which enables them to meet their developmental needs.

## CARER CONCERNS

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Over 25% of all current and past carers were concerned about:

- a future loss of companionship
- losing touch with things in their own life that were important to them
- accessing appropriate residential care for the person in their care
- costs of low and high care residential care
- dealing with conflicted feelings about the care recipient going into formal care.

Carers were also concerned about the development of their own health issues.

A few carers expressed concerns about dealing with various agencies including Centrelink (during bereavement), the Department of Health and Ageing, Carers SA, RDNS, private operators and Government in general. A view was expressed that carers lacked an independent body which they could utilise to make complaints about both carer support services they received and services provided to the care recipient.

Relocation also emerged as a small but significant issue amongst carers.

## STAYING CONNECTED

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Over 70% of survey respondents said that they had experienced difficulties staying connected to their community, family and friends during their caring role. The 6 primary reasons why carers had difficulty in staying connected were:

- lack of time (35%)
- fatigue (32%)
- unable to leave caree (31%)
- family and friends not understanding (22%)
- personal health problems (20%)
- lack of money (19%) (Figure 12).

Survey respondents said it is the caring role itself which is creating the biggest difficulties with staying connected and feedback at community meetings and discussions with workers supported this finding. The average number of weekly activities undertaken outside the home by current carers was activities per week before caring and 2.5 activities per week whilst caring. Agencies also indicated that a lack of time and fatigue made it difficult for carers to maintain their links with their community, family and friends.

Caring impacted negatively on some family relationships in a number of ways. Carers social lives were affected and a strong theme throughout was that carers said they had lost friends with previous social networks weakened by the caring experience.

## CARER SUPPORT

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The most common types of support offered to carers by HACCC funded agencies were information (83%), followed by respite (75%), one on one support (71%), advocacy (67%) and counselling (67%). A number of agencies indicated that they provided support to carers through emails, Facebook and SMS bulk messaging. These were predominately to younger carers between the ages of 17-30 years.

Carers nominated a support group, respite and friends as their top 3 sources of both formal and informal sources of support. Carers said that friendships in support groups were very important and they had lost touch with many of their other friends.

Eight general supports carers found helpful or would have found helpful in their caring role were:

- regular review of services and support needs (37%)
- flexible respite (36%)
- weekend respite (25%)
- emergency respite (22%)
- all day respite (20%)

- transport assistance (20%)
- more social support (20%)
- clear information about HACC when commencing the service (20%)

Some carers wanted to be able to buy in the services they specifically required.

The four major forms of assistance or activities which enabled carers to stay connected to their community, family and friends were:

- assistance and visits from family, friends and neighbours (47%)
- support groups (44%)
- respite (33%)
- phone (30%).

CALD and ATSI carers all stated that culturally and linguistically specific support groups enabled them to remain connected to their communities, families and friends.

Many carers, particularly younger carers relied on the internet (17%), to remain connected to the wider community, family and friends.

Support was important in letting carers know that they were not in it alone. It gave them reassurance and encouragement. Quite a few past carers at meetings said they used support to catch up on sleep or relax.

The following helped carers to care for themselves: time for themselves; retreats; respite; family support; support groups; their own personality and or a positive attitude; counselling; staying fit and healthy and undertaking recreational activities. When family support was forthcoming, it was particularly appreciated.

Other areas which assisted carers to care for themselves were:

- *'pampering'*, such as massages, lunches and visits to physiotherapists, chiropractors and hairdressers
- information or courses on stress management
- maintaining their voluntary activities
- maintaining employment

- financial support
- their faith
- additional domestic assistance to allow carers more time to relax at home.

Carers stated that respite was crucial for them to be able to care for themselves. They wanted respite to be flexible, overnight, weekend and long stay. Younger carers and regional carers wanted additional respite to be provided. The agency survey confirmed this indicating that agencies saw respite as a crucial component in enabling carers to build resilience and maintain their connectedness in their community.

Support groups were particularly valued by carers who did not have supportive friends or families. Support groups offered carers:

- strength
- guidance
- information
- a learning environment
- a sense of belonging
- an ability to connect with other carers in similar circumstances
- a non-judgmental environment
- shared experiences.

The requirement for extra counselling was mentioned by carers of all ages, in both metropolitan and regional locations and by carers of both genders. Those in challenging ongoing care situations indicated that they required monthly counselling to enable them to cope with their circumstances. Carers said that counselling was useful because:

- it helps to share your problems with someone not involved
- it assisted them to stay connected with their own needs
- it assisted them to deal with the emotional experiences they experienced caring
- it helped them to develop strategies to cope
- it was help provided specifically for the carer.

Carers indicated that there were a range of supports which assisted them to be able to continue with their interests, namely:

- respite
- support from family or friends
- transport assistance
- availability of the internet
- support group activities/ outings.

Carers in the workforce stated that a number of supports assisted them to continue working and caring:

- flexible respite
- flexible working conditions and hours
- support from colleagues
- the ability to work from home
- assistance from families and friends.

Many carers wanted to continue working as this took them away from their caring role and gave them some relief. They highlighted the importance of having an employer and colleagues who understood and supported them when they were not able to attend work because of a caring-related crisis.

## INFORMATION

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Education and/ or information is an ongoing necessity for most carers, it assists carers to:

- help reduce stress levels
- better deal with health related issues
- better care for themselves and the care recipient
- access support
- enhance their emotional wellbeing
- social support
- improve self esteem.

Carers nominated a range of information which was or would be helpful in the caring role including:

- managing stress (39%)
- organisations which provide support for carers (31%)
- preventing and or dealing with depression (31%)
- legal issues (31%)
- organisations which provide support for care (31%)
- Centrelink entitlements (29%).

Carers also wanted information on carer support groups (24%) and dealing with loss and grief (20%).

Agencies indicated that many carers did not absorb all the material they were provided with initially and need to be provided with it in a drip approach, rather than flooded with information early in their life as a carer. Transition times are emotionally difficult for carers and carers varied in how they preferred to be provided with information.

## LITERATURE SURVEY

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The literature survey found a range of supports are critical to carers making an effective transition when the person they care for died, and the withdrawal of these should be gradual rather than sudden and linked to the death of the cared-for person. This research was supported by the findings of this project.

There is a need for new service models to ease the transition between providing home based care and supporting care in a formal environment which acknowledge this as a time when carers are likely to continue to need a range of supports.

Formal services have a key role to play during this time recognising that although the caring role at home has ceased, its impact on the carer continues and is evident in the profound sense of loss experienced by many. Such services include counselling, advice, information and carer support groups.

There is also potential for former carers to play a role in supporting carers in this phase and for carer services to employ them for this purpose.

## AUSTRALIAN OVERVIEW

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A range of Australian HACC funded agencies in New South Wales, South Australia, Victoria, Queensland, Tasmania and Western Australia recognised that there were gaps in supporting carers whose care recipients moved to higher care packages, into residential care or passed away.

Agencies struggle to end the relationship with carers particularly when they need the support the most and a number of the agencies are prepared to support carers for as long as is needed.

Participation in broader activities is encouraged to assist carers to maintain their own identity whilst in the caring role. HACC agencies refer carers onto other supports (75%), regularly review the service and support needs (71%), inform carers when eligibility to HACC services ends (71%) and provide carers with information on how to deal with loss and grief (71%).

Nearly 60% of agencies indicated that they provided support to carers who were no longer eligible for HACC.

HACC agencies believe that carers are most vulnerable and need additional support to get them through a very difficult time when their caring role alters and the person they are caring for moves into care or passes away.

At times of bereavement or the move to formal care many carers found that two or three counselling sessions were not enough to get them through such a difficult time.

Agencies tended to provide the most support to past HACC carers who had placed their family/friend into residential care or supported accommodation.

The most common supports provided to past HACC carers were information, telephone support and one on one support. It would be challenging to charge full fees for these services.

Agencies indicated that supporting past HACC carers:

- reduced the threat of social isolation
- assists them to work through their loss and grieving process
- assists them to work through their changed role
- assists them to re-establish their links with family, friends, and community
- helps them to navigate through the system.

The agency survey found that only 59% of past HACC carers received agency services after their eligibility ended with 13 % receiving services for 1 to 13 weeks, 8% receiving services for 14 to 26 weeks and 8% receiving services for 27 weeks to 1 year. Seventeen percent stayed between 1 to 3 years and a further 13% remained for over 3 years.

Establishing time limits on the transition period was viewed as unworkable in some instances and not needed in others because the majority of past HACC carers take up their new lives of their own accord.

The primary reason given by Agencies for providing this support was carers requesting to stay on the programs (21%).

Only 8% of these past HACC carers were paying the full cost of the service and participating as user pays. Quite often agencies used alternative more flexible funding sources and volunteers to assist in providing these services.

Agencies varied in the amount of time they said they spent on support to past HACC carers. Agencies cannot report this support activity back to the funding body through MDS.

Agencies indicated that an allocation of dedicated funds to supporting carers move through their caring role would have beneficial impacts for carers and agencies.

This transition time is emotionally difficult for carers and this is supported by the research findings, agency feedback, and carers' comments.

Past carers found:

- continuing to attend a support group which they are already attending (39%)
- friends and family (30%)
- information about residential care options (26%)

the most helpful types of support when the person they were caring for moved to either residential or supported accommodation.

Current carers were more focused on the process and the 'how to' of managing the move to formal care with 58% nominating information about residential care options and processes and 48% nominating support and advocacy in choosing an appropriate facility as the types of help they anticipated would be helpful. As with past carers support from family and friends was anticipated to be the second most useful type of support with 49% indicating that they would find this helpful.

26% of current carers aged 25-64 indicated that respite, information about return to work options, retraining/up skilling and flexible work arrangements would assist them to return to work and 14% wanted to access a return to work program. Two carers over 65 also wanted to access a return to work program.

Some carers who had been out of the workforce for some time expressed fear and apprehension about reentering the workforce.

The Framework reflects both the feedback from carers and carer support agencies (via surveys and face to face consultations) and the findings of the literature review. They link to the seven Principles of the South Australian Carers Charter, the six South Australian HACC Service Principles as well as to the National Carer Recognition Framework and the Community Care Common Standards. The proposed Carer Practice Principles which follow add a further dimension to the current policy directions, underpinning principles and goals that are relevant and appropriate for carers and support recent moves to consumer directed support (that is, the tailoring of services and supports to individual need, and increasing the control by consumers of their own support).

### **Carer Practice Principles**

1. Services and support should be individualised to reflect the fact that carers' needs differ according to their cultural and linguistic background, language spoken, health status, age, gender, location, formal and informal support networks, community connections, employment status, time spent caring, nature of caring role, care recipient needs and their ability to utilise respite.
2. Agencies should adopt a holistic approach to providing services including exploring the availability of formal and informal supports, interacting with other agencies and the broader community and/or utilising multiple funding sources to meet carers' individual needs.
3. Carer services and support should be sufficiently flexible, responsive, timely and accessible across the caregiving journey, including the period following the cessation of caregiving responsibilities.
4. As carers' needs change across the caregiving journey and the process of change differs from one carer to another, regular reviews of carers' needs should be undertaken and support and information provided to reflect changes in the caring role and prepare carers for upcoming transitions.

5. Services and supports for carers should play a critical proactive role to prevent and/or address the negative impacts of caring, including poor physical and mental health outcomes, loss of earning and career development opportunities, and loss of social, and sometimes, family relationships.
6. Carer support services should be well publicised and easy to access with clear communication to carers about eligibility criteria and what a particular service can and cannot provide.
7. Information should be provided to carers:
  - at the beginning of the caring role to increase their awareness of what assistance is available and to navigate the service system
  - in a variety of mediums and in a format requested by the carer
  - that is timely to prepare and support carers through transitions
  - about community support and short and long term formal care options for frail older people and younger people with a disability if the carer is unable to continue caring.
8. The impacts of the caregiving role are profound and enduring and service policies and guidelines should reflect the fact that carers' need for support does not necessarily end with the death of the care recipient or the care recipient's entry in to full time formal care. Agencies should take a supportive approach to prepare carers for periods of transition by linking to counselling and other options that will assist carers to:
  - increase their resilience
  - work through their loss and grieving process
  - work through their changed role
  - re-establish their links with family, friends, and community
  - navigate through the system.

9. Agencies should adopt a flexible approach to providing respite services and should explore the provision of non-traditional forms of respite, for example, internet access, driving lessons, and assistance to maintain interests.
10. Agencies should develop programs and prioritise the provision of carer respite to enable carers to lead a balanced life by maintaining their interests, connections with the community and to family and friends, their social networks and employment.
11. Agencies should offer some carer support services outside of working hours so that working carers have the ability to access them.
12. Agencies should develop a policy to support their employees who undertake a caring role, and where possible offer flexible working arrangements and the ability to work from home.

## RECOMMENDATIONS

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The following recommendations are based on the findings of the consultation process and the literature review. A number of carers who participated in the consultation were no longer eligible for HACC services and a number also spoke about services that affect them outside the scope of the HACC program. As a result, a number of these recommendations fall outside the scope of the HACC program, however they are included as they are important for both State and Commonwealth governments and service providers to consider for delivering services for carers in the future.

1. It is recommended that HACC funded agencies and other agencies that support carers adopt the Carer Practice Principles outlined in the Carer Practice Framework.
2. It is recommended a review is undertaken within the next three years to evaluate the uptake of the Carer Practice Principles and HACC Carers Project recommendations to ascertain the impact of their adoption on the lives of carers and their success in keeping carers connected to their community.
3. It is recommended that a level of service approach is developed and applied to carers including programs to reflect that carers' needs change across the caregiving journey and the process of change will differ from one carer to another.

4. It is recommended that information sessions and/or support groups are established specifically for carers whose care recipient is entering residential care or supported accommodation (both at the places of formal care and independent of these) which as part of its role:
  - meets some of the information needs of carers during this period
  - provides support in this transition stage
  - assists carers to reconnect with their interests, the community, family, friends and employment (depending on their age).
  
5. It is recommended that information sessions and/or support groups are established for bereaved carers which:
  - assist with grief, loss and guilt
  - assist carer to transition from the caring role and reconnect with their interests, the community, family, friends and employment (depending on their age).
  
6. It is recommended that support group members are informed how they could establish a past carer support group, some of the activities which existing groups undertake and what formal assistance might be available to them.
  
7. It is recommended that other support options such as ongoing engagement in existing support groups, counselling, visits from former carers and volunteers and membership of established groups of past carers such as the Barossa group and the Mt Barker group are also explored.
  
8. It is recommended an evaluation is undertaken within the next three years to review the various benefits of new carer support groups (Recommendations 4, 5, 6 and 7) versus and/or in conjunction with other transition supports.
  
9. It is recommended that the Commonwealth Government undertake research into extending the Carers Payment for a period of time to carers who are under the Aged Pension age to enable them to recover from the caring period before transitioning to Newstart payments or employment.

10. It is recommended that carers are encouraged to develop emergency care plans and these are updated as part of a regular review of carer needs to reflect the changing needs of both the carer and care recipient.

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### WORKING CARERS

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11. It is recommended that carers who want to remain working or to enter or re-enter the workplace are provided with a range of support options to assist them to balance work and care. This could include development of a program of support offering counselling, respite, assistance to explore training or education and support to negotiate flexible working arrangements.

12. It is recommended that further research is undertaken into the needs of working carers including respite and flexible working arrangements and based on this research a three year pilot program is developed and implemented.

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### SUPPORTING CARERS

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13. It is recommended a Carer Advocacy Service is established and further exploration is undertaken to explore its role, scope and the benefits.

14. It is recommended a subsidy scheme for carers which utilises a discount card scheme to enable carers to access discounts from Government services and businesses (similar to Seniors card) is established.

15. It is recommended that further research be undertaken to explore how family and friends can support carers in their caring role and how shared care arrangements can be supported.

16. It is recommended that further research into a holistic approach to carer support be undertaken for carers who have difficulty utilising respite, attending retreats and/or support groups. As a result, a pilot program should be developed and trialed.
17. It is recommended that future research is undertaken on the carer support needs of high need carers including those caring for more than one person, sequential carers, long term carers and young carers.
18. It is recommended that research is undertaken to develop programs to reduce the financial impact of caring. Consideration for Recommendations 9, 14, 22 and 27 should be included in this research.

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#### STAYING CONNECTED

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19. It is recommended there is a renewed focus on the development of flexible respite for evening, weekend and occasional longer periods of respite based on carers individual needs.
20. It is recommended that a strategic approach to the development of programs trialing non-traditional forms of respite based on carer feedback is established, for example internet access and driving lessons for carers.
21. It is recommended that activity-based meaningful respite programs are explored and further developed to encourage care recipients to utilise respite programs and allow carers to have a break from the demands of caring. Priority should be given to programs for carers of people with dementia and younger people with a disability past school age.

22. It is recommended that additional respite is provided for carers of:
- younger onset dementia care recipients as their needs and behavioural issues increase
  - children with a disability to assist carers access education and work
  - younger carers to assist them to access work and education programs.
23. It is recommended that there is further research into transport assistance for carers which takes into account the fact that carers often have reduced financial capability. This research should explore options such as the multiple use of SATSS vouchers for a single taxi trip and petrol subsidies and approaches for carers without access to alternative means of transport.

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#### MAINTAINING CARERS WELLBEING

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24. It is recommended a national program of free preventative health checks, home and community based exercise programs, relaxation and stress management programs for carers is developed. This could include the use of massage to reduce carer stress.
25. It is recommended that the National Carer Counselling Service is expanded to provide regular counselling if required, access to counselling at key transitions (including bereavement, entry of the care recipient into formal care and return to work) and that past carers should remain eligible for 12 months after their caring role ceases.
26. It is recommended carers are supported to focus on their personal wellbeing. This could include programs to support carers to develop time management skills to schedule breaks for themselves which they can utilise for exercise, relaxation, stress management or recreational activities such as hobbies or gardening.

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## YOUNGER CARERS

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27. It is recommended that a specific program of support for young carers to support them to meet their development needs is developed in conjunction with FaHCSIA and other appropriate agencies. It would include:

- more socialisation
- information and support in formats utilised by youth
- training and information pertinent to the caring role and household tasks if necessary
- access to regular counselling and mentoring
- advocacy support
- internet access
- study subsidies
- a pilot on line support group
- respite to access work and study programs
- transport assistance to attend group activities
- specific youth positions
- early intervention strategies and programs.

28. It is recommended that there is an automatic fee waiver for young carers.

29. It is recommended that the needs of young carers are reassessed in three years' time following the implementation recommendation 26 and 27.

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## FUNDING

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30. It is recommended that additional flexible funding is provided for early intervention and proactive programs to ensure carers are supported to stay connected to their community and to prepare for periods of transition.

31. It is recommended that a mechanism is established which will enable agencies to report on transition support and support for past carers.

## 2 INTRODUCTION

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### 2.1 STRATEGIC CONTEXT

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The current Home and Community Care (HACC) program is a joint Australian Government, State and Territory initiative to provide low level support to frail older people and younger people with a disability with low level needs to help them remain living independently in the community and to help prevent premature admission to residential care. The HACC program also provides support to the carers of HACC eligible people to assist them in their caring role. The two HACC services available to eligible carers are respite and counselling support information and advocacy (carers).

The National Program Guidelines for the Home and Community Care Program states the Program should be directed towards assisting:

a) the 'target population'—people in the Australian community who, without basic maintenance and support services provided under the scope of the National Program, would be at risk of premature or inappropriate long term residential care, including—

- (i) older and frail people with moderate, severe or profound disabilities;
- (ii) younger people with moderate, severe or profound disabilities; and
- (iii) such other classes of people as are agreed upon, from time to time, by the Commonwealth Minister and the State Minister; and

b) the unpaid carers of people assessed as being within the National Program's 'target population'. (Commonwealth of Australia 2007, National Program Guidelines for the Home and Community Care Program).

From 1 July 2012, the total funding and administrative responsibility for the HACC population over the age of 65 and for Aboriginal people over 50 will be with the Commonwealth Government Department of Health and Ageing (DoHA). The South Australian Government will retain the funding and administrative responsibility of the HACC population under the age of 65 and under 50 for Aboriginal people.

Both the Commonwealth and the South Australian Governments are undertaking work to develop levels of service. It would be prudent to acknowledge the levels of carer needs may also increase.

In preparation for these changes, the Department for Communities and Social Inclusion, who currently administer the HACC Program, have commissioned this report into the needs and choices of HACC eligible carers. The recommendations from this report will be used to inform future funding, planning and administration decisions for both the Commonwealth and State components of the HACC program.

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## 2.2 PROJECT SCOPE

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At present there are two types of HACC supports for carers: 'Respite' and 'Counselling, Support, Information & Advocacy (Carer)'. These supports may be delivered in a variety of ways. For instance some organisations may have carer support groups, one-on-one counselling, exercise programs or information sessions.

Over the years it has become clear that some carers need different or additional support as their caring role changes or increases. It has also become clear that some carers would benefit from knowing what support is available when the person they are caring for passes on or moves to residential care.

Disability, Ageing and Carers, part of the South Australian Department for Communities and Social Inclusion commissioned the HOKJOK consultancy to undertake the HACC Carers Project. The HACC Carers Project explores ways to respond to the needs and choices of HACC eligible carers.

This project explored how the HACC Program can support carers' to maintain and strengthen the friendships, networks and community connections that carers already have and successfully manage transitions in their caring role.

It needs to be acknowledged that carers have varying levels of need and require services responses which match their needs.

## 2.3 PROJECT PURPOSE

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The project aims to:

- find out how the HACC Program can help support carers to stay connected to their communities and prepare them for changes in their caring role
- identify what can be done within the HACC Program to help carers:
  - live their own lives
  - stay connected to their communities
  - maintain their interests and employment
  - maintain a sense of worth and what is important to them
  - maintain and strengthen what they already have e.g. friendships, social networks
  - understand HACC and purpose of HACC carer supports
  - prepare for the time when they are no longer eligible for HACC support.
- develop a framework of practice about how the HACC Program could maintain and strengthen carers' existing networks and supports.

## 3 METHODOLOGY

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### 3.1 COMMUNITY DEVELOPMENT MODEL

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The project methodology is based on a community development model which empowers people to effect change in their community. Carers and service agencies embraced the consultation and were actively involved in the project with the understanding that the outcomes may influence future service provision for carers and agencies. The methodology included a literature survey, the establishment of an Advisory committee, face to face consultations and two surveys one completed by current and past carers and one by Agencies. More than 500 carers participated in this project either by attending meetings and/or completing the carer survey.

### 3.2 LITERATURE SURVEY

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A literature review which looked at Australian and international literature focusing on transition issues for carers was undertaken.

### 3.3 ADVISORY COMMITTEE

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An Advisory Committee was established comprising of representatives from a broad range of community, Government, non-Government, Aboriginal, Culturally and Linguistically Diverse (CALD), advocacy and residential organisations (Appendix 1). The Advisory Committee provided guidance to the project, assisted with the development of the survey questionnaire and facilitated linkages with appropriate agencies, carers and the distribution of the questionnaire for the broader consultation.

### 3.4 CONSULTATION PROCESS

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An extensive consultation process with funded agencies, carer support agencies and carers was undertaken. This included:

- four Advisory committee meetings
- one meeting with Commonwealth Respite and Carelink Centre and the Department of Health and Ageing
- one meeting with the Carer Support Network SA
- four meetings with Culturally and Linguistically Diverse communities
- three meetings with Aboriginal and Torres Strait Islander communities
- three meetings (regional and metropolitan) specifically with younger carers (10 -25 years)
- one meeting with a male carers group
- five metropolitan small group meetings
- eight regional and extended metropolitan meetings
- one metropolitan public meeting
- a carer survey
- a questionnaire for agencies providing HACC carer support
- regular briefings with the Department for Communities and Social Inclusion.

Regional meetings were held in the Iron Triangle (Port Augusta and Port Pirie); the Riverland (Loxton and Waikerie); the Barossa (Nuriootpa); Mount Barker and Murray Bridge. Mount Gambier input was received by phone.

Four culturally and linguistically diverse groups were consulted. These were from the Hungarian, Chinese, Croatian and Italian communities.

A survey was developed for carers and past carers. This was available on the worldwide web and in printed form. HACC carer support agencies and community organisations were sent information regarding the project and encouraged to pass this information on to carers. The HACC Carers Project and the metropolitan public

meeting were advertised in all metropolitan Messenger press papers. Large number of carers, community workers, volunteers and agencies helped facilitate aspects of the meetings and dissemination of the Current and Past Carers survey (Appendix 2).

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### 3.5 CONFIDENTIALITY

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The specifics of written comments were confidential to the consultants. Whilst general points were summarized within the text no identifying specific or actual quotes have been provided without either the permission of the respondent on the response form or the verbal or written permission of respondents who wanted to know which of their comments would be used in the final report prior to publication.

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### 3.6 ANALYSIS OF SURVEY RESULTS

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It was difficult to determine from the survey results if carers were current HACC carers or past HACC carers. Only 52% of current and past carers said they understood the HACC Program (Section 5.3). Some carers who were attending groups were caring for someone who would not access any formal support and not all carers were sure what services the care recipient was receiving. As Section 6.4 outlines only one third of current carers said that they were receiving HACC support, 12% were unsure where the person they were caring for was getting assistance from and 33% said that the person they cared for was not receiving any assistance.

Where the term current carer is used carers identified as a current carer and some of these were receiving assistance from higher level packages or the person they were caring for is in formal care (Section 6.4). The term past carers refers to bereaved carers and people who identified as past carers.

## 4 CONSULTATION PROCESS

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### 4.1 CONSULTATION SUMMARY

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A total of 43 Agency workers were consulted through meetings, by telephone and carer consultations with 25 Home and Community Care Agencies responding to the Agency questionnaire (Appendix 2).

An extensive consultation process was undertaken with carers. This involved:

- over 500 past and current HACC carers participating in the consultative process
- 196 current and past HACC carers participating in 23 community meetings
- 434 people responding to the Current and Past HACC Carers survey
- participation from over 80 people from a culturally and linguistically diverse background
- 53 Aboriginal and Torres Strait Islander people participating with 12 responding to the survey and 41 participating in community consultations.
- 20 younger carers aged 10 to 25 years attending two meetings. None of these completed the Current and Past HACC Carers survey. The needs of younger carers are discussed throughout the report where relevant.

In addition some feedback was provided by telephone from carers.

Not all meeting participants chose to complete the survey.

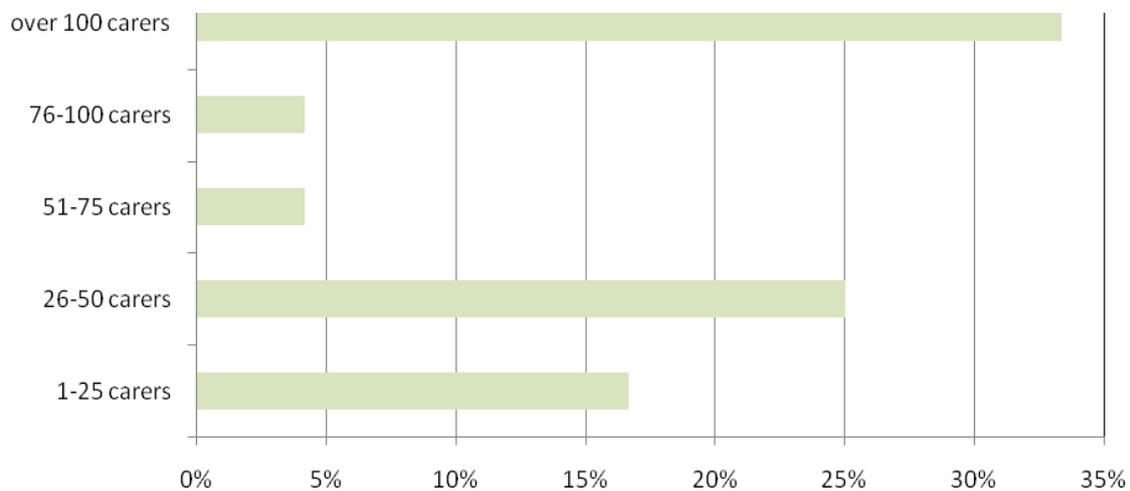
Although one HACC funded Agency and 21 current and past carers responded after the survey deadline, their qualitative comments have been taken into consideration.

## 4.2 AGENCY SURVEY

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The agency survey was sent to 85 Home and Community Care funded agencies with a 29% participation rate of returning a completed survey. One third of these agencies reported they provided services for over 100 carers whilst 25% stated they provided services to between 26 and 50 carers (Figure 1).

FIGURE 1: NUMBER OF HACC ELIGIBLE CARERS RECEIVING SERVICES IN EACH AGENCY



The type of service provision was fairly equally spread between respite and counselling, support, information and advocacy with 71% of agencies providing respite and 75% indicating that they provide counselling, support, information and advocacy (carers)

### 4.3 CURRENT AND PAST CARERS SURVEY

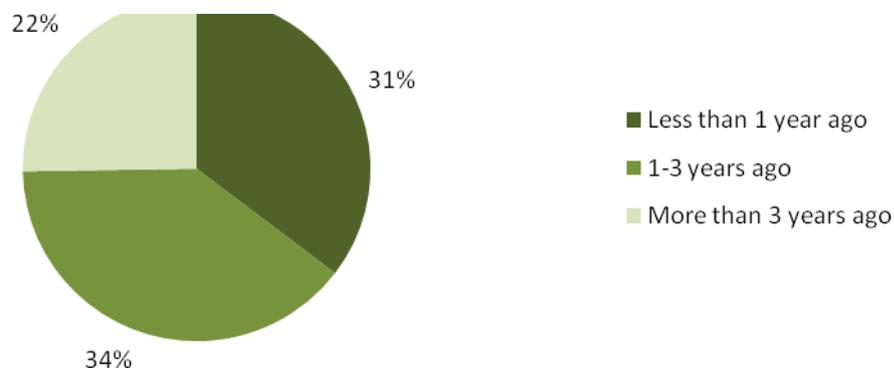
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A total of 432 current and past carers completed the survey. Whilst the survey was aimed at HACC eligible carers only 52% of those surveyed indicated that they understood the HACC program and the purpose of HACC carers supports. As carers were often unaware or unsure if they were HACC eligible all responses have been analysed. Of the 432 responses, 19 surveys were only considered for qualitative evaluation due to their late return. The quantitative survey responses are based on 413 responses. In summary:

- 299 (72%) identified as current carers and 114 (28%) as past carers
- 236 (57%) came from metropolitan Adelaide and 142 (35%) from regional South Australia
- Carers came from over 75 different geographic locations throughout the State
- 12 (3%) people identified as Aboriginal or Torres Strait Islander
- 67 (16%) spoke a language other than English.
- 226 (55%) of respondents were born in Australia
- 172 (42%) were born overseas.
- 239 (58%) were aged 65 or over
- 154 (37%) were aged 64 years or under
- 318 (77%) of respondents were female and 83 (20%) were male.
- 57 (14%) of respondents were employed
- 8 (2%) were looking for work
- 7 (2%) were students (Appendix 3).

Of the 114 carers who identified in the survey as past carers, 22% had ended their caring more than 3 years ago (Figure 2).

FIGURE 2: PERIOD SINCE THE CARING ROLE ENDED FOR PAST CARERS RESPONDENTS



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#### 4.4 KEY POINTS TO NOTE

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The project findings are based on large samples of both qualitative and quantitative data with over 196 current and past HACC carers participating in 23 community meetings and 434 people responding to the Current and Past HACC Carers survey. While some survey sample sizes were comparatively smaller i.e. for males, employed respondents and the CALD community they were still larger than the previous qualitative studies on transition issues reported on in the literature survey. Large samples of both current and past carers responded as did carers from both metropolitan Adelaide and Regional South Australia. The 23 meetings aimed to cover a representative group of carers in terms of age, gender, geographic location, illness or disability of the care recipient and caring status. When assessing the extent to which the project findings can be generalised sections 3.4 and 4.3 should be read in detail.

## 5 HACC CARER SUPPORT

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### 5.1 ACCESSING HACC SERVICES

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Carers often accessed Home and Community Care (HACC) services late in their caring role with some care recipients requiring greater assistance but only being able to receive low level HACC support.

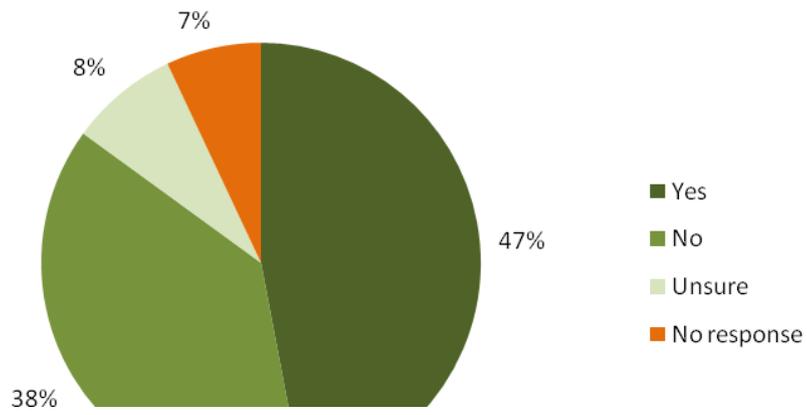
A number of carers at the consultations spoke of:

- being unaware of what services were available to support them and of their availability
- the difficulty and frustrations they faced navigating a *'complex carer support system'*
- being asked to *'surf the net'* for information, this angered older carers
- being flooded with information all at once and not having time to absorb and digest and seek clarification
- carer support programs requiring more publicity.

Of the current and past carers surveyed 47% indicated that they received details of their eligibility for HACC (Figure 3). In the Agency questionnaire a small number of organisations stated that this was an area that they could improve upon.

'HACC programs and services are available in our community in a limited capacity because of funding. The terms of eligibility were explained but it would be better if more information was written in culturally appropriate languages'.

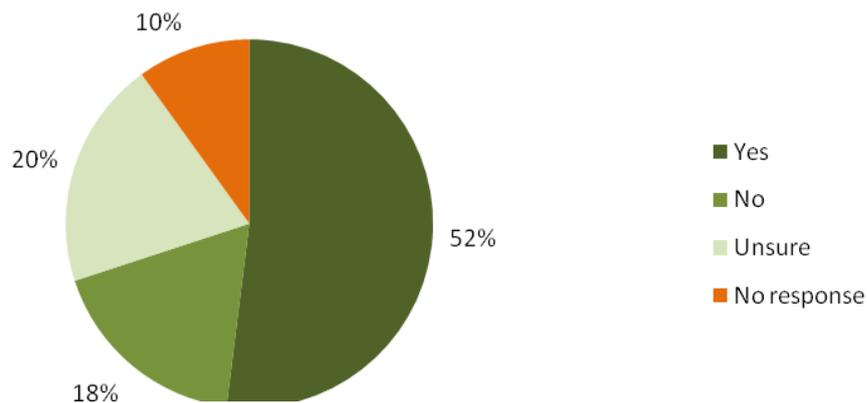
FIGURE 3: PERCENTAGE OF CARERS WHO HAD THEIR HACC ELIGIBILITY EXPLAINED TO THEM



## 5.2 CARER UNDERSTANDING OF THE HACC PROGRAM

Of the current and past carers surveyed 47% indicated that they received details of their eligibility for HACC and 52% believed that they understood the HACC program and the purpose of HACC carer supports (Figure 4). Given that HACC support is entry level support for care recipients this number is relatively low and indicates that there could be additional promotion of HACC services both for care recipients and carers. Eighteen percent of carers said they did not understand the HACC program, 20% were unsure and 10% did not respond to this question.

FIGURE 4: CARERS VIEWS OF WHETHER THEY UNDERSTAND THE HACC PROGRAM



Although carers indicated that they believed they knew what the HACC program and the purpose of HACC supports were, some of the carer comments did not reflect this. Some people were confused with terms and acronyms and believed that HACC covered all health services. Some just saw it as for people over 65 years of age, whilst a few people weren't sure how to *'qualify for this type of help or where to learn about these organisations'*.

*'HACC is a mystery.'*

Respondents comments indicated that a large proportion of survey respondents did have a reasonable to good understanding of the HACC program and carer support. Some respondents indicated that their understanding was as a direct result of either having worked or currently working in the sector as well as being a carer.

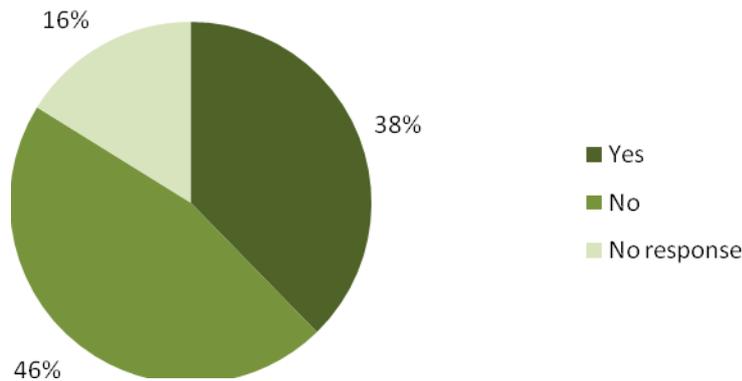
*'The purpose of HACC carer support is to enable the carer and the person they care for to remain in their own home and remain connected to their community as long as possible and not have to become a permanent resident in an aged care facility'.*

### 5.3 FUNDING SOURCES

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Nearly half of the agencies surveyed (46%) indicated that they did not receive additional funding outside of HACC (Figure 5).

FIGURE 5: AGENCIES RECEIVING OTHER SOURCES OF FUNDING TO PROVIDE SERVICES



The agencies who did receive other sources of funding were able to be responsive and flexible in the delivery of services to carers. These funding sources included:

- Dementia Policy and Programs and Aged Care Workforce Section, Department of Health and Ageing
- Grants and trusts
- FaCHSIA
- SA Department of Health
- Regional Development Boards
- Locally raised community funds
- National Respite for Carers Program, Department of Health and Ageing
- Targeted Community Care (Mental Health)
- Mental Health Carers Program, SA Department of Health (Mental Health Unit)
- SA Department of Community and Social Inclusion, Disability, Ageing and Carers
- Department of Veteran Affairs.

#### 5.4 KEY POINTS TO NOTE

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Carers often accessed Home and Community Care (HACC) services late in their caring role with some care recipients requiring greater assistance but only being able to receive low care HACC support.

While approximately half of the respondents did understand the HACC Program 18% of carers said they did not understand it and 20% were unsure.

## 6 OVERVIEW OF THE CARING ROLE

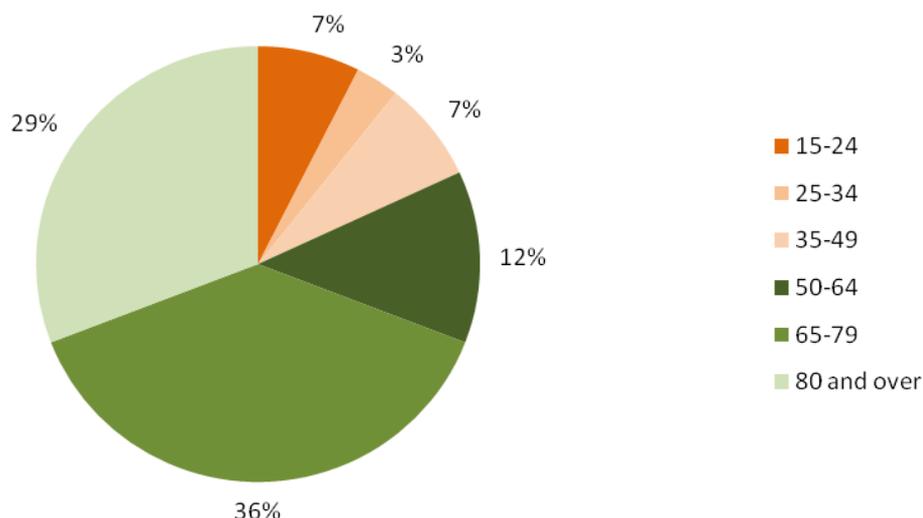
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### 6.1 AGE OF CARE RECIPIENT

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Whilst carers are caring for people of all ages, two thirds of the people who responded to the survey were caring for people aged 65 or over with 29% caring for someone aged 80 or over (Figure 6).

FIGURE 6: AGE IN YEARS OF CARE RECIPIENTS BEING CARED FOR BY SURVEY RESPONDENTS

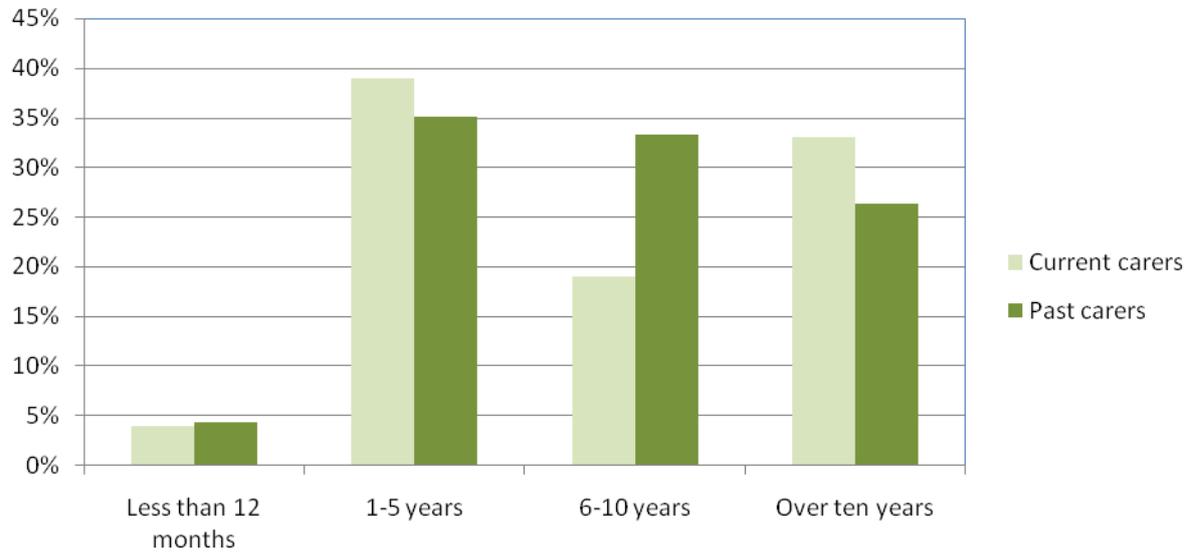


### 6.2 LENGTH OF TIME SPENT CARING

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Whilst 39% of past carers and 43% of current carers provided care for 5 years or less nearly 60% of both current and past carer respondents provided care for more than 6 years. Long term caring was higher amongst current carers with 33% of current carer respondents indicating that they have spent more than 10 years caring at this point in time versus 26% for those identifying as past carers. A number of survey respondents and attendees at consultations who were caring for children with disabilities, had been doing so for several decades (Figure 7).

FIGURE 7: AMOUNT OF TIME CURRENT AND PAST CARERS SPENT CARING FOR THEIR CARE RECIPIENT

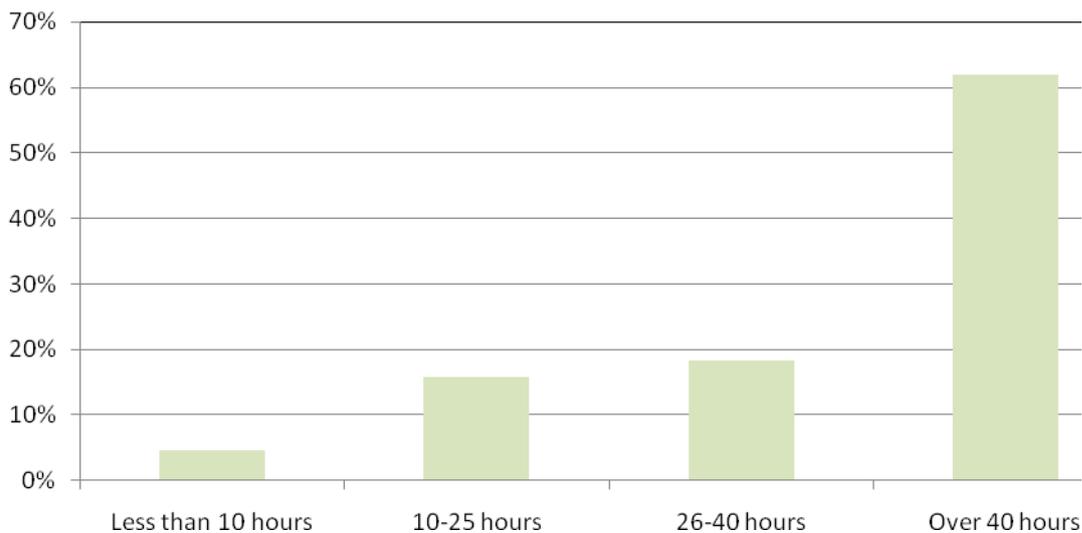


### 6.3 TIME SPENT CARING

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Current carers were asked how long they spent caring each week in the survey. Of the 299 respondents who identified as being in a current caring role, 62% said they spend more than 40 hours a week providing care (Figure 8). In spite of this only 11% indicated that they were receiving a higher care package (i.e. CACP, EACH or EACHD) (Figure 9). In survey responses and at consultations approximately 10% of respondents and attendees indicated that they provide care 24 hours a day 7 days a week.

FIGURE 8: HOURS PER WEEK SPENT CARING BY CURRENT CARERS

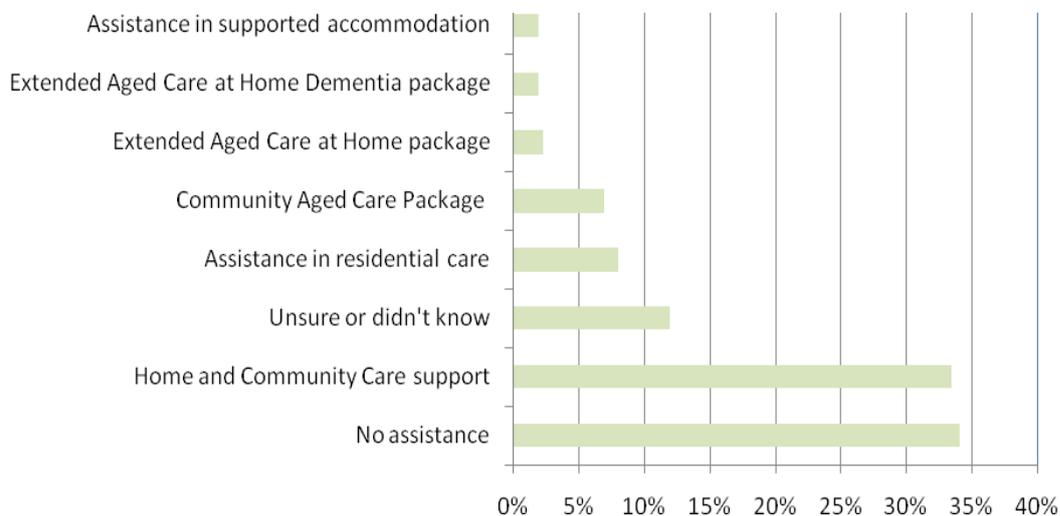


## 6.4 ASSISTANCE RECEIVED BY CARE RECIPIENT

Only those identifying as current carers in the survey were asked what type of support the person they were caring for receives. One third identified that their care recipient received support from HACC. Over 33% said that the person they cared for was not receiving any assistance and 15 respondents said they were receiving assistance from the Department of Veteran Affairs. Twelve percent of current carers were unsure where the care recipient was getting assistance from. This was reflected in the consultations in which some carers identified with the provider or the staff rather than the program from which they were receiving assistance (Figure 9).

It is worth noting that 10% of those who identified as a current carer have a care recipient in residential care or supported accommodation (Figure 9).

FIGURE 9: FORMAL ASSISTANCE RECEIVED BY CARE RECIPIENTS OF CURRENT CARERS



NB Respondents could select more than one response, so percentages may add up to more than 100%.

## 6.5 KEY POINTS TO NOTE

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Two thirds of the people who responded to the survey were caring for people aged 65 or over with 29% caring for someone aged 80 or over.

Whilst 39% of past carers and 43% of current carers provided care for five years or less nearly 60% of both current and past carer respondents provided care for more than 6 years. Long term caring was higher amongst current carers with 33% of current carer respondents indicating that they have spent more than 10 years caring at this point in time versus 26% for those identifying as past carers.

Of the 299 respondents who identified as being in a current caring role, 62% said they spend more than 40 hours a week providing care however only 11% indicated that the person they were caring for was receiving a higher care package (i.e. CACP, EACH or EACHD).

One third identified that their care recipient received support from HACCC, 33% said that the person they cared for was not receiving any assistance and 12% were unsure where the care recipient was getting assistance from.

## 7 THE IMPACT OF THE CARING ROLE

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No review of carers' needs can be fully understood without understanding the impact that the caring role has had on them. Many carers consulted during this project wanted to have their say and carers wrote extensively in response to various survey questions. A representative group of their comments is included (Appendix 4).

It is clear that there is no single impact of caring. The impacts vary from person to person depending on a range of circumstances including:

- the age of the carer
- the needs of the care recipient
- the resources they have to meet their financial needs
- the health of the carer
- the level of their desire to take on the caring role
- the level of restrictions and losses caring entails
- the support that is available from family, friends, neighbours and organisations
- the attitude of the carer
- whether they have had to relocate geographically to care
- the skills and knowledge base of the carer
- their employment status
- the number of people they cared for
- if they had cared for several people sequentially
- the period spent caring.

The negative impacts of caring and the challenges of caring far outweighed the positive comments in the survey responses and at the various meetings by a ratio of about 20 to 1. As discussed in Section 5 over 60% of survey respondents are or have been caring for over 40 hours a week and 38% of current carers said they had been caring for more than 10 years versus 26% of past carers. Further research is needed to ascertain if the length of the caring period is increasing.

## 7.1 THE POSITIVE IMPACTS OF CARING

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### 7.1.1 AN INNER JOURNEY

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For some carers, caring has been an inner personal journey as well as an outer journey. Carers spoke and wrote about growing as a person and developing patience, calmness, understanding, compassion and tolerance. One said that caring had taught them to *'... moderate my responses to problems - think before acting when problems arise'*.

A number of carers said caring had made them a stronger and more independent person and an advocate for their family.

*'The highs and lows of caring have been very hard but I believe it has made me a stronger person... more independent.'*

Some carers found that caring helped them to value life, their own situation as a carer rather than a care recipient, their friends and family, time to themselves and the simple things in life. They were able to accept the changes in their life situation and accept life as it came.

Improving self care skills and focusing on the positives assisted some carers to change how they viewed life as a carer.

A number of carers indicated an increase in awareness of the needs of people with disabilities, health related issues, ageing issues, the general lack of understanding of the needs of those with health issues and disabilities.

## NEW SKILLS

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As well as learning more about life, carers said they learned new skills in caring, housekeeping, health issues, finance and tax, about managing time and how to plan activities which were achievable. Some carers said that their communication and advocacy skills were stronger.

## LOVE AND CLOSENESS

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*'Learning to love more fully'*

Many carers caring for parents or in-laws said they had developed a stronger relationship with the person they were caring for, learned more about the family history and/or understood their parents better. Some carers said they enjoyed looking after their parents. A few, whose parents lived with them, said it was easier to look after them at home and better than visiting daily in residential care because it enabled the care recipient to easily stay part of the family.

Caring brought some partners and husbands and wives closer together. Carers of parents, children and siblings said they valued the extra time they spent together because of the caring role. Some carers said that the whole family was strengthened by caring as it brought them all closer or that they realised the importance of family above all else.

Many carers felt valued, acknowledged and appreciated by the person for whom they were providing care.

## A CHANCE TO GIVE BACK

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A few carers saw the caring role as a chance to give back something for the love they had received. They spoke of it being a privilege to have the chance to do so.

Others felt that they made life better for the care recipient. Several CALD carers also saw it as a way of fulfilling family responsibilities and obligations.

*‘The main impact that caring had on my life is the satisfaction it gave me being able to give back something to someone who had given me so much during my life, my mother. It also enabled me to develop a closeness to my mother which I otherwise possibly may not have been able to develop. And one cannot describe the feeling one gets when you see the look of appreciation in those eyes and on that face knowing that in her time of need there is someone who cares just as she cared when I needed her. That feeling is priceless.’*

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### 7.1.2 SUPPORTED BY OTHERS

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Some carers spoke highly of the support which they received from friends, church parishioners, and organisations (Sections 11 and 12). Some said that they would not have been able to cope without the organisational help they received and that one of the positive impacts of caring was knowing that help existed. Carers expressed appreciation for the support of workers who helped them.

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### 7.1.3 SUPPORT GROUPS

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Whilst many carers did say that they had become disconnected from friends over the course of the caring role many also said how much they valued the friends they had gained through carers support groups and retreats. This was seen as a very positive outcome of caring with people saying that these friends were *‘wonderful, treasured, like family, caring and supportive’* (Sections 10 and 11).

As well as friendship and companionship support group members were seen as a useful source of advice they could relate well to because of their common shared experiences as carers.

*'On the positive aspect of caring we have become involved with a wonderful group of carers and in some ways they have become like family. If not for dementia we would never have met them.'*

---

### OTHER POSITIVES

Carers also mentioned counselling and volunteering as positives arising from the caring role. For some current carers volunteering provided a break from their domestic situation and helped to put their own problems as a carer in perspective.

A small number of carers liked solving the challenges presented by caring and some were philosophical and accepting of the caring role.

Several carers said that they were managing at present, were happy with the help they were receiving or that they had all the help they needed. A few said that they had no difficulty staying connected with their community, family or friends.

For some the caring role became easier with time.

*'It takes a lot to get used to at first but later it comes easier'*

## 7.2 CHALLENGES AND NEGATIVE IMPACTS

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### 7.2.1 LOSS & RESTRICTIONS

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The majority of carers spoke of changes in their lifestyle because of their caring role. They spoke or wrote of their life having been put on hold or having come to a halt as they no longer had time for the activities and interests in which they used to participate.

*‘Personally, after three years of caring most of my previous live does not exist.’*

There was a strong theme of loss and restrictions in current and past carers comments.

Carers stated that the caring role restricted them from taking holidays and enjoying their retirement. It also restricted their ability to undertake regular tasks such as home maintenance and ‘normal activities’. In some instances these restrictions continued when the person they were caring for was in residential care.

For many carers the person they were caring for took priority over their own needs and well being. Some carers said that this was at the expense of their own health with insufficient time or energy to attend to their own health checks.

Whilst many carers acknowledged the value of carer support particularly support groups they also talked about what they had lost by becoming a carer: These included:

- loss of time for self
- loss of future plans

- loss of a future together
- loss of retirement
- loss of friends/ friendships/contact with friends
- loss of the relationship with some or all family members
- loss of alone time
- loss of financial security
- loss of a partner (husband /wife relationship)
- loss of intimacy
- loss of their best friend
- loss of the person who cared for me
- loss of a life together
- loss of child /parent relationship
- loss of conversations
- loss of holidays
- loss of income
- loss of skills
- loss of business partnership
- loss of someone to plan things with
- loss of someone to discuss problems with
- loss of time with other family members
- loss of time with friends
- loss of friends and family members
- loss of health
- loss of time for work
- loss of personal time
- loss of links to organisations and clubs
- loss of full or part-time work
- loss of an ability to study
- loss of a future
- loss of an ability to go out
- loss of fitness
- loss of energy
- loss of the ability to travel or restrictions on travel
- loss of the ability to help family

- loss of the freedom to do volunteer work
- loss of time for interests and hobbies
- loss of time to play sport
- loss of time to go for walks
- loss of the person they knew (dementia)
- loss of companion to go out with
- loss of independence
- loss of time out alone
- loss of freedom
- loss of social activities
- loss of control over their life
- loss of my own life
- loss of own identity/self
- loss of time for marital relationship
- loss of time for romantic relationships.

*'I feel as if my life has been taken away from me for over 15 years now. I am trying not to be bitter'*

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## 7.2.2 TIME PROBLEMS

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Time emerged in a number of ways as a challenge for carers with carers indicating that caring was a very time consuming task. Carers with other work and family responsibilities found it hard to find sufficient time to undertake all the tasks associated with caring. Attending medical appointments, dealing with incontinence and accessing information were nominated as very time consuming tasks. Lack of time for the carer's own needs impacted negatively on their life in a variety of ways.

As well as insufficient time some carers found it hard to manage the time they did have available because the needs of the care recipient made it difficult to make planned arrangements.

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### 7.2.3 DIFFICULTIES IN MAINTAINING EMPLOYMENT

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Some carers retired early (by up to 10 or 15 years) or left work because of the difficulty of balancing the caring role and work. Those who stopped work when younger found that they could be out of the workforce for a decade. Some believed that their own physical or mental health issues had been exacerbated or caused by caring and made returning to work challenging or impossible.

One respondent changed jobs *‘to a less demanding role, less money, less prestige’* whilst others worked part-time or struggled with the challenge of getting sufficient support to work part-time. Agencies indicated that specific respite allocated to help working carers was fully utilised and insufficient.

*‘It has turned my life upside down. It is tough managing work and caring.’*

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### 7.2.4 HEALTH IMPACTS

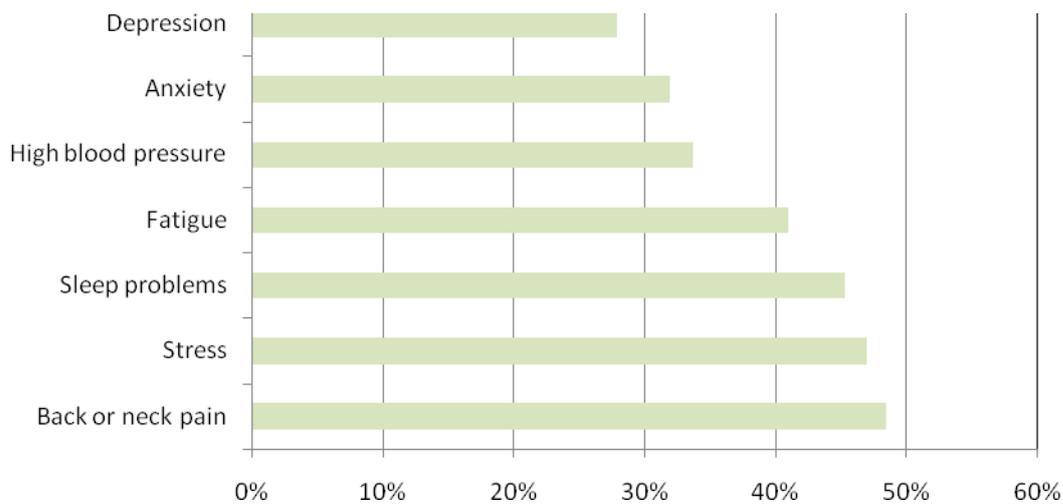
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Carers reported that caring was a significant physical and emotional commitment and for some carers this led to negative health outcomes.

Significant numbers of carers and past carers surveyed reported that they either currently experience or have previously experienced one or more of the following: back or neck pain, stress, sleep problems, fatigue, high blood pressure, anxiety and depression. Caring was also believed to have exacerbated other health problems such as diabetes, asthma and muscular tension (Figure 10).

The loss of time to exercise was seen as a cause of physical deterioration.

FIGURE 10: SELF REPORTED HEALTH COMPLAINTS OF CURRENT AND PAST CARERS



NB Respondents could select more than one response, so percentages may add up to more than 100%.

People who ceased paid employment to be a carer reported significantly higher health issues than other carer groups in this sample (Figure 10 above). Of this group, 63% said they experienced back or neck pain versus 48% across the whole sample.

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#### 7.2.4.1 NEGATIVE FEELINGS

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A few current and past carers were unable to find anything positive in the caring role. They said it was too hard, devastating, challenging and tiring. Some people shared that felt suicidal or had thought of suicide /murder. A number spoke of having been treated for depression.

A small number of carers discussed having breakdowns from the caring role or developing health problems as a result of caring. Some carers spoke of feeling very isolated as a carer and/ or becoming withdrawn.

### FEELINGS OF HELPLESSNESS

Some carers who were caring for a person in pain or facing a terminal or degenerative illness expressed feelings of helplessness either because they were unable to alleviate the pain or to prevent their deterioration. Others felt helpless because they were unsure what to do as a carer or because they were unable to prevent some aspects of people's behavior (i.e. driving when they had been put on restricted driving), aggressive or disruptive behavior or continually 'shadowing' the carer. A few carers indicated that their feelings of helplessness were linked to feelings of frustration.

### LONELINESS

Some carers spoke of feeling isolated either by the time spent caring or because they felt socially isolated because of features of their care recipient's illness or disability. Carers said that they felt lonely either because they could no longer converse with their partner, they were caring for a child with language difficulties or autism or were unable to see friends or relatives (see also Sections 8 and 9).

### GUILT

Guilt was a theme which came up a number of times with both current and past carers. Some past carers felt guilt over care recipient moving into residential or supported accommodation and some felt guilty over hospital care or respite which they felt worsened the care recipient's health and/or hastened their death.

A few current carers said that they felt guilty about going out and enjoying themselves when the care recipient couldn't do the same. Others felt guilty because they felt that they were not doing enough.

### GRIEF

It was clear at the meetings that some past carers were still dealing with grief after a number of years. People also discussed the grief associated with an early diagnosis of dementia and the loss *'of the life we had together and the future we had together.'*

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## 7.2.5 FINANCIAL IMPACT

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There are primarily two negative financial impacts on carers. The first is a decreased income and the second an increase in unavoidable additional expenses.

Carers who retired early, temporarily left the workforce, changed to lower paid less stressful paid employment, moved to self employment with reduced but flexible hours or moved to part-time work all reported a loss in income. For some this loss of income had been the biggest negative impact or challenge of caring. Some long term carers who had a caring role spanning decades said part-time work and an associated drop in income had led to a life of poverty.

Carers also stated that financially they struggled to meet the extra costs associated with caring. These included the cost of respite, incontinence aids, extra heating and cooling, medicine costs (particularly those not on the Pharmaceutical Benefits Scheme), transport costs (particularly carers living in regional South Australia or outer metropolitan areas and those needing to utilise taxis). In some cases this also included the cost of relocation.

Many carers were worried about the costs of accommodation and meeting ongoing costs associated with residential care on a reduced income with no financial buffer left.

A lack of funds prevented some carers from undertaking activities or socialising.

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### 7.2.6 BEHAVIOURAL ISSUES WITH CARE RECIPIENT

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Stress and distress at coping with the behavioural problems of some care recipients were negative impacts for some carers of the caring role. Carers stated they faced difficulty coping with moodiness, personality changes, aggression, mood swings, memory loss and anger. A number of carers of people with dementia said that the person they were caring for denied their memory loss and blamed it on the carer which was challenging for the carer.

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### 7.2.7 CARING FOR GRANDCHILDREN AND CHILDREN

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Grandparents caring for their children talked about finding it stressful and challenging and said caring impacted on their health and family life. However they were committed to caring for their grandchildren.

Carers of both young and adult children with disabilities found it a time consuming role particularly if there was a need to maintain constant supervision. Children with high needs often required appointments for therapy and medical issues which could be time consuming. There were other impacts on family life which have been highlighted in Section 9.

A major concern for many of these carers was what would happen to the care recipient when they became ill, unable to care or died.

Some carers of adult children wanted them to be settled in supported accommodation or have activities to occupy them.

*'The one thing I would really like is peace of mind about where our son will go when we are no longer able to care for him.'*

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### 7.2.8 IMPACT ON RELATIONSHIPS WITH FAMILY MEMBERS AND FRIENDS

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A reduction or loss of contact with family members and friends was mentioned many times throughout carers' and past carers' comments as a negative impact of caring. This issue is addressed more fully in Section 9.

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### 7.2.9 YOUTH

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The Consultants spoke with a range of younger carers between the ages of 10 to 25 years. The questions varied because of their age and the interviews explored the tasks they undertook, their level of connectedness, their engagement in activities such as sport and hobbies and what they believed they would do in the future for instance more schooling, training or employment. Young carers primarily cared for parents with health related issues and some cared for siblings with disabilities.

Young carers both male and female between the ages of 10-17 years predominately worried about friendships and schooling. Many of the young carers indicated a decrease in the number of friends or did not have any friends due to their caring role. They were embarrassed by their home life and chose not to bring school friends home to avoid explaining their circumstances. Invitations to parties, '*sleep-overs*' or '*play-dates*' were not forthcoming to these children.

Many young carers indicated they felt older than their years with some undertaking adult responsibilities such as managing home accounts, arranging meals before and after school, acting as interpreters for parents and taking care of household duties (washing, cleaning, gardening, and shopping). For many of the young carers school work was often the last thing that was attended to, if at all.

Carers in years 11 and 12 found schooling difficult and they struggled to balance their caring role and school needs. For many it meant taking 2 or 3 years to successfully complete Year 12 and being concerned about the possibility of undertaking further studies. The young teenage carers were greatly concerned about

not being able to obtain their driver's license due to financial constraints and their parent's capacity to teach them.

The young adult carers aged between 18-25 years who were interviewed were struggling more in their caring role than the very young carers. They indicated that they felt 'cheated' of their youth and in many instances had been thrown into the caring role without being asked. There was a pattern in those interviewed of older children leaving home and the youngest left to care.

They were provided with limited supports and struggled to find the balance between their caring role and developing a life for themselves. In many instances young adult carers had to leave their schooling or first paid positions to take on caring for a parent full time and felt let down by the 'system'. They felt despondent and that they had no future to look forward to.

Their greatest fear was what was going to happen to them once their caring role ended in 10 to 20 years time with 'no education, no job, no career path, no superannuation'. A number indicated that the care recipient was using the carer's funds and many had little to no money left near the end of most fortnights. Many spoke of depression and suicide as a possible way out when life got tough. They spoke of 'friends running' when they learnt of their situation and their social isolation due to not having the finances to go out with friends. Many relied on the internet as their source of communication.

Young adult carers were concerned about their:

- lack of work
- lack of opportunities
- non-existent career path
- lack of qualifications
- lack of long-term savings
- lack of money on a regular basis
- lack of emotional support
- transport difficulties

- lack of a license
- limited or non-existent friendship group
- lack of a social life
- lack of a significant relationship with the opposite sex
- lack of family support
- the potential of not having children.

*'I have lost my life and I don't know what will happen to me when I stop caring. I will have nothing to fall back on, no education, no job and no money. I often think about killing myself.'*

See also Section 12.7.

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#### 7.2.10 OTHER CHALLENGES

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Other challenges faced by carers included:

- communication difficulties because of physical and mental issues
- dealing with one's own ageing whilst undertaking the caring role
- dealing with one's own health issues whilst undertaking the caring role
- taking on more responsibilities and obligations
- a lack of self esteem
- 'modifying what you do and how you do it'
- dealing with incontinence
- dealing with medical emergencies
- not being able to plan for the future because the caring timeframe is unknown
- feeling that one's own mental health and stability was being affected by the caring role
- learning how to look after someone with a terminal illness
- learning to care for someone with dementia

- learning how to manage one's own frustration and anger at either the care recipient's behavior or the care situation
- difficulties dealing with government departments
- difficulty accessing modified rental housing
- difficulties finding the right agency to deliver various support services
- lack of respite at times
- difficulties undertaking shopping
- carer becoming hyper vigilant from having to stay constantly alert
- having to think for 2 people
- dealing with major change in one's life to the extent that for many it felt like a 'new life'
- being unprepared mentally for the challenges of caring
- dealing with people's lack of understanding
- managing the caring role with multiple family responsibilities
- coping with the caring role as an only child
- dealing with a parent's degenerative disease and knowing that you are in an 'at risk' group
- dealing with the challenge of long term caring and how to create a life within that
- obtaining suitable respite
- getting the care recipient to accept respite care
- a lack of carer support where one or both are aged under 65
- continuing to care for a spouse/partner/ child as long as possible
- worrying about what will happen to the care recipient if the carer becomes ill or unable to continue caring
- envying other people's lives
- being asked to leave support groups at the time of bereavement or when the care recipient entered formal care
- being unable to attend retreats after the care recipient entered formal care or died at a time when they felt in great need of a supported break
- being asked to pay for HACC services at a time when their financial situation had deteriorated due to the loss of the care recipient's income.

*'It has been very hard to deal with all the day to day challenges we face and continues to be so.'*

### 7.3 KEY POINTS TO NOTE

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Over 60% of survey respondents are or have been caring for over 40 hours a week.

It is clear that there is no single impact of caring. The impacts vary from person to person depending on a range of circumstances.

For some carers, caring has been an inner personal journey and they said they had grown as a person, developing patience, calmness, understanding, compassion and tolerance. A number of carers said caring had made them a stronger and more independent person and an advocate for their family.

Improving self care skills and focusing on the positives assisted some carers to change how they viewed life as a carer.

Many carers said they had developed a stronger relationship with the person they were caring for and some carers said that the whole family was strengthened by caring.

Carers were appreciative of the support of workers who helped them.

Many carers valued the friends they had gained through carers support groups and retreats. As well as friendship and companionship support group members were seen as a useful source of advice they could relate well to because of their common shared experiences as carers.

The majority of carers spoke of changes in their lifestyle because of their caring role.

The negative impacts of caring and the challenges of caring far outweighed the positive comments in the survey responses and at the various meetings by a ratio of about twenty to one. There was a strong theme of loss and restrictions in current and past carers comments.

For many carers the person they were caring for took priority over their own needs and well being. Lack of time for the carer's own needs impacted negatively on their life in a variety of ways.

Carers with other work and family responsibilities found it hard to find sufficient time to undertake all the tasks associated with caring.

Some carers retired early or left work because of the difficulty of balancing the caring role and work.

Carers reported that caring was a significant physical and emotional commitment and for some carers this led to negative health outcomes.

The loss of time to exercise was seen as a cause of physical deterioration.

A few current and past carers were unable to find anything positive in the caring role. They said it was too hard, devastating, challenging and tiring. Some people shared they felt suicidal or had thought of suicide /murder. A number spoke of having been treated for depression.

Carers spoke of feelings of helplessness, loneliness, guilt and grief.

There are primarily 2 negative financial impacts on carers. The first is a decreased income and the second an increase in unavoidable additional expenses. Carers said that financially they struggled to meet the extra costs associated with caring. A lack of funds prevented some carers from undertaking activities or socialising.

Carers caring for someone with behavioral issues faced difficulty coping with moodiness, personality changes, aggression, mood swings, memory loss and anger.

Grandparents said caring impacted on their health and family life.

Carers of both young and adult children with disabilities found it a time consuming role particularly if there was a need to maintain constant supervision. A major concern for many of these carers was what would happen to the care recipient when they became ill, unable to care or died.

Young carers both male and female between the ages of 10-17 years predominately worried about friendships and schooling.

Many young carers indicated they felt older than their years with some undertaking adult responsibilities.

Carers in years 11 and 12 found schooling difficult and they struggled to balance their caring role and school needs.

The young adult carers aged between 18-25 years who were interviewed were struggling more in their caring role than the very young carers. They indicated that they felt 'cheated' of their youth and in many instances had been thrown into the caring role without being asked. There was a pattern in those interviewed of older children leaving home and the youngest left to care. They were provided with limited supports and struggled to find the balance between their caring role and developing a life for themselves. Their greatest fear was what was going to happen to them once their caring role ended in 10 to 20 years time. Many relied on the internet as their source of communication.

Young adult carers were concerned about their:

- lack of work
- lack of opportunities
- non-existent career path
- lack of qualifications
- lack of long-term savings
- lack of money on a regular basis
- lack of emotional support
- transport difficulties

- lack of a license
- limited or non-existent friendship group
- lack of a social life
- lack of a significant relationship with the opposite sex
- lack of family support
- the potential of not having children.

## 8 CARERS CONCERNS

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A key issue emerging from carers written and verbal feedback was their concern about what would happen to the care recipient when they could no longer provide care for them. Carers caring for grandchildren worried about their future capacity to do so, carers of adult children with a disability worried about how they could find alternative accommodation for them, carers with health issues worried about what would happen when they could no longer care. Carers of various ages worried about what to do in an emergency situation.

Carers were also concerned about the development of their own health issues and perceived that the caring role had taken a toll on their own health which they now had to deal with in addition to caring.

Carers also expressed concern about the high cost of respite and the cost of accommodation bonds and entry to low care residential accommodation. Carers on low incomes who had moved to a single income said that they found it very difficult meeting the additional needs of the care recipient once they were in formal care as well as their own costs. Section 6 on the financial impacts of caring expounds on some of these issues.

A few carers expressed concerns about dealing with various agencies including Centrelink (during bereavement), the Department of Health and Ageing, Carers SA, RDNS, private operators and Government in general. A view was expressed that carers lacked an independent body which they could utilise to make complaints about both carer support services they received and services provided to the care recipient.

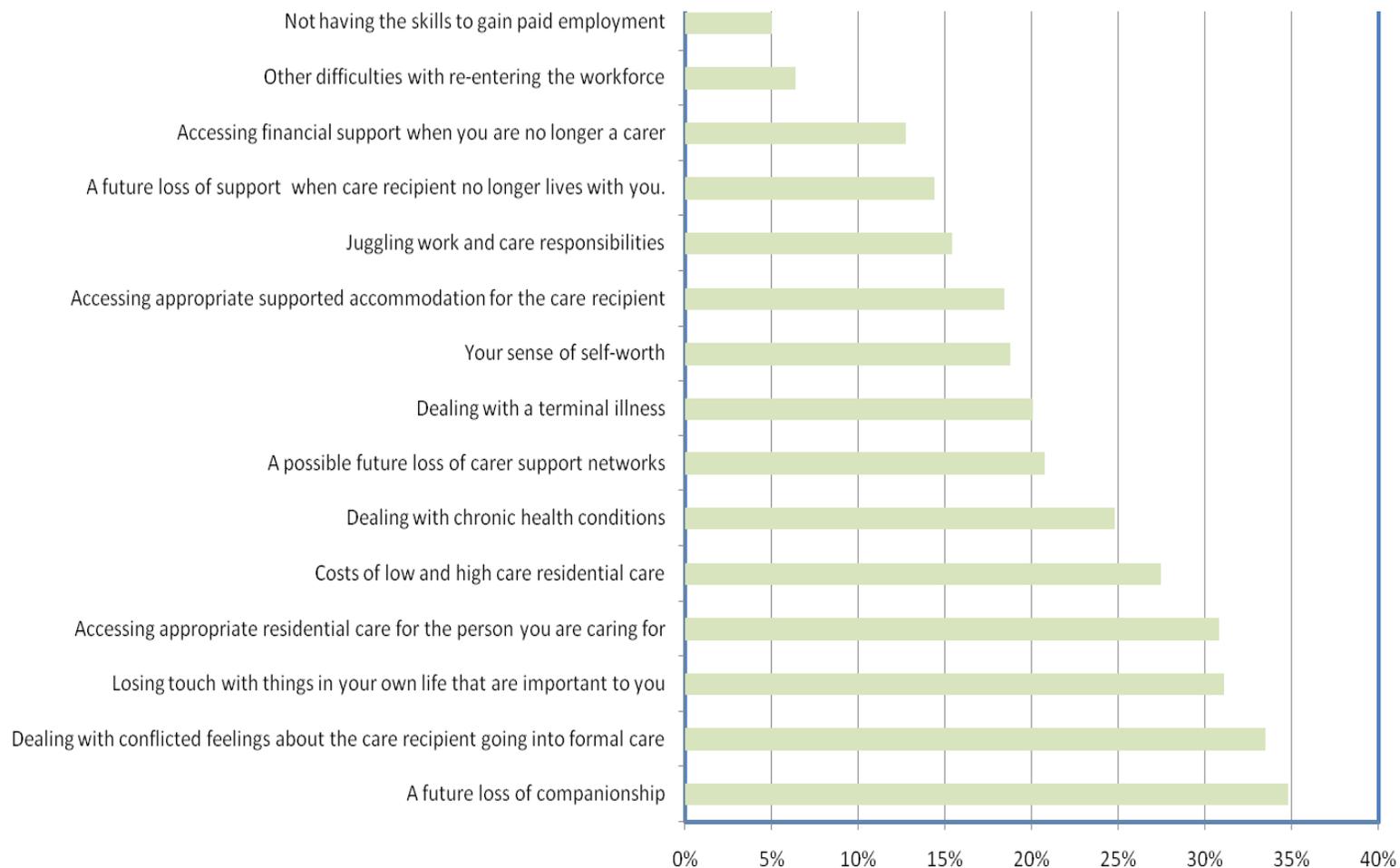
Carers who were able to undertake activities with the care recipient said that it was challenging finding information on travel options and disability access in hotels and motels.

Over 25% of all current and past carers were concerned about:

- a future loss of companionship
- losing touch with things in their own life that were important to them
- accessing appropriate residential care for the person in their care
- costs of low and high care residential care
- dealing with conflicted feelings about the care recipient going into formal care (Figure 11).

Whilst only 18% of all respondents were concerned about accessing appropriate supported accommodation for the care recipient, these respondents were very concerned. This lower figure may be a bias in the sample given the fact that 65% of care recipients from the survey were aged 65 and over (Section 6, Figure 6.)

FIGURE 11: CONCERNS OF CURRENT AND PAST CARERS



NB Respondents could select more than one response, so percentages may add up to more than 100%.

## 8.1 KEY POINTS TO NOTE

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Over 25% of all current and past carers were concerned about:

- a future loss of companionship
- losing touch with things in their own life that were important to them
- accessing appropriate residential care for the person in their care
- costs of low and high care residential care
- dealing with conflicted feelings about the care recipient going into formal care.

A key issue emerging from carers was their concern about what would happen to the care recipient when they could no longer provide care for them.

Carers were concerned about the development of their own health issues.

Carers also expressed concern about the high cost of respite and the cost of accommodation bonds and entry to low care residential accommodation.

A few carers expressed concerns about dealing with various agencies including Centrelink (during bereavement), the Department of Health and Ageing, Carers SA, RDNS, private operators and Government in general. A view was expressed that carers lacked an independent body which they could utilise to make complaints about both carer support services they received and services provided to the care recipient.

## 9 CARERS' DIFFICULTIES IN STAYING CONNECTED WITH COMMUNITY, FAMILY AND FRIENDS

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Carers said caring impacted negatively on family relationships in a number of ways, including:

- marriage/ partnership difficulties
- marital breakdown
- children missing out on sufficient attention from their parents
- children missing out on activities, outings and events
- siblings mental health affected
- children being reluctant / or unable to bring friends home
- grief over the loss of a child's previous functionality
- children suffering because of parents stress
- negative impacts on children of having a parent or grandparent with mental illness
- relationship changes with a loss of intimacy as the carer role increases
- family tensions increasing between carer and care recipient because of differing expectations of what the caring role means
- less quality time for other family members
- a reduced ability to support other family members such as grandchildren
- difficulties entertaining other family members and less regular contact because of the needs of the care recipient
- difficulties visiting family members based interstate or overseas
- tension between adult siblings because of different views of the care relationship and needs of the care recipient
- emotional distance between family members where one or more members felt they were carrying the burden of care
- a lack of acknowledgement of the care recipient's health issues (particularly with dementia) by some family members and /or a lack of understanding by some family members.

Carers social lives were affected and a strong theme throughout was that carers said they had lost friends. Many had also gained valued friends through support groups or retreats but carers previous social networks often appear to be weakened rather than strengthened by the caring experience.

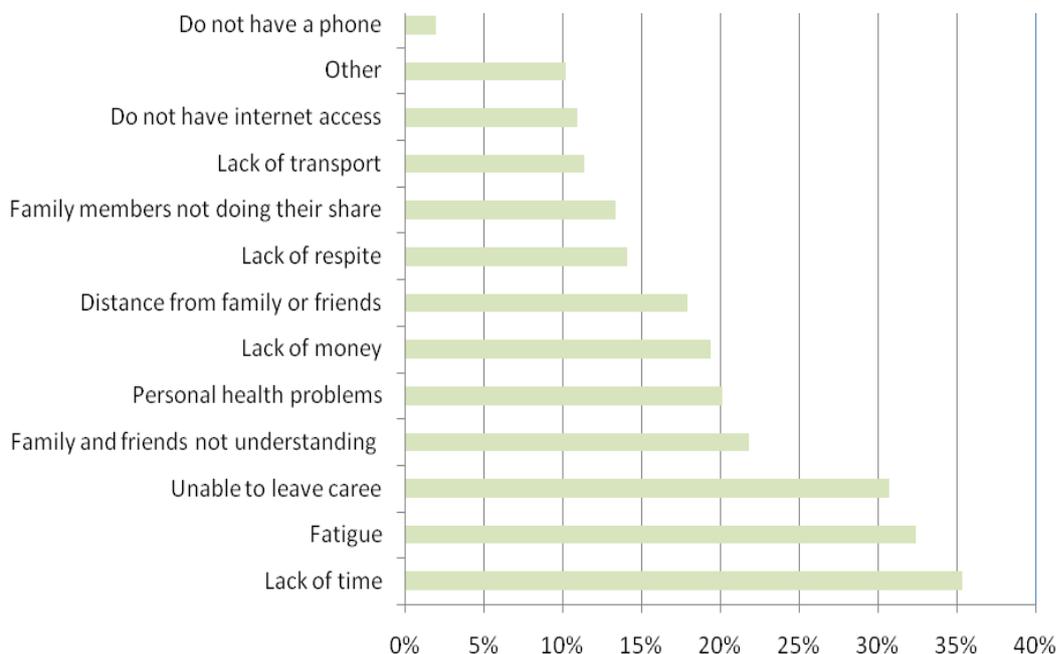
Some carers said that this was because they had limited quality time to spend with friends and others that friends left their lives because of the caring role.

This theme of losing touch with friends and family members was repeated many times at the meetings with various reasons being put forward as to why this was the case. These included uneasiness amongst people about the care recipient's health issues and/or behavior and a fear that they might be asked to help. Some made the comment that people were happy to see them out socially but not to visit them at home.

Over 70% of all current and past carers (299) who responded to the survey said that they had experienced difficulties staying connected to their community, family and friends during their caring role. The 6 primary reasons why carers had difficulty is staying connected were:

- lack of time (35%)
- fatigue (32%)
- unable to leave caree (31%)
- family and friends not understanding (22%)
- personal health problems (20%)
- lack of money (19%) (Figure 12).

FIGURE 12: REASONS WHY CURRENT AND PAST CARERS FOUND IT DIFFICULT TO REMAIN CONNECTED TO THEIR COMMUNITY, FAMILY AND FRIENDS



NB Respondents could select more than one response, so percentages may add up to more than 100%.

Whilst finances and personal health problems were certainly significant issues survey respondents said it is the caring role itself which is creating the biggest difficulties with staying connected. Feedback at community meetings and discussions with workers supported this finding.

It appears that people are caring for longer and that the level of care they are undertaking is increasing. Carers and workers in some regions indicated that there were long waiting lists for CACPs, EACH and EACHD packages. Some carers are continuing to care at home because of the cost of the accommodation bond.

Fourteen percent of respondents with difficulties said that other reasons were stopping them staying connected and half of these gave at least one reason. These included:

- difficulties with the care recipient because of behavioural issues
- exclusion by other people either because of the care recipient's behavior or because they are too confronted i.e. by dementia or disability
- care recipients refusing outside help
- needing two people to take care of a care recipient while on excursions
- care recipient continually calling them on their mobile phone
- care recipient being totally dependent
- reluctance to leave the care recipient
- difficulty in finding quality affordable care for someone with a disability
- problems with finding 'good' carers; carers with language skills
- needing to use the time for appointments'
- having a school aged child
- transport issues
- length of the caring role (40 years)
- a lack of other family members to assist in the caring role
- pride
- guilt at asking for help
- difficulty discussing problems
- time management issues.

## RELOCATION

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Relocation also emerged as a small but significant issue amongst carers, with some indicating that they had relocated to undertake the caring role for a relative and in doing so had lost their own support structures and/or employment.

A few carers had moved from the city to the country and vice versa or had moved to South Australia from interstate or overseas. Some carers had moved into retirement villages to access assistance in the caring role. For the carer relocating to Australia

to care there were issues with the culture and language. Some carers spoke of the difficulties of making new friends or creating a new life when they were older.

## 9.1 KEY POINTS TO NOTE

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From the survey results it appears that people are caring for longer and that the level of care they are undertaking is increasing.

Over 70% of survey respondents said that they had experienced difficulties staying connected to their community, family and friends during their caring role. The 6 primary reasons why carers had difficulty is staying connected were:

- lack of time (35%)
- fatigue (32%)
- unable to leave caree (31%)
- family and friends not understanding (22%)
- personal health problems (20%)
- lack of money (19%) (Figure 12).

Survey respondents said it is the caring role itself which is creating the biggest difficulties with staying connected and feedback at community meetings and discussions with workers supported this finding.

Caring impacted negatively on family relationships in a number of ways.

Carers social lives were affected and a strong theme throughout was that carers said they had lost friends. Many had also gained valued friends through support groups or retreats but carers previous social networks often appear to be weakened by the caring experience.

Relocation also emerged as a small but significant issue amongst carers.

## 10 CHANGES IN ACTIVITY LEVELS

Carers activity levels reported in the survey were consistent with their written and verbal comments about the losses, restrictions and difficulties they faced.

There was a significant decrease in the number of activities undertaken by current carers compared to the number undertaken before they became carers. Of the current and past carers who completed the survey 30% were undertaking more than 5 activities a day before they became carers and this decreased to 8% for those who are currently caring. There was a slight increase in the post caring role to 12% undertaking more than 5 activities a day (Figure 13).

FIGURE 13: WEEKLY ACTIVITIES UNDERTAKEN OUTSIDE THE HOME

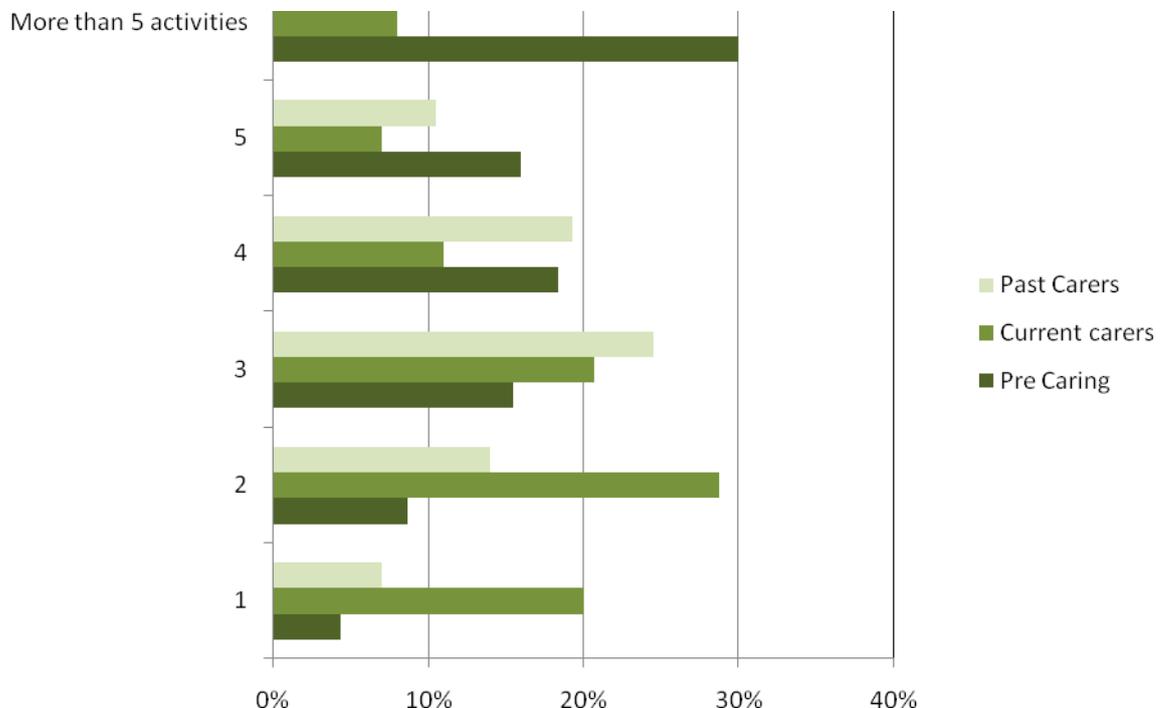
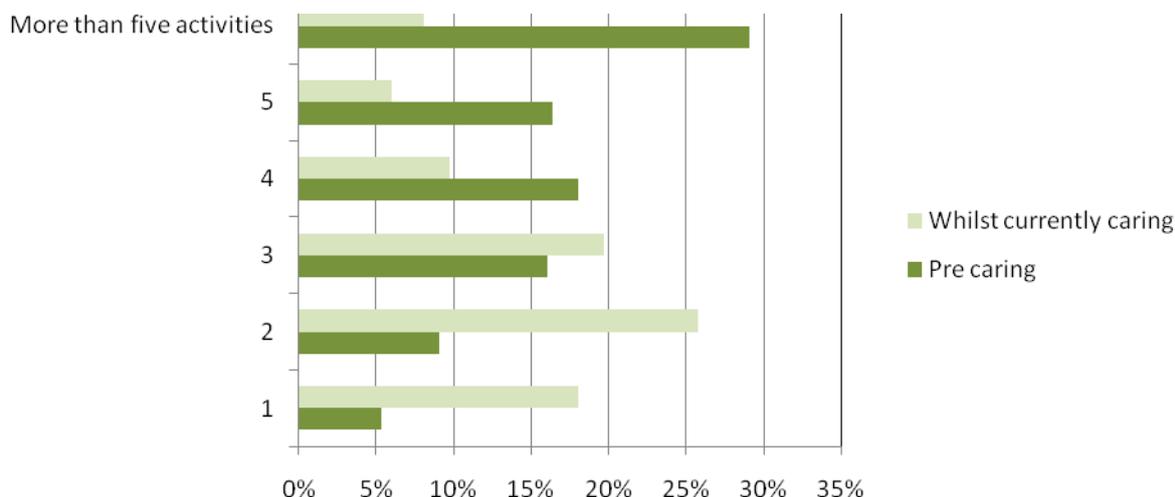


Figure 14 examines the activity levels pre caring and whilst caring of the 299 current carers who responded to the survey. As can be seen activity levels decreased whilst caring.

FIGURE 14: NUMBER OF WEEKLY ACTIVITIES OUTSIDE THE HOME UNDERTAKEN BY CURRENT CARERS



To examine the overall impact of this across the group of current carers the conservative assumption was made that carers who indicated that they undertook more than 5 activities a week undertook 6 activities per week. Only 251 carers provided information on their activity levels both before they became a carer and at present whilst they are currently caring. Calculations used this as the base sample. Utilising this assumption the average number of weekly activities undertaken outside the home by current carers was 4 activities per week before caring and 2.5 activities per week whilst caring.

Tables 1 to 6 examine current carers' average weekly activity levels by:

- main language spoken at home by carer
- hours spent caring each week
- location of carer
- age of carer
- time spent in the caring role
- gender of carer.

Several results stand out from these tables. Namely:

- the highest activity levels whilst caring is amongst non-English speaking carers and those undertaking the caring role for less than 10 hours per week (Tables 1 & 2).
- metropolitan carers have more activities before and after caring role than regional carers (Table 3)
- regional carers and carers aged 25-34 indicated the lowest levels of activities outside the home (Tables 3 & 4).
- caring per se rather than other variants appear to be the major factor impacting on activity levels outside the home (Tables 1-6).

The question also arises from these results if people are overestimating past activity levels given that those who had been caring for less than 12 months has the lowest level of precaring activity levels (Table 5).

Respondents were not asked if the time spent on total outside activities had increased or decreased or if there had been activity substitution i.e. if for instance a former sporting activity had been replaced by visits to the doctor and appointments. This information could have provided more detail about the impact on carers as they transition through the caring role.

TABLE 1: CURRENT CARERS AVERAGE LEVEL OF WEEKLY ACTIVITIES OUTSIDE THE HOME BY MAIN LANGUAGE SPOKEN AT HOME BY CARER

Language spoken by carer	Number of respondents	Before caring commenced	Whilst currently caring	Variance
English is main language spoken at home	212	4.2	2.8	-1.4
A language other than English is main language spoken at home	38	4.9	3.3	-1.6

NB 1 respondent did not indicate their language spoken at home.

TABLE 2: CURRENT CARERS AVERAGE LEVEL OF WEEKLY ACTIVITIES OUTSIDE THE HOME BY HOURS SPENT CARING EACH WEEK

Number of hours spent in caring role per week	Number of respondents	Before caring commenced	Whilst currently caring	Variance
Less than 10 hours	12	3.8	3.7	-0.1
10-25 hours	35	4.3	2.9	-1.4
26-40 hours	44	3.9	2.8	-1.1
More than 40 hours	146	4.4	2.7	-1.7

NB 14 respondents did not provide information on the hours per week they spend caring.

TABLE 3: CURRENT CARERS AVERAGE LEVELS OF WEEKLY ACTIVITIES OUTSIDE THE HOME BY LOCATION OF CARER

Location of carer	Number of respondents	Before caring commenced	Whilst currently caring	Variance
Metropolitan Adelaide	151	4.4	3	-1.4
Regional South Australia	88	4.1	2.5	-1.6

NB 12 respondents did not provide their location.

TABLE 4: CURRENT CARERS AVERAGE LEVELS OF WEEKLY ACTIVITIES OUTSIDE THE HOME BY AGE OF CARER

Age in years	Number of respondents	Before caring commenced	Whilst currently caring	Variance
25-34	6	4.5	2.5	-2
35-49	28	4.5	2.8	-1.7
50-64	65	4	2.9	-1.1
65-79	116	4.3	2.9	-1.4
80 and over	28	4	2.9	-1.1

NB 8 respondents did not provide age data.

TABLE 5: CURRENT CARERS AVERAGE LEVEL OF WEEKLY ACTIVITIES OUTSIDE THE HOME BY TIME SPENT IN THE CARING ROLE

Time spent in current caring role	Number of respondents	Before caring commenced	Whilst currently caring	Variance
Less than 12 months	11	3.7	2.8	-0.9
1-5 years	105	4.1	2.8	-1.3
6-10 years	50	4.4	2.7	-1.7
More than 10 years	85	4.4	2.8	-1.6
All current carers	251	4.3	2.8	-1.5

NB All 251 respondents indicated the time they have spent in the caring role

TABLE 6: CURRENT CARERS AVERAGE LEVEL OF WEEKLY ACTIVITIES OUTSIDE THE HOME BY GENDER OF CARER

Gender of carer	Number of respondents	Before caring commenced	Whilst currently caring	Variance
Female	187	4.3	2.8	-1.5
Male	50	4.2	3	-1.2

NB 14 respondents did not indicate their gender.

## 10.1 KEY POINTS TO NOTE

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There was a significant decrease in the number of activities undertaken by current carers compared to the number undertaken before they became carers. Of the current and past carers who completed the survey 30% were undertaking more than 5 activities a day before they became carers and this decreased to 8% for those who are currently caring. There was a slight increase in the post caring role to 12% undertaking more than 5 activities a day.

The average number of weekly activities undertaken outside the home by current carers was 4 activities per week before caring and 2.5 activities per week whilst caring.

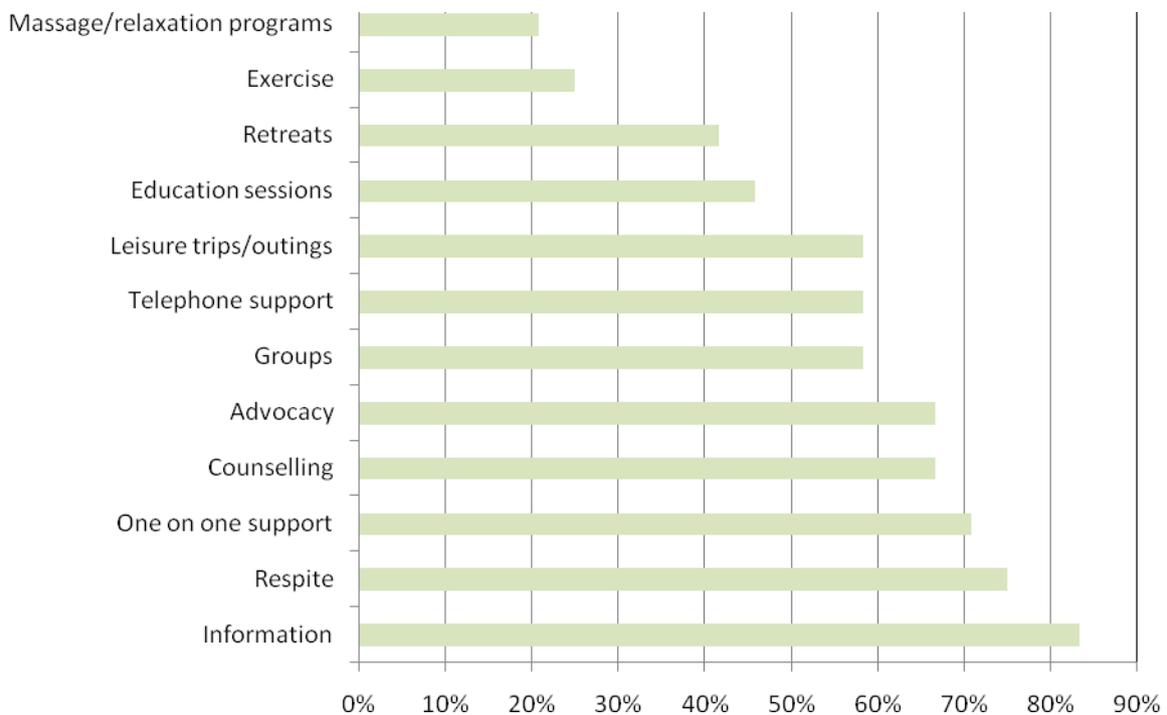
Caring per se rather than other variants, appear to be the major factor impacting on activity levels outside the home.

## 11 CARER SUPPORT

### 11.1 HACC ASSISTANCE

HACC agencies indicated that they offer a range of support to eligible HACC carers. The most common types of support offered were information (83%), followed by respite (75%), one on one support (71%), advocacy (67%) and counselling (67%) (Figure 15). A number of agencies indicated that they provided support to carers through emails, Facebook and SMS bulk messaging. These were predominately to younger carers between the ages of 17-30 years.

FIGURE 15: TYPE OF SUPPORTS OFFERED FOR HACC ELIGIBLE CARERS



NB Respondents could select more than one response, so percentages may add up to more than 100%.

## 11.2 FORMAL AND INFORMAL SOURCES OF SUPPORT

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When carers were asked what support they were receiving or had received as a carer from both formal and informal sources they nominated:

- support from a support group
- respite
- support from friends (Figure 13)

as their 3 top forms of support.

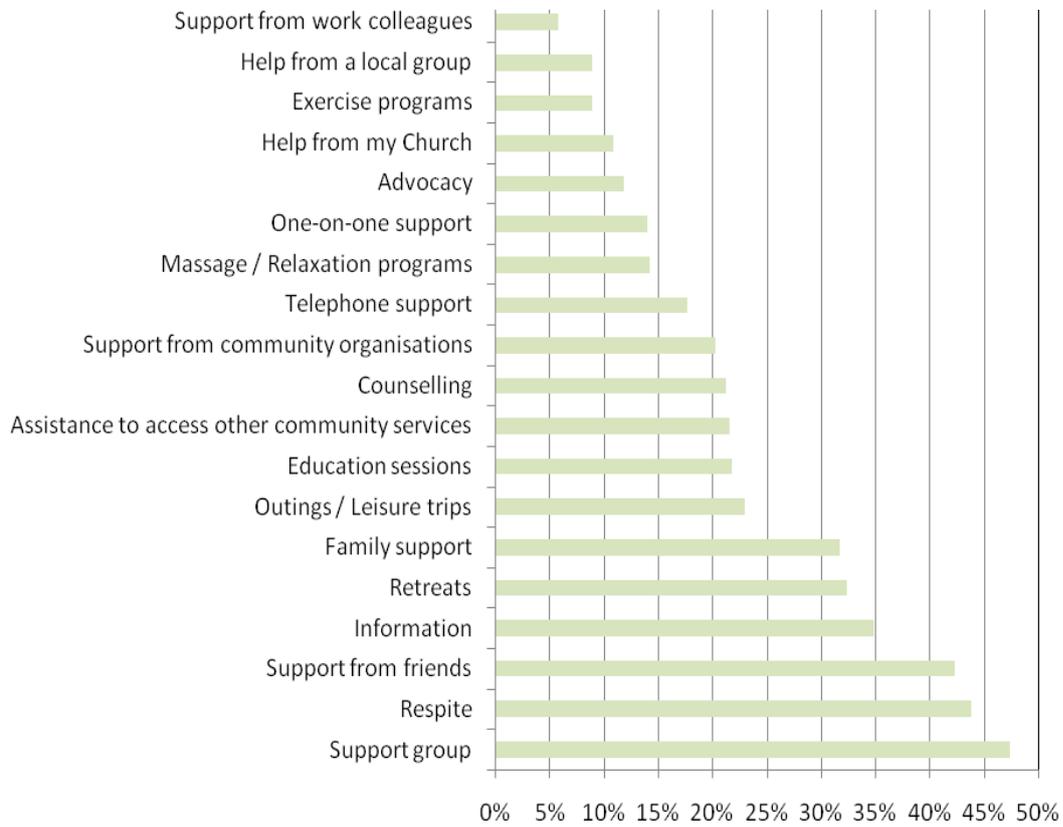
Of the 413 current and past carers surveyed 47% had or were attending a support group and 44% had or were receiving some form of respite (Figure 16).

*‘two hours for me to do shopping, have a coffee out or a short walk. About once every two months I get 5½ hours to attend a luncheon in Adelaide with old workmates.’*

Many carers at consultation meetings and in their survey responses said that friendships in support groups were very important and they had last touch with many of their other friends. In the survey carers were not asked to distinguish between friends from support groups and other friends. Based on the verbal and written feedback received this question may have elicited a different response if there had been a distinction between the two friendship groups.

Carers also indicated that they received support from various organisations including local groups, dedicated volunteers, transport assistance from friends and organisations, grief counselling and support for the person they were caring for.

FIGURE 16: FORMAL AND INFORMAL SUPPORT RECEIVED BY CURRENT AND PAST CARERS



NB Respondents could select more than one response, so percentages may add up to more than 100%.

## 11.1 KEY POINTS TO NOTE

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The most common types of support offered to carers by HACC funded agencies were information (83%), followed by respite (75%), one on one support (71%), advocacy (67%) and counselling (67%).

A number of agencies indicated that they provided support to carers through emails, Facebook and SMS bulk messaging. These were predominately to younger carers between the ages of 17-30 years.

Carers nominated a support group, respite and friends as their top 3 sources of both formal and informal sources of support.

Carers said that friendships in support groups were very important and they had last touch with many of their other friends.

## 12 HELPFUL SUPPORT FROM THE CARER'S PERSPECTIVE

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### 12.1 BENEFITS OF SUPPORT

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Support groups and respite were frequently nominated in responses as beneficial sources of support. In some instances respite was provided from an organisation and in other cases by friends or family members. Carers who had access to formal and/or informal support indicated that support provided a multitude of benefits including:

- enabling carers to undertake their 'normal' activities, be a 'normal' family or maintain a sense of 'normality' in their life (respite)
- time for activities including music lesson, book club, going to movies, the theatre, craft group, bowls, sport, exercise classes, gardening, renovating, fishing, walking and work in their shed (respite)
- the ability to maintain some of their former activities and interests (respite)
- time to spend with community clubs and in volunteering activities
- time for physical fitness (respite)
- a chance to try new activities
- time to attend to their own affairs, medical appointments and business matters
- time for domestic duties
- time for their own outings and social time with friends including lunches, coffee, breakfast, an evening girls group
- time to catch up with other family members
- enhanced their emotional wellbeing
- helped to reduce stress levels (support group and other types of assistance)
- giving carers a chance to regroup and regenerate
- strategies for caring and for looking after themselves (support group)
- assistance in navigating the 'system' and accessing services (support group)
- reassurance that they were not 'alone' in their caring role (support group)

- social support (support group)
- new friendships (support group)
- a chance to earn additional income
- the ability to spend time with other men (male carers)
- the ability to spend time with their community (CALD and ASTI carers) (support group)
- the ability to problem solve with other carers and find caring solutions faster (support group)
- helping them to develop a positive attitude (support group)
- helping them come to terms with their circumstances
- a place and a space to deal with their negative feelings about their caring role and the difficulties they were facing (support group)
- the ability to relax and talk to people in similar circumstances who were compassionate, understanding and non-judgmental (support group)
- a chance to take holidays
- the ability to attend church
- time for couples to spend together
- enabled them to maintain their family commitments
- enabled them to attend family days and outings which connect them to their community
- improved their self esteem
- enabled keep them to keep in touch with current and former co-workers
- widened their network of friends and enabled them to make very close good friends (support group)
- provided formal and informal therapy gave carers a chance to laugh (support group)
- provided a sense of relief (support group)
- provided a shoulder to cry on ( support group and friends)
- provided sounding boards and enabled them to debrief
- transport assistance
- allows access to services to improve situation
- helped carers with the day to day issues (support group)

- helped carers understand what the caring role can entail and prepared them for some aspects of the caring role (support group)
- eased carers stress and help them cope with situations (support group)
- let carers know what was available to look after themselves
- gave carers 'permission' to talk and ask for help and support (support group)
- helped carers understand the health issues and/or disability of the person they were caring for
- kept carers up-to-date with what support is available for the elderly and what their needs are.

*'it gave us the strength to approach caring more positively'*

*'it has given me more freedom to do my own thing.'*

*'Makes you realise you are not alone at a time when you most need someone to talk to.'*

Current and past carers were asked about what support been helpful and enabled them to stay connected to other important aspects of their lives.

Six types of support were looked at in more detail:

- general support which carers either found helpful as a carer or believed would be helpful (Section 12.2)
- support which assisted in maintaining carers' connections to their community, family and friends ( Section 12.3)
- support which assists carers to care for themselves (Section 12.4)

- support which assist carers to maintain their interests and employment (Section 12.5)
- information which was or would be helpful (Section 12.6)
- youth support (Section 12.7).

## 12.2 GENERAL SUPPORT

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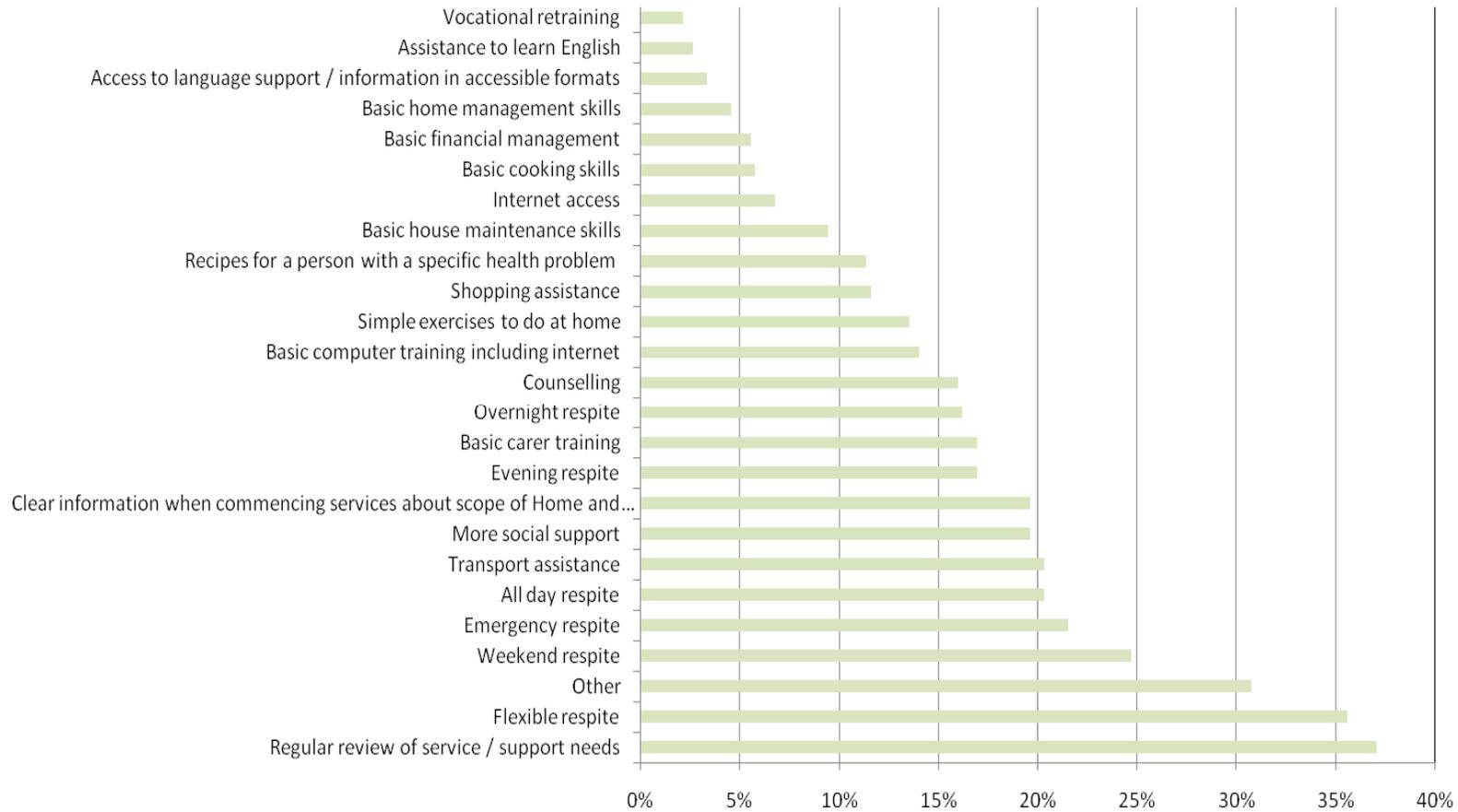
The following are 8 supports carers found helpful or would have found helpful in their caring role were:

- regular review of services and support needs (37%)
- flexible respite (36%)
- weekend respite (25%)
- emergency respite (22%)
- all day respite (20%)
- transport assistance (20%)
- more social support (20%)
- clear information about HACC when commencing the service (20%)

(Figure 17).

It was clear that many carers recognise that their role will change either as their care recipients needs increase or as their child ages and for this reason they want flexible and changing support as their needs change.

FIGURE 17: ASSISTANCE WHICH HAS BEEN OR WOULD BE HELPFUL FOR CARERS WHILST IN THE CARING ROLE



NB Respondents could select more than one response, so percentages may add up to more than 100%.

Carers at consultations stated many times over that support or services offered to them were often either not appropriate or insufficient for their needs. Some carers wanted to be able to buy in the services they specifically required such as domestic support to assist them in their caring role and enable them to remain connected to family, friends employment, social interests and community.

Carers also listed a variety of other areas in which they require support (some of which fall outside of HACC guidelines) including:

- activity based support for care recipients in their sixties with either dementia or physical disabilities
- dementia link worker
- telephone buddy system
- youth link worker
- counselling for children whose parent or grandparent is suffering from a mental illness
- an easier process to get ACAT assessments
- petrol money
- help with housework
- first aid course
- support with Centrelink
- legal and financial services re superannuation and pensions
- more multi-faceted services
- food supplements for cancer patients to maintain weight.
- grief counselling
- having a cancer support group within Whyalla
- social activities for the kids and family days.

### 12.3 SUPPORT WHICH ASSISTED CARERS TO MAINTAIN THEIR CONNECTIONS TO COMMUNITY, FAMILY AND FRIENDS

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The 4 major forms of assistance or activities which enabled carers to stay connected to their community, family and friends were:

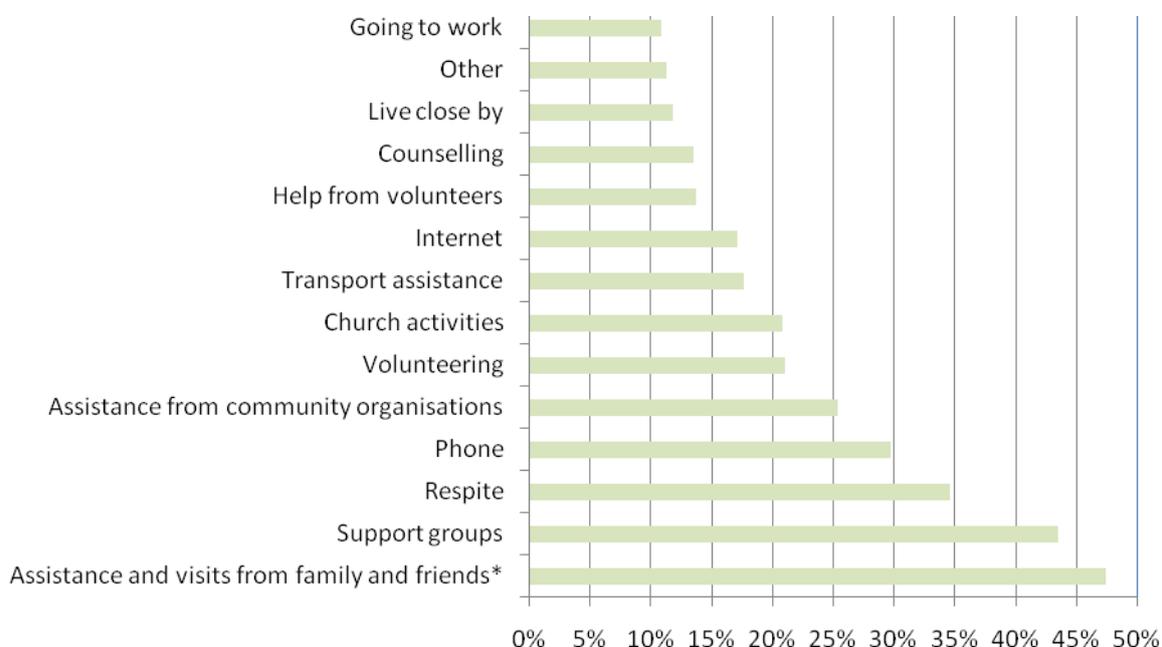
- assistance and visits from family, friends and neighbours (47%)
- support groups (44%)
- respite (33%)
- phone (30%) (Figure 18).

CALD and ATSI carers all stated that culturally and linguistically specific support groups enabled them to remain connected to their communities, families and friends.

Many carers, particularly younger carers relied on the internet (17%), to remain connected to the wider community, family and friends. Younger carers communicated and sought information using the internet however some found the cost of the service prohibitive and struggled to continue using the service. Older carers reported using the internet to source information and to keep abreast of family, particularly grandchildren.

*'I have got used to being on my own. I didn't mind my own company although there are times I can feel the lack of one on one communication and understanding mainly because my son doesn't communicate well or respond to my feelings. I have learnt to live with this. I phone my daughter fairly regularly - she lives interstate, rarely see her, talking to her can help.'*

FIGURE 18: ACTIVITIES AND ASSISTANCE WHICH HELPED CARERS TO STAY CONNECTED TO THEIR COMMUNITY, FAMILY AND FRIENDS



\* Assistance and visits from family, friends and neighbours

NB Respondents could select more than one response, so percentages may add up to more than 100%.

The following also helped carers to remain connected:

- being open about the difficulties being encountered by the person they were caring with family, friends and acquaintances
- undertaking more activities
- help from their husband
- sporting activities including bowls
- collecting mail from the Post Office
- taking the person they are caring for to activities
- receiving information in the post about activities
- proximity to respite services
- receiving taxi vouchers for the care recipient
- transport assistance for the care recipient
- HACC programs

- service providers such as Uniting Care Wesley, Disability SA, Time out for Kids, Essence of Hope
- attending healing retreats and workshops.

*'Healing retreats and workshops - Traditional and cultural healing with Ngankari - Aboriginal healers. Going back to country retreats - Northern Carers took us on a retreat to our country in the Flinders Ranges, I reconnected to the community I was taken from as a child. The support group is great, we have a good laugh and a good cry. We are there for each other'*

In addition carers wanted to be able to:

- fly interstate to visit their children
- go on family holidays
- attend family days and excursions which connected them to the community
- have time for their own outings
- have coffee with friends or go out in the evening with friends
- meet friends and colleagues for lunch or breakfast
- get away from everything and have time just for themselves.

Support was important in letting carers know that they were not in it alone. It gave them reassurance and encouragement. Telephone support and talking to care workers helped carers.

*'it's comforting to know that there are people that we can rely on 'for assistance' '*

Refer to Sections 7.1.2 and 7.1.3 for further information on the positive impacts of support.

## 12.4 SUPPORT WHICH ASSISTED CARERS TO CARE FOR THEMSELVES

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### 12.4.1 'ME TIME'

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A very strong theme amongst carers at consultations and through the surveys was that having a break from caring assisted them to care for themselves. Having *'some me time'* to be able to read a book, drink a cup of coffee uninterrupted or just sleep, in order to recharge their *'batteries'* and be able to cope with their caring role.

*'It is the constant responsibility of caring 24/7 which takes its toll and having a break from caring is what helps most.'*

### 12.4.2 RETREATS

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Carers wanted retreats and weekend outings. Sometimes they wanted to go with the person they were caring for, however many just wanted to have a holiday on their own, but found this difficult financially. A number of male carers caring for children with disabilities indicated that they wanted to go away with their partner for a weekend and be like other *'normal couples'*. Couple time was often difficult for young families.

Working carers particularly wanted weekend supports and activities as they found it difficult to juggle work, caring responsibilities and trying to attend retreats or support groups.

*'It would be helpful if the carers centre held things after hours or at weekends. I miss out because I have to work. I finally got a day of retreat but I had such a job trying to juggle care for kids and hubby and take a day off work to attend.'*

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### 12.4.3 RESPITE

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Carers stated that respite was crucial for them to be able to care for themselves. Respite was used for both relaxation and for household tasks i.e. shopping, cleaning, doctors' visits, exercise classes. Carers wanted respite to be:

- flexible
- overnight
- weekend
- long stay.

Younger carers and regional carers wanted additional respite to be provided.

A worker in the South Australian Riverland region stated that providing carers with flexible respite made a world of difference, she had seen some '*miraculous changes to people's outlook with only 4-5 hours of respite particularly when it has been flexible to suit carers needs*'.

*'I always tried to do something for myself while he was in respite. Either see a movie, get my hair done or have a massage or sometimes just have a day where all I did was watch DVDs or read a book. These things kept me sane.'*

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#### 12.4.4 FAMILIES

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For many carers when family support was forthcoming, it was particularly appreciated. Supportive family and friends helped them remain connected to their community with many offering much needed respite or a listening ear. One carer stated that *'her family keeps an eye on her and lets her know when she needs a break'*. By having strong supportive family and friends carers felt less and isolated and were able to ask for help when they needed it. Carers often felt that the burden of caring was lighter.

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#### 12.4.5 SUPPORT GROUPS

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Whilst many used support groups they were particularly valued by carers who did not have supportive friends or families, and for many, group members became their surrogate families and friends. Support groups for some were *'life lines'*. Support groups offered carers:

- strength
- guidance
- information
- a learning environment
- a sense of belonging
- an ability to connect with other carers in similar circumstances
- a non-judgmental environment
- shared experiences.

For some carers being part of a support group enabled them to remain connected to the community and feel good about themselves.

*'I have been very lucky to have plenty of support from my family, friends and support group which I still attend.'*

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#### 12.4.6 PERSONALITY

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Carers and workers alike stated that a person's own personality or positive attitude sometimes better equipped them to care for themselves and undertake their caring role. Carers spoke of their own self-determination, inner strength and belief in themselves as qualities which enabled them to get through the difficult times. Being more flexible and adjusting easily to different situations in life were mentioned as qualities which enabled carers to move through their caring role a lot easier.

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#### 12.4.7 COUNSELLING

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Those in challenging ongoing care situations indicated that they required monthly counselling to enable them to cope with their circumstances.

In general carers indicated that when they received counselling it was beneficial although there were some exceptions to this. Carers said that counselling was useful because:

- it helps to share your problems with someone not involved
- it assisted them to stay connected with their own needs
- it assisted them to deal with the emotional experiences they experienced caring
- it helped them to develop strategies to cope
- it was help provided specifically for the carer.

One carer would ring her daughter every evening to '*offload her day*' of caring and this would then enable her to carry on.

Many carers used counselling (both formal and informal) to help them care for themselves. Some used the free services provided by carer support agencies, others used families and friends. Some carers paid for professional counselling, although for many carers the cost of professional counselling was prohibitive. Generally carers

did not indicate if the counselling they received was HACC, Medicare subsidised or through the National Carer Counselling Service. Those that did mention the National scheme said that the number of sessions offered was insufficient.

*'Counselling and talking to people has helped me look after myself.'*

The requirement for extra counselling was mentioned by carers of all ages, in both metropolitan and regional locations and by carers of both genders.

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#### 12.4.8 PHYSICAL HEALTH AND RECREATION

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Carers said that keeping fit and healthy enabled them to care for themselves. Older carers mentioned lawn bowls quite frequently as a way of staying connected. Many carers had regular massages, undertook yoga, walking, swimming, maintained a fitness regime or played sport and looked after their diet. Looking after their physical and mental well-being always made them feel better and enabled them to undertake their caring responsibilities.

Quite a few past carers at meetings said they used support to catch up on sleep or *'veg out with a movie'* and relax. Carers with disturbed sleep mentioned the value of being able to get *'quality sleep'*.

Many carers indicated that *'pampering'*, such as massages, lunches and visits to physiotherapists, chiropractors and hairdressers often assisted them to help care for themselves.

Massages were very popular with those who had had them and for some it was the only support they thought they could have had if the person would not use respite care. Some carers said that the massages were beautiful, wonderful and a lovely treat. For one, *'massages helps to manage the pain level'* whilst another said that they have a massage once a fortnight, see a chiropractor once a month and regularly see a Naturopath. Some carers said that they have less success at

exercising regularly because it is hard to fit it in but that they always felt better when they exercised.

Other areas which assisted carers to care for themselves were:

- information or courses on stress management
- maintaining their voluntary activities
- maintaining employment
- financial support
- their faith
- additional domestic assistance to allow carers more time to relax at home.

*'Practical assistance every week/fortnight so that I have more time to relax at home, rather than work. After 15 years, I'm burning out.'*

## 12.5 SUPPORT WHICH HELPED CARERS MAINTAIN THEIR INTERESTS OR EMPLOYMENT

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Carers at the consultations and through the survey responses indicated that there were a range of supports which assisted them to be able to continue with their interests, namely:

- respite
- support from family or friends
- transport assistance
- availability of the internet
- support group activities/ outings.

*'Local aged group activities and respite for the person I care for has enabled me to continue my interests.'*

The internet provided young carers with an enormous sense of connection, with some carers viewing it as their lifeline to the outside world and their friends.

Time management was something which helped some carers cope. One carer said that she always stopped at 4pm in the afternoon just to knit and keep up with her hobby. She did this for years and it allowed her to relax away from her caring role, which required her to always be present in the home.

Carers stated that having a positive attitude and personal determination enabled them to stay connected with family, friends and their interests.

Carers in the workforce stated that a number of supports assisted them to continue working and caring, namely:

- flexible respite
- flexible working conditions and hours
- support from colleagues
- the ability to work from home
- assistance from families and friends.

Many carers wanted to continue working as this took them away from their caring role and gave them some relief. A number of carers at the consultations indicated that they shifted to employment that was closer to home in order to remain in the workforce. Long travelling times between home, caring and work often took their toll on carers and this often led to carers leaving work or placing care recipients into care.

Many carers highlighted the importance of having an employer and colleagues who understood and supported them when they were not able to attend work because of a caring-related crisis. Carers were able to care for longer periods at home knowing that their work environment was not placing unrealistic demands on them.

*'My sister has helped me greatly by being there for mum if I was not able to. This has helped greatly for my employment and sometimes weekend activities'*

*'Flexibility in the work environment, understanding colleagues and management'*

*'Work is my only sanity'*

## 12.6 INFORMATION WHICH CARERS EITHER FOUND HELPFUL OR WOULD FIND HELPFUL

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Information which carers either did find helpful or would have found helpful in their caring role included information on:

- managing stress (39%)
- organisations which provide support for carers (31%)
- preventing and or dealing with depression (31%)
- legal issues (31%)
- organisations which provide support for care (31%)
- Centrelink entitlements (29%).

Carers also wanted information on carer support groups (24%) and dealing with loss and grief (20%) (Figure 19).

Stress was a major issue for many carers and some spoke of suicide. Many wanted support and guidance in alleviating the stress in their lives. Current and past carers found stress related courses offered by many HACC agencies in South Australia particularly helpful.

Carers commented on the usefulness of the information they received *'the information points us in the direction we need to go'*. Many used the information to improve their caring and assist them with day to day issues.

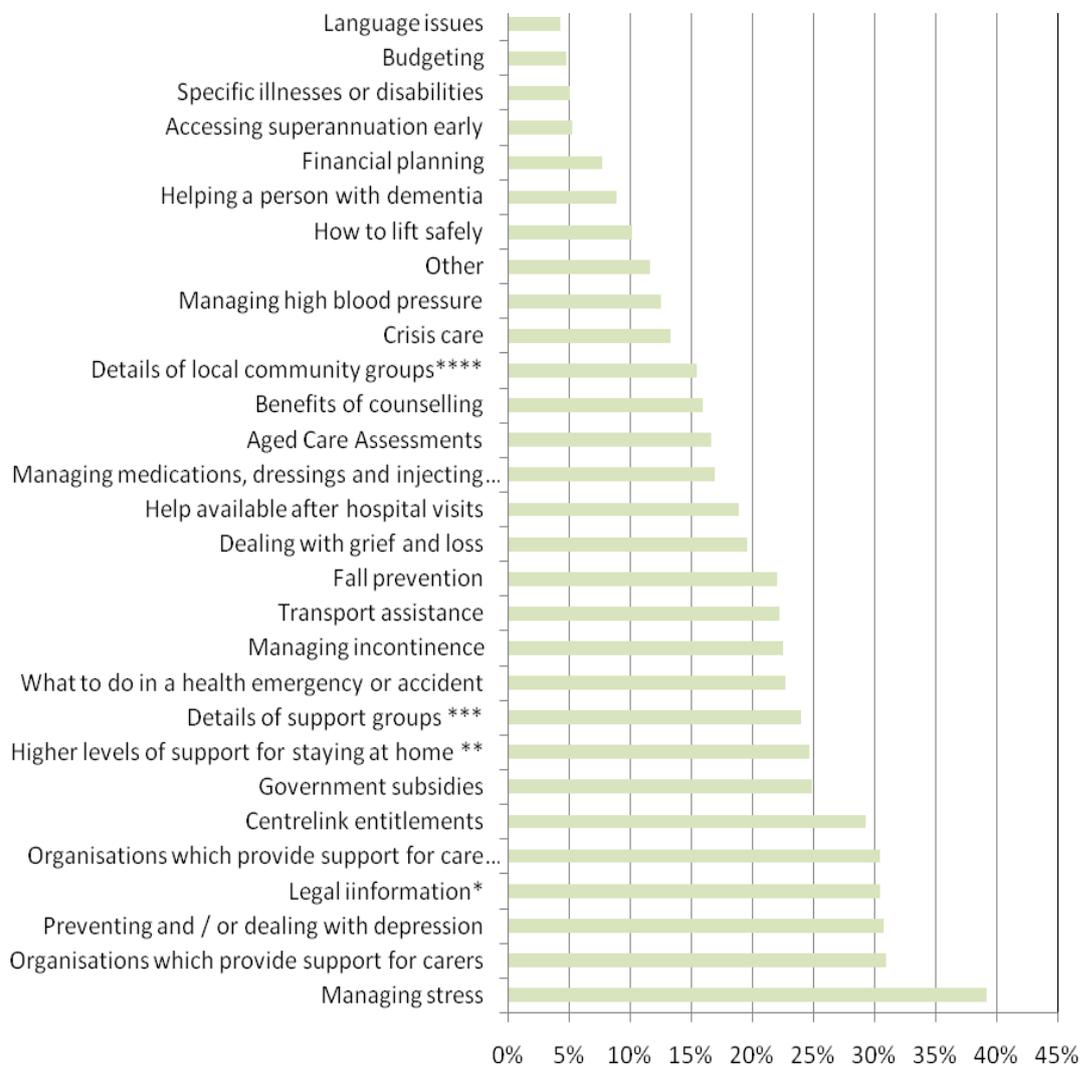
Education and/ or information is an ongoing necessity for most carers, it assists carers to:

- help reduce stress levels
- better deal with health related issues
- better care for themselves and the care recipient
- access support

- enhance their emotional wellbeing
- social support
- improve self esteem.

*'INFORMATION AND HELP WITH ACCESSING SERVICES WAS IMPORTANT IN NAVIGATING THE MAZE OF SERVICES, SERVICE PROVIDERS AND ELIGIBILITY FOR SERVICES.'*

FIGURE 19: INFORMATION CARERS FIND HELPFUL



NB Respondents could select more than one response, so percentages may add up to more than 100%.

\* Legal issues including Power of Attorney, Enduring Power of Attorney, Enduring Power of Guardianship and Wills

\*\* Higher levels of support for staying at home, Community Aged Care (CACAP) and Extended Aged Care at Home (EACH) packages

\*\*\*Support groups including their location, time, activities and languages

\*\*\*\*Local community groups including their location, time, activities and languages

## 12.7 YOUTH SUPPORT

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Younger carers aged between 10 and 14 years sought additional respite options such as activity groups, camps and organised excursions as a way of staying connected to young people their age with similar issues. Carers 15-18 years sought additional tutoring and support at home with the caring role to be able to undertake their year 11 and 12 studies. They also sought assistance to learn to drive and viewed this as critical in being able to stay connected with friends.

Young adult carers 18-25 years spoke of needing:

- additional counselling to work through career options and family issues
- to complete their schooling
- additional respite and financial support to be able to obtain qualifications either tertiary or secondary and training
- additional respite and financial support to attend work
- internet access, as some did not have the financial capacity to pay for it
- assistance to learn to drive
- additional organised support group meetings/activities with carers in similar situations
- cooking and home maintenance skill development.

Some young adult carers had become disconnected from their community.

Learning to drive and completing schooling were seen as critical issues for both groups of young carers.

See also Section 7.2.9 above.

## 12.8 NOTHING COULD HELP

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Some carers said nothing could help them care for themselves. They felt despondent about their life and the position they were in. Life was a huge effort.

*'Nothing, my job had to stop, I now have lost my window of opportunity to go back. My ongoing education and updated knowledge have now passed on. Who has the time to do anymore? I start at 8am or earlier if it is a stinking hot day. I finish at 11.30pm and wake at 3am to check on everything. Getting back to sleep at 5.30am if I am lucky, my asthma has returned, my mother's Macular Degeneration is hereditary and my eyes are going. She also has glaucoma along with her vascular dementia. At times I am in so much pain I can hardly walk let alone drive and we are so reliant on my ability to drive safely for provisions.'*

## 12.9 KEY POINTS TO NOTE

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Carers who had access to formal and/or informal support indicated that support provided a multitude of benefits.

Eight general supports carers found helpful or would have found helpful in their caring role were:

- regular review of services and support needs (37%)
- flexible respite (36%)
- weekend respite (25%)
- emergency respite (22%)
- all day respite (20%)
- transport assistance (20%)
- more social support (20%)
- clear information about HACC when commencing the service (20%)

Some carers wanted to be able to buy in the services they specifically required.

The 4 major forms of assistance or activities which enabled carers to stay connected to their community, family and friends were:

- assistance and visits from family, friends and neighbours (47%)
- support groups (44%)
- respite (33%)
- phone (30%).

CALD and ATSI carers all stated that culturally and linguistically specific support groups enabled them to remain connected to their communities, families and friends.

Many carers, particularly younger carers relied on the internet (17%), to remain connected to the wider community, family and friends.

Support was important in letting carers know that they were not in it alone. It gave them reassurance and encouragement.

The following helped carers to care for themselves: time for themselves; retreats; respite; family support; support groups; their own personality and or a positive attitude; counselling; staying fit and healthy and undertaking recreational activities.

When family support was forthcoming, it was particularly appreciated.

Quite a few past carers at meetings said they used support to catch up on sleep or relax.

Other areas which assisted carers to care for themselves were:

- *'pampering'*, such as massages, lunches and visits to physiotherapists, chiropractors and hairdressers
- information or courses on stress management
- maintaining their voluntary activities
- maintaining employment
- financial support
- their faith
- additional domestic assistance to allow carers more time to relax at home.

Carers stated that respite was crucial for them to be able to care for themselves. They wanted respite to be flexible, overnight, weekend and long stay. Younger carers and regional carers wanted additional respite to be provided.

Support groups were particularly valued by carers who did not have supportive friends or families. Support groups offered carers:

- strength
- guidance
- information
- a learning environment
- a sense of belonging

- an ability to connect with other carers in similar circumstances
- a non-judgmental environment
- shared experiences.

The requirement for extra counselling was mentioned by carers of all ages, in both metropolitan and regional locations and by carers of both genders. Those in challenging ongoing care situations indicated that they required monthly counselling to enable them to cope with their circumstances. Carers said that counselling was useful because:

- it helps to share your problems with someone not involved
- it assisted them to stay connected with their own needs
- it assisted them to deal with the emotional experiences they experienced caring
- it helped them to develop strategies to cope
- it was help provided specifically for the carer.

Carers indicated that there were a range of supports which assisted them to be able to continue with their interests, namely:

- respite
- support from family or friends
- transport assistance
- availability of the internet
- support group activities/ outings.

Carers in the workforce stated that a number of supports assisted them to continue working and caring:

- flexible respite
- flexible working conditions and hours
- support from colleagues
- the ability to work from home
- assistance from families and friends.

Many carers wanted to continue working as this took them away from their caring role and gave them some relief. They highlighted the importance of having an employer and colleagues who understood and supported them when they were not able to attend work because of a caring-related crisis.

Education and/ or information is an ongoing necessity for most carers, it assists carers to:

- help reduce stress levels
- better deal with health related issues
- better care for themselves and the care recipient
- access support
- enhance their emotional wellbeing
- social support
- improve self esteem.

Carers nominated a range of information which was or would be helpful in the caring role including:

- managing stress (39%)
- organisations which provide support for carers (31%)
- preventing and or dealing with depression (31%)
- legal issues (31%)
- organisations which provide support for care (31%)
- Centrelink entitlements (29%).

Carers also wanted information on carer support groups (24%) and dealing with loss and grief (20%).

Younger carers need more research and a specific program of support developed which enables them to meet their developmental needs.

## 13 CARERS IN TRANSITION: LITERATURE REVIEW

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### 13.1 THE TRANSITION CONCEPT

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The care giving process is fluid and dynamic, responding to changing needs of the carer and the person receiving their care and the resources and supports received to assist that process. Consequently, there will be periods throughout that process when carers are in transition as they move from one phase on the caring continuum to another.

Some of these points of transition will be subtle, others will be more dramatic, with the most dramatic associated with the person receiving care moving out of home and into residential care, or dying. A number of terms are associated with this end-phase of caregiving – ‘relinquishing care’ being one – but more recently, as our understanding improves of the evolving nature of the caring pathway, and for the need to adopt a ‘whole-of-life’ perspective, the concept of carers being in ‘transition’ at certain points of the pathway is gaining credence.

The concept of transition accurately suggests that change is occurring, and that key points of transition can also be times of significant vulnerability for the carer. This highlights the importance of support that is flexible and responsive to changing need, and the importance of avoiding ‘one-size-fits-all’ approaches to designing and providing that support.

Most of the research reviewed argues that a timeframe is not realistic as carers not only differ in how effectively they make the transition, but may move between different phases in the post-caring journey before they can be said to have adjusted to their new way of life.

## 13.2 RESEARCH FINDINGS

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The research literature focuses on two experiences of carers in transition – one triggered by the person receiving care entering long term residential care and the change in carer role, and the other caused by the ending of the caregiving role, mainly because of the death of the person receiving care. Each brings different challenges requiring different interventions and supports to facilitate these transitions.

The literature on both is relatively small, but larger in relation to the pre- and post-admission to residential care transition. The predominant methodology used by researchers is qualitative, involving very small samples of carers but intense and detailed exploration of their needs, perceptions and expectations. The majority of carers studied are female, with the very small number of males in the samples making it difficult to generalise findings to men with any confidence. Similarly, there is a gap in research studies with a culturally specific focus, and on young carers experiencing care transitions.

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### 13.2.1 ENTRY TO RESIDENTIAL CARE

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Although awareness is growing of the significance for carers of the care recipient's admission to residential care relatively few studies have explored the impact of this experience and how carers can be most effectively supported to adapt to a new role during this transition (Edge: 2007: 1; Davies & Nolan 2003: 429-430).

Entry to a care home is a difficult period for most carers and care recipients, but is poorly understood. Moreover, most studies have examined the views of older people ... while the experiences of family care-givers have been relatively under-explored (Davies & Nolan 2003: 430).

In her review of the literature, Edge (2007: 2) noted admission to long term care usually fails to recognise that family caring is a critical component of the care of frail older people, and that in many care settings, family carers' needs are 'invisible' because they are no longer considered to be a carer.

... the literature suggests that admission into long term care rarely takes into account family members needs .... The challenge for nurses is to understand transition processes and develop interventions to help families regain stability and a sense of well-being.

The literature that does exist explores factors that influence carers to accept residential care, their experiences following the admission process, the impact of that admission on them, and factors that support carers in making the transition to a new role.

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### 13.2.2 THE POST-ADMISSION EXPERIENCE

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Researchers have identified carers' dissatisfaction with inadequate support and information during the transition period, particularly when the transfer to residential care had occurred from the hospital setting (and was therefore associated with a crisis, and a dominant role by professionals in making the placement decision). Carers in these circumstances were found to share conflicting feelings about the placement decision, describing a loss of control and a feeling of disempowerment with some feeling they have been forced into what they view as a 'negative' choice, or feel defeated by the inevitability of the need for formal care (Ryan & Scullion 2000; Kellett 1999; Dellasega and Nolan 1997).

In order to minimise these feelings, Kellett (1999) found that carers seek the sanction of health professionals as a legitimate reason for placing their relative in a long stay setting. Information is also of critical importance in facilitating carers' role transition (Dellasega & Nolan 1997: 443).

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### 13.2.3 MIXED EMOTIONS: THE IMPACT ON CARERS OF ADMISSION OF THE CARE RECIPIENT TO RESIDENTIAL CARE

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Once the decision to place a relative in a long stay setting has been reached, the process of finding a suitable facility and preparing their relative for a move begins. As family care is not only a practical task but also takes place within the context of emotional bonds, long standing relationships and reciprocity, this process is often underscored by significant emotion. It is important to differentiate between different groups of carers as the experience will be diverse, albeit linked with commonly experienced feelings. For example, co-resident partners tend to find the separation from their loved one more challenging than do the cared-for person's children (Edge 2007: 3).

The need to take into account different carer circumstances was highlighted in research undertaken in South Australia by Bond, Clark & Davies (2003). This used a longitudinal design, in which a group of 150 dementia caregivers were interviewed 2 years apart with data collected from both continuing caregivers and those who had relinquished care (either because the cared-for person had died, or because they had been admitted to long term care). Different patterns of quality of life changes were observed between these groups, with both positives and negatives associated with disengagement from the caregiving role.

The mixed feelings experienced by carers in transition are likely to be compounded by the attitudes of others. Wider cultural and social norms usually encourage families to care for their loved ones at home, for as long as possible. In a study of daughters relinquishing care of a parent, both family and wider societal expectations were found to add to emotional turmoil, with demands on daughters often being more extreme than for sons (Read & Wuest 2008: 937). These expectations can also bring stigmatisation of long term care and a sense of failure for carers associated with the decision to accept residential care. This can be particularly pronounced in certain cultural groups (Kate Barnett & Associates 1999).

Analysis of family carers' reactions following placement has identified the experience of loss of control, feeling disempowered, feeling angry, feeling guilty due to a perception that they are no longer fulfilling their caregiving responsibilities, simultaneous sadness and relief, a sense of failure, resentment or despair, generalised psychological distress, and for some, feeling that a forced and negative choice had been imposed on them (Kellett 1999: 1474; Ryan 2002: 324; Ryan & Scullion 2000: 1187).

Kellett (1999) conducted a qualitative study with 14 carers in Australia who had experience of recently placing a relative in a long stay setting. She identified the tension carers experience, often feeling guilt, sadness and relief simultaneously. Argyle *et al* (2010: 21) also identified multiple emotional responses among carers following residential placement – relief, ambivalence, guilt, loss, loneliness and bereavement and adjusting to taking on new roles. Although the physical demands of care may be relieved following placement, the emotional demands may be exacerbated by the circumstances associated with the decision to end home care (Ryan 2002: 324; Ryan & Scullion 2000: 1187).

Research found that it is important to support carers during the transition period from home care to residential care. This has been found to be essential to carer well being, and to assisting carers in reshaping a meaningful caring role within the residential context. This is facilitated by the development of effective and collaborative relationships between residential staff and families and by providing information to carers as part of this process.

### 13.3 THE TRANSITION EXPERIENCE ASSOCIATED WITH THE END OF THE CAREGIVING ROLE

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#### 13.3.1 A DOUBLING OF LOSS: THE IMPACT ON CARERS AT THE END OF CARING

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The literature associated with the post-caring transition is sparse, compared to that on the transition associated with the end of home-based care and the beginning of residentially-based care. However, a group of Irish researchers have recently undertaken research which clearly depicts the emotional impact of the death of the cared-for person on their carer, and identifies key phases in the post-caring transition period.

... the loss of the pre-caring world (ie life prior to becoming a full-time, primary carer with all its social contacts, employment and other opportunities) is followed post-caring/care transitions with the loss of a 'caring world'; daily routines, carer role and identity, close relationship with the care receiver, and social network of medical personnel visiting their home have suddenly dissipated. The double losses create a profound sense of loss and emptiness. The loss of the pre-caring world is more distant; the transition is instead between their just-ended caring world and a newly constructed world after caring. In this transitional state carers feel 'worldless', not belonging to any particular place and not having any particular label or identity that applies to them (McCarron *et al* 2011 : 7).

These researchers have also examined the existing literature and found a clear trend for carers whose loved one has died to experience grief, guilt, relief, loneliness, loss of purpose and loss of identity, and for emotions to be multiple and mixed. While these reactions may be shared by carers, and for most, the experience is one of profound loss on a number of levels, it is also evident that carers do not react uniformly to the death of the person in their care.

The losses of the caring world are multi-dimensional and range from the emptiness of the house ... to the loss of the social network of regular visitors to the home, to the loss of one's role in life and sense of self. The loss and emptiness of post-caring/care transitions is so profound that ... [carers] equated it to being 'worldless'. The loss of the uniquely close relationship ... that had

developed between carer and care receiver further compounds the feelings of loss and emptiness (McCarron *et al* 2011 : 42).

The impact of the post-caring transition is not only profound for many carers, but can be lasting. For example, leaving the paid workforce to provide care can see a long term de-skilling and difficulties in returning to paid work, or to paid work at a prior level. In turn this can bring significant financial consequences, while the period of caring can see a breaking of social bonds that results in isolation. These were key findings from Read and West's 2008 study of daughters caring for dying parents.

Each choice to relinquish or sustain a role has enduring consequences ... that sometimes last long after the parent dies (Read & West 2008: 937).

Carers in transition have also been found to face physical and mental health challenges. In a major longitudinal study undertaken for the Australian Department of Health and Ageing, McKenzie *et al* (2009) examined the transitions into and out of caring, carer needs, and the use of interventions and services by carers and care recipients. The research was part of the wider *Australian Longitudinal Study on Women's Health*. A key finding was that poorer physical and mental health was statistically significantly related to carers transitioning into or out of providing care for a care recipient with whom they lived, and by comparison those providing care to someone with whom they did not live had better health (McKenzie *et al* 2009: 18).

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### 13.3.2 PHASES IN THE POST-CAREGIVING TRANSITION PROCESS

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Researchers also describe a '*post-caring void*' that is marked by feelings of loss and loneliness as contact ceases with the network of professionals who have often provided years of care and support, and a loss of purpose and role dominates. As routines change a number of closure activities occur in a '*closing down the caring time*' transition phase. This can involve no longer buying special foods or goods, disposing of care related equipment and no longer visiting a care facility. In the '*constructing life post-caring*' phase, carers often increase their time undertaking

recreational activities, seeking work or sometimes other caregiving activities (Larkin 2009).

McCarron *et al* (2011: 8) distinguish three stages in the transition process associated with the post-caring experience. These are sequential and involve:

1. **Loss of the Caring World**, a time of multiple losses including loss of identity as carer, loss of role as carer, loss of the close bond with the cared-for person, and loss of the social relationships associated with a network of care professionals.
2. **Living in Loss**, a process of continually experiencing the losses associated with the post-care transition phase and experiencing a range of profound emotions that are aggravated by formal care systems withdrawing support to carers because their role is seen as completed. Other challenges faced in this phase include financial difficulties associated with loss of carer allowances and benefits and difficulties in returning to the paid workforce.
3. **Moving On**, a process where former carers no longer view themselves as *'worldless'* and construct new identities and ways of life. However, some are unable to make this transition and remain trapped in the *'living in loss'* phase or move between this phase and the *'loss of the caring world'* phase. Facilitators identified to make the transition to the *'moving on'* phase include family support and continued support from carer organisations and services.

In their extensive review of the literature, McCarron *et al* (2011: 16-18) identified four theoretical models which attempt to delineate the different stages of being a family carer, noting at the same time, the limited studies focusing on former carers and their transitions. They note that –

*... all models view the post-caring/care transitions phase as a crucial element of the total caring experience (McCarron et al 2011: 17).*

The most interesting of the models they reviewed proposes a six stage model of the caring experience that focuses on the shifts in carer-care receiver relationships.

These are:

- **Building on the past** – the pre-caregiving relationship
- **Recognising the need** - changing relationships based on changing needs
- **Taking it on** - fundamental change in the relationship in recognition of the caring role
- **Working through it** - carers respond to their caring role
- **Reaching the end** - as a result of placement of the cared-for person in residential care, or because of their death
- **A new beginning** - reconstructing the caring role after placement or dealing with bereavement and beginning a different phase of life (Nolan *et al* 2003).

#### 13.4 THE TRANSITION EXPERIENCE FOR YOUNG CARERS

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Young carers often slip ‘under the radar’ of the formal service system, and changes in their caring role are intertwined with other major life transitions, such as, moving from school to further study or to employment. This means that transitions are magnified in their impact on them. Many young carers find that their caring responsibilities significantly disrupt or curtail their education (Carers Australia 2009: 5). Research by Carers Australia found that:

- ⇒ Only 4 per cent of primary carers between the ages of 15-25 years are still in education compared to 23 per cent of the general population in that age group.
- ⇒ 60 per cent of young primary carers aged 15-25 are unemployed or not in the paid workforce compared to 38 per cent of the general population in that age group (Carers Australia 2009: 6).

A British study of 60 young carers explored how caring during childhood affects young people’s transition into adulthood. The researchers concluded that the effects are largely negative because of inadequate professional service supports tailored to

the needs of young carers, educational difficulties, social exclusion and stress (Deardon & Becker 2000).

There is an even higher risk of not making the transition from education to employment for young carers from Indigenous or multicultural backgrounds as educational participation rates are much lower for young carers from these groups (Carers Vic 2011: 12; Carers Australia 2009: 6). Interrupted schooling experienced by many young carers adversely affects their long-term earning capacity. Carers Australia believes that there is a policy vacuum in educational policy which recognises the needs of young carers who are students, and in providing supports that enable them to access the same educational opportunities as all young Australians (Carers Australia 2009: 12).

Research by Australia's Social Policy Research Centre (Cass *et al* 2011, Cass *et al* 2009) identifies a range of barriers affecting young carers' transition to employment and to a financially secure adult life, finding that formal services exist to assist young people to care but rarely to prevent the negative impacts of caring at their source (Carers Vic 2011: 17).

### 13.5 FACILITATING THE TRANSITION EXPERIENCE FOR CARERS

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Payne (1999) compared key activities undertaken by 50 former Australia spouse carers in the pre-caring, caring and post-caring phases of their lives. Most of the sample were women aged 65 and over who had been carers for at least two years. The research identified distinct patterns in activities associated with participation in the life of the community and the fulfillment of social roles for each of the three phases studied.

During the caring phase, those activities dropped substantially, especially in relation to activities outside of the home. However, during the post-caring phase carers returned to pre-caring activity levels, but not necessarily to activities of the same kind. Most found the caring phase to have been particularly stressful, but were able to 'pick up the threads' of their former lives despite the significant nature of their losses and the difficult adjustment associated with their transition through the post-caring phase (Payne 1999: 2-3).

Making that transition had been assisted by a range of support sources – family support was received by some 90 per cent of the sample and help from friends or neighbours assisted about two-thirds. More than three-quarters perceived their own coping skills as having helped them to adjust while only about a third identified community services as a source of support. The minority who continued to participate in carer support groups found them helpful. Only seven out of the 50 carers had received grief counselling and all but one found this helpful.

One of the study's recommendations was for the gradual withdrawal of formal support services for carers, recognising that while the caring role had ceased, its consequences for carers can be expected to continue (Payne 1999: 3-4).

The post-caring adjustment is not a one-off event. It is a process which has many aspects and may last many years. Post-caring adjustment is experienced in a very individual way. It involves two major aspects: the practical and the emotional (Payne 1999: 33).

Payne also identified the need for multiple forms of support to assist carers, finding that those who received several forms of support (both formal and informal in kind) made the most effective post-caring adjustment.

Due to the number of losses of the carers after their spouses died and the significant nature of those losses, multiple forms of support are generally required for the post-caring adjustment. Any single form of support is, by itself, unlikely to be enough... (Payne 1999: 39).

Researchers in Ireland have identified a major service gap in supporting carers' transitions in the post-caring phase, noting the need for support structures, including bereavement support and continued carer support services, as well as policies that provide financial, employment and other services to enable this transition. Their research with carers identified the need for formal support services to address a range of issues including:

- **financial issues** associated with cessation of income support for carers (for example, by extending the period for which this can be paid to leave a reasonable amount of time to find paid work);
- **interventions prior to the end of the caring process** designed to reduce the risk of long term unemployment arising from extended years of caring and absence from the paid workforce (for example, a tailored care recipient advice and support program);
- **psychological support**, in particular, counselling to address the loss, guilt, loneliness and other emotional issues faced by carers in the post-caring transition phase. This includes conflict resolution support to better equip carers with difficult family relationships that sometimes characterise the post-caring phase, as well as stress management support;
- **interventions to address social isolation**, including post-caring support groups, and visiting from former carers or volunteers;
- **awareness-raising for professionals** about the different impacts of the post-caring transition phase and how best to support carers during this process (McCarron *et al* 2011: 43-44).

The researchers also suggest that carers who have completed the transition could be effectively employed in supporting carers making the transition, and that toolkits and other resources also have a role to play in preparing carers for the post-caring period (McCarron *et al* 2011: 10).

### 13.6 CONCLUSIONS: NEW MODELS TO SUPPORT THE CARER TRANSITION EXPERIENCE

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The transition process is not linear, but is dynamic and varies according to carer need and the context in which carers' roles are changed. Therefore, service models designed to support carer transitions need to be **flexible** and **responsive** to individual and/or changing need (Edge 2007: 6, citing other researchers). The literature reviewed identifies the need for this support to occur **early** in the caregiving role (during what some researchers term the 'pre-caring phase'), during the active caring phase and in the post-caring phase.

It is in this third phase, following the death of the cared-for person, that carers often find formal services are not funded to assist them. Policy reflects an assumption that the end of caregiving represents the end of the need for formal support, when the research literature has clearly identified that this is not the case - due to the lingering impact of the caring role in combination with the impact of bereavement and loss.

For those carers in transition because their care in the home has been replaced by care provided in a residential setting, the need for support is also evident, but of a different kind from that in the post-caring phase. The research literature frequently identifies that carers' need for continuity is not supported by residential care practice, and that their involvement is sometimes blocked by formal care providers (Edge 2007; Lundh *et al* 2000).

A **holistic** approach to the caregiving process recognises that family carers have an important role to play in the care and well being of a care recipient, a role that complements that of the formal care provider. Ideally, both should work in partnership, addressing different care needs and respecting the knowledge and expertise of the other. The literature review undertaken by Edge (2007: 6) concluded that a holistic approach needed to be reflected in assessment processes as well as in the provision of care. This involves an integrated assessment of need that sees professionals working with carers to address the needs of the care recipient and of the carer, with this being '**... one of the touchstones of good practice.**'

Outside of the formal aged care system, there is a need for support tailored to carers that addresses their difficulties in finding employment and potential financial difficulties associated with lack of paid work and loss of carer income support entitlements. Researchers have identified the disadvantages faced when carers have had to leave paid employment, and need to be upskilled and supported to obtain paid work once again.

It is likely that a supported pathway that prepares carers for return to work, involving collaboration between the aged care and employment and training sectors is needed.

Many of the employment programs that provide this support (particularly for mature aged Australians) are linked to receiving income support payments, and again, loss of carer benefits and allowances means reduced access to such support. For those carers who are able to remain in employment, much depends on employers being sufficiently aware of carer needs and challenges so that carers are treated flexibly and with understanding in the workplace. Carers leave is an important part of the solution, and is reinforced by a supportive work environment.

## 13.7 KEY RESEARCH FINDINGS

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The literature on key transitions is relatively small, but larger in relation to the pre- and post-admission to residential care transition. The predominant methodology used by researchers is qualitative, involving very small samples of carers but intense and detailed exploration of their needs, perceptions and expectations. The majority of carers studied are female making it difficult to generalise findings to men with any confidence. Similarly, there is a gap in research studies with a culturally specific focus, and on young carers experiencing care transitions.

A range of supports are critical to carers making an effective transition when the person they care for died, and the withdrawal of these should be gradual rather than sudden and linked to the death of the cared-for person.

There is a need for new service models to ease the transition between providing home based care and supporting care in a residential environment, and which acknowledge this transition as a time when carers are likely to continue to need a range of supports.

Formal services have a key role to play during this transition, recognising that although the caring role at home has ceased, its impact on the carer continues and is evident in the profound sense of loss experienced by many. Such services include counselling, advice, information and carer support groups.

There is also potential for former carers to play a role in supporting carers in this phase and for carer services to employ them for this purpose.

## 14 CARERS IN TRANSITION: AUSTRALIAN OVERVIEW

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A range of Australian HACC funded agencies in New South Wales, South Australia, Victoria, Queensland, Tasmania and Western Australia were contacted to gauge:

- what type of assistance, if any, they offered HACC eligible carers and non-eligible HACC carers
- if there were programs which were specifically designed for carers to assist them in their transition process out of HACC.

Agencies such as Carers Australia, Carer Support, Alzheimer's Australia, Catholic Care, Partners in Culturally Appropriate Care, Spanish Latin American Services of Australia (SLASA), Migrant Resource Center Southern Tasmania and Nova Community Care all spoke of a range of programs which they offered carers. These included:

- 'Planning ahead, Planning for the future, When they need more care' programs which provided carers with information on:
  - preparing for emergencies
  - residential care
  - financial, health and lifestyle decisions
  - loss, grief and bereavement
- 'Taking a break'
- 'Taking care of yourself'
- 'Connecting carers'
- carers education programs.

All agencies contacted indicated that their mandate was to support HACC eligible carers however they recognised that there were gaps in supporting carers whose care recipients moved to higher care packages, into residential care or passed away.

Some agencies indicated that whilst they were formerly able to provide support groups for carers who had transitioned out of HACC services into higher levels of care they were not now able to provide these services legitimately due to funding restrictions. Agencies struggle to end the relationship with carers particularly when they need the support the most and they often allowed carers to continue on programs that they had attended whilst a HACC carer. Some agencies spoke of the inflexibility of HACC guidelines and believed that they needed to be amended.

All HACC funded agencies contacted indicated that carers should be supported and encouraged to maintain their links with their communities to minimise dependency on support agencies and to assist them to transition back to life after their caring role ends. Agencies acknowledged that this may not be possible for some carers due to the length and circumstances of their caring and their specific needs.

One agency dealt with carers in the following way:

“If someone is caring for a client, whether they are caring for a HACC Client or a Commonwealth funded program client they are registered with our HACC funded Carer Support Programs as a client in their own right so they can continue to be supported by our programs.

When the person they are caring for moves into permanent residential care there is a transition period of approximately 3 months.... taking into account their caring role [sic]. This usually continues with more complexity e.g. transport to the aged care facility, feeling guilty, a sense of failure . . .these people are a group that do not have a lot of support and we offer counselling to them.

I know that some areas do have support groups for people who are caring for someone in an aged care facility, but they are rare.’

A number of the agencies indicated that they are prepared to support carers for as long as is needed. They are very flexible in their approach around carers’ need for support and have no cutoff time. Although they receive some HACC funding they don’t impose HACC requirements in this area.

Alzheimer's Australia Tasmania are currently setting up a new support group specifically for people who are no longer in the caring role. They believe that having a person no longer in the carer role staying on with their support group, somehow changes the dynamics and for that reason one to one usually works better. They indicated that carers sometimes may need support a few years after the caring role ends.

Interstate agencies agreed that all carers need to be assessed individually and transitioned out of programs accordingly. This was also found in discussions with South Australian agencies and in the survey responses.

No agency contacted nationally indicated that they provide programs which assist carers connect back into the community. However, Mount Barker Council in South Australia is currently developing a program which will be looking at how to connect people back into the local community. This program is in its early stages and would be useful to follow up.

## 14.1 KEY POINTS TO NOTE

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A range of Australian HACC funded agencies in New South Wales, South Australia, Victoria, Queensland, Tasmania and Western Australia recognised that there were gaps in supporting carers whose care recipients moved to higher care packages, into residential care or passed away.

Agencies struggle to end the relationship with carers particularly when they need the support the most.

A number of the agencies are prepared to support carers for as long as is needed.

## 15 THE ROLE OF HACC AGENCIES IN CARER TRANSITIONS

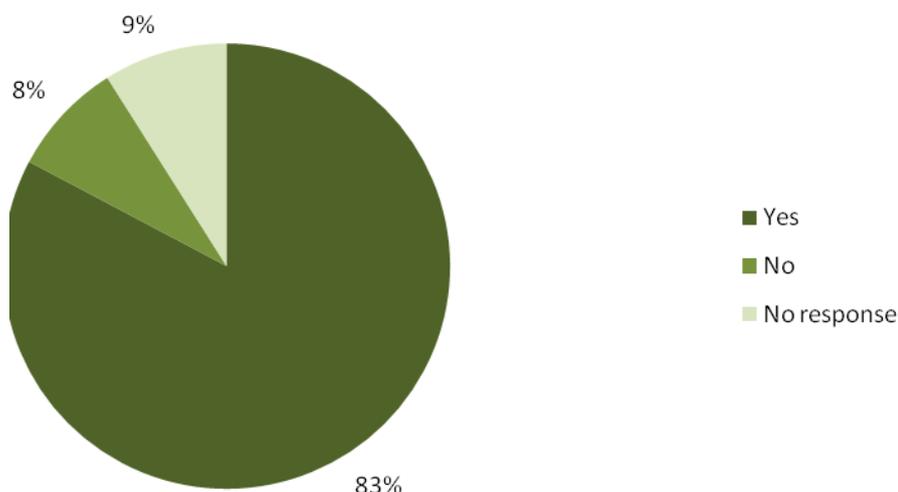
### 15.1 EARLY INFORMATION PROVISION

When carers first register with an agency they are provided with a range of written and verbal information on their entitlements whilst a carer and a list of other services available to assist them as they transition through their caring role. They are encouraged to refer to this information when needed.

Most carers appreciated this information, however many found this approach as *'information overload'* and quite often did not absorb all the material they were provided with initially. Some services understood this and provided information to carers in a *'drip'* approach, rather than *'flooding'* with information early in their life as a carer.

The majority of the agencies surveyed (83%) stated that they provided information on entry and exit points of service and broader carer entitlements (Figure 20).

FIGURE 20: PERCENTAGE OF AGENCIES INFORMING AGENCIES OF THEIR BROADER ENTITLEMENTS WHEN THEY COMMENCE HACC



## 15.2 BUILDING RESILIENCE AND INDEPENDENCE

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HACC Agencies indicated that they promote empowerment of HACC eligible carers, they do not use a 'nurturing' model. Members of the Carer Support Network employ the Carer Support Model a value based service. This provides support through education, information, advocacy and a range of services and programs which ensure that whilst carers are associated with the agency they build resilience and remain as independent as possible.

The 5 key components of the model are:

- Counselling – qualifies staff are available to listen to carers
- Advocacy- staff support and empower carers, and will walk alongside carers as they seek appropriate services of acknowledgement of their role
- Individual and group support- carer support workers spend time with carers listening to their stories and needs, and assisting as required. Carers can share with others in similar situations through regular support meetings.
- Respite – respite staff assist carers to have a break from their role or meet their other obligations whilst the person they care for is looked after.
- Information and education – staff will link carers to relevant organisations, provide information to assist carers. Staff also facilitate courses to expand carers knowledge of the disability or illness of the person they care for or how to cope in their caring role.

(<http://www.carersupportsa.org.au/model.html>)

Services offer a range of programs which '*teach independence with home life skills and financial management*'. All agencies supported carers to '*take time out for themselves*' so that they were better equipped to continue caring. Carers are encouraged to meet and talk outside of agency functions and activities.

Respite was a crucial component in enabling carers to build resilience and maintain their connectedness in their community by providing carers with short breaks.

Agencies encourage carers to maintain their outside interests, levels of fitness and health and stay connected to family and friends. Participation in broader activities is encouraged to assist carers maintain their own identity whilst in the caring role.

HACC agencies support carers to build and maintain regular and sustainable social links within their community which take into account carers unique and individual situation. These links help to ensure that the carer has a life beyond their caring role.

One agency stated that their mandate was to *'support carers in their role, build confidence, be available to counsel or connect as carers indicate, connect and link or relink to community/family, give information, encouragement, training and empowerment'*, all of which should lead to increasing or maintaining a carer's independence and building resilience.

*'Carers are supported to continue their own interests i.e. lawn bowls, fitness groups or art classes however, many carers are so consumed by their role of caring that there is not enough energy or time left for their own needs to be met'.*

The agency comment above is supported by the carers comments at meetings and survey responses in which over 30% of carers said that a lack of time and fatigue made it difficult for them to maintain their links with their community, family and friends.

### 15.3 LINKING TO OTHER SERVICES AND SUPPORTS

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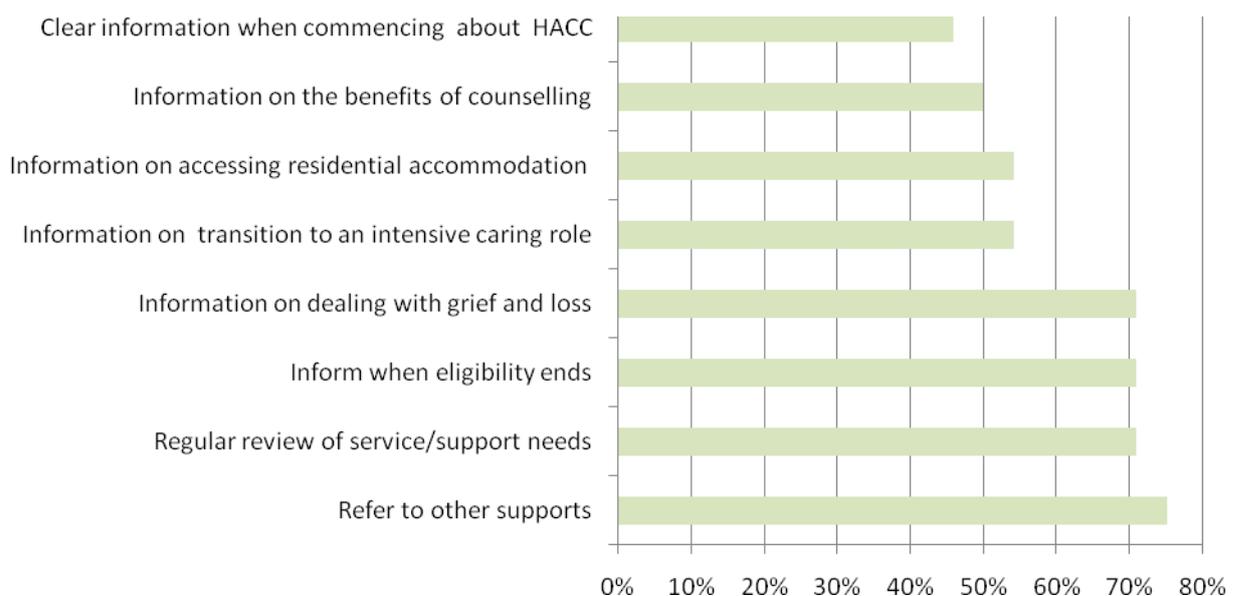
Agencies understand that they cannot meet the total needs of the carer and that part of their mandate is to link carers in with other services to assist them to achieve what is best for their family, their caring circumstances and themselves. They ensure that carers are aware of the agency's limitations in service provision if, due to funding constraints, the agency is not able to provide the carer with the full range of services that they require. Agencies encourage carers to use other services if they are better suited to the carers needs and provide information and referrals to other support agencies. In addition to providing information for self-referral agencies were often happy to provide a facilitated referral on a carer's behalf if required because of a lack of confidence or language difficulties.

*'Agencies 'walk alongside of carers, provide information and guidance and encourage their independence as much as possible'.*

## 15.4 PREPARING CARERS FOR TRANSITIONS IN THE CARING ROLE

HACC agencies indicated they prepare carers for life beyond HACC from the moment they register with the agency. They do this by referring carers onto other supports (75%), regularly reviewing the service and support needs (71%), informing carers when eligibility to HACC services ends (71%) and providing carers with information on how to deal with loss and grief (71%) (Figure 21).

FIGURE 21: PERCENTAGE OF AGENCIES UNDERTAKING SPECIFIC ACTIVITIES TO PREPARE CARERS FOR THE TIME WHEN THEY ARE NO LONGER ELIGIBLE FOR HACC SERVICES



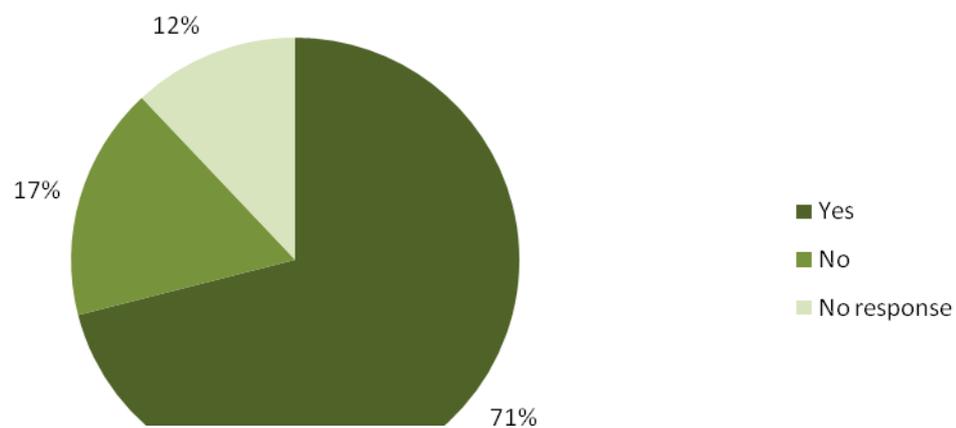
NB Respondents could select more than one response, so percentages may add up to more than 100%.

*‘Carers have great concerns and issues facing ‘the now’. Once relationships have been established and the ‘load’ lightened some information may be provided at the ‘relinquishing end’ to guide the Carer into the future. Generally carers choose the time for them to ‘not need services’ they often say ‘give the assistance to some one more needy’.*

Agencies refer or link carers into other community groups and networks as well as loss and grief workshops or counselors if deemed appropriate or the carer requests it. At times of bereavement or the move to formal care many carers found that two or three counselling sessions were not enough to get them through such a difficult time.

Of the agencies responding to the survey 71% of agencies surveyed indicated that they supported carers to leave their agency's services. (Figure 22).

FIGURE 22: PERCENTAGE OF AGENCIES WHO SUPPORT CARERS TO LEAVE THEIR SERVICES



## 15.5 CARERS NEEDS FROM HACC AGENCIES AT TIMES OF TRANSITION

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As discussed in the literature review (Section 13) there are a number of stages in transition in the caring role including when care recipients move to formal accommodation, the carer is bereaved or when the carer returns to employment.

When carers are no longer eligible for HACC carer support they are sometimes reluctant to move on to other programs. Many have formed strong bonds and relationships with other carers in similar situations and are provided a genuine social support through their ongoing involvement with the agency. Quite often this minimal support assists in the grieving, 'letting go' process.

Most agencies indicated that once carers transitioned into either a higher caring role or were no longer caring (bereaved/past carers) many of them wanted to stay on programs which were familiar to them. They wanted to stay connected with friendships which they had established and maintained within the support group (often for a significant part of their life).

Of the bereaved carers in the survey 50% said that attending a support group helped them deal with their loss (Section 16.4 Figure 31). Just over a third (39%) of past carers found that continuing to attend their existing support group provided support when the person they were caring for moved to supported accommodation or residential care. This was nominated as the most useful form of support out of 13 support options (Section 16.2 Figure 29).

Agencies and carers indicated through the consultations that it was at this time that many carers needed the most support and assistance. Due to current policies carers said that they *'felt abandoned'* or that the *'system had let them down'*. A number of carers consulted were very angry that they could no longer participate in programs that they had been attending (some for over 10 years). Some were also upset that they had been unable to attend any retreats because of their particular caring role or have any kind of holiday and that when they were finally able to attend they were no

longer eligible. Whilst there is the possibility of paying full fees a number were not in a financial position to avail themselves of this opportunity as their income decreased when the care recipient moved into residential care and they had other incidental costs to pay for the care recipient which they were struggling to meet.

Current carers expressed different support preferences with 30% of current carers indicating that they wanted to keep attending the same support group, 30% indicating they wanted to attend a group dealing specifically with these issues (i.e. formal care) and 25% wanting to attend a support group at the place of formal care (Section 16.2 Figure 29).

As discussed in more detail in section 16.2 above current carers were more focused on the process and the 'how to' of managing the move to formal care with 58% nominating information about residential care options and processes and 48% nominating support and advocacy in choosing an appropriate facility as the types of help they anticipated would be helpful (Section 16.2 Figure 29).

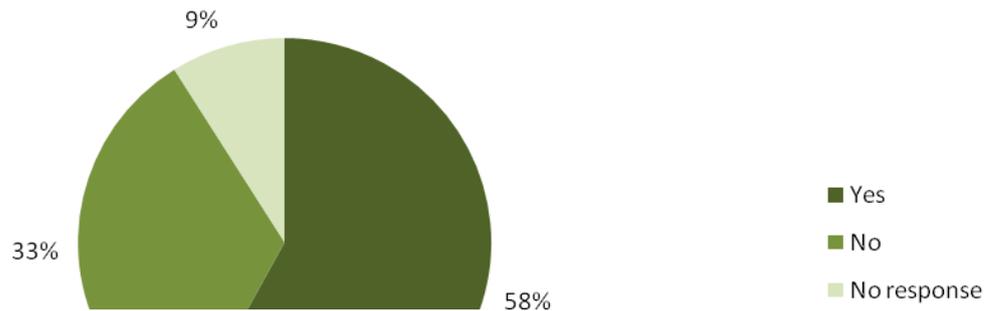
Counselling was also considered important by current carers with 22 % nominating counselling per se and 25% education and counselling re changes in the caring role as types of support anticipated to be helpful if the person they are caring for moved to formal care (Figure 18). This was supported by staff in residential facilities who indicated that informal counselling of carers could take up substantial periods of time.

## 15.6 HACC AGENCIES LEVEL OF SUPPORT TO PAST HACC CARERS

Nearly 60% of agencies indicated that they provided support to carers who were no longer eligible for HACC (Figure 23). Agencies of all sizes answered in the affirmative to this question.

Some agencies however, do not have the financial capacity to support carers beyond their HACC life and in many instances reluctantly withdraw their support almost immediately following the change in the caring responsibility of carers and on many occasions to the detriment of the carer.

FIGURE 23: PERCENTAGE OF AGENCIES SUPPORTING PAST HACC CARERS



Only 60 % of agency survey respondents (24 agencies) indicated how many non-eligible HACC carers they serviced. The largest groups were in agencies who also provided services to over 100 HACC eligible carers. Three agencies appear to have high ratios of non-eligible HACC carers to eligible HACC carers. The relatively low response rate from agencies (29%) needs to be taken into account as agencies may be uncomfortable providing this information. Many agencies have indicated they believe that it is essential to provide this service but they are not receiving funding to do so. (Table 7)

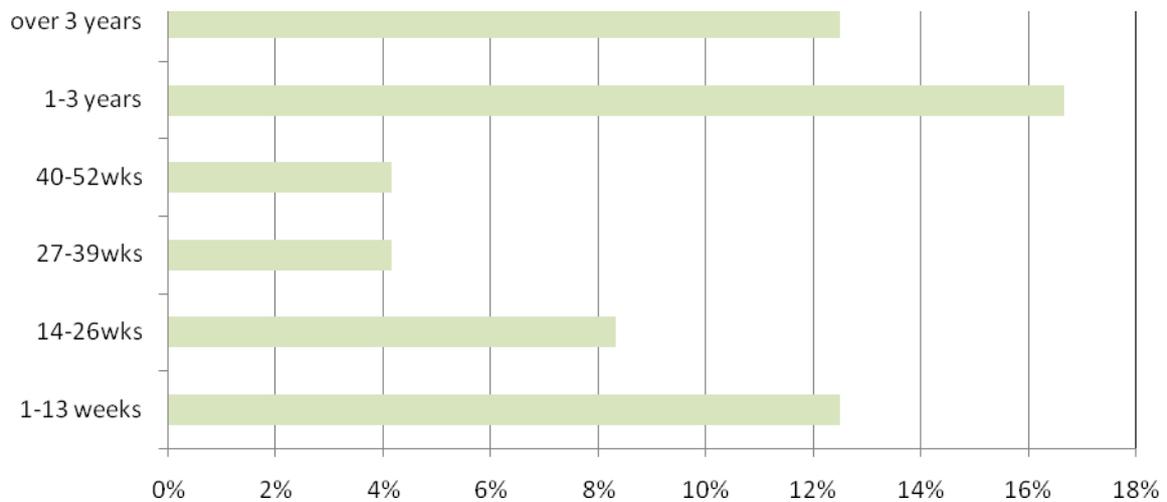
TABLE 7: LEVELS OF AGENCY ASSISTANCE TO PAST HACC CARERS

Number of non - eligible HACC carers receiving services with this agency	Agency service provision				
	Number of Agencies providing services to 1-25 HACC eligible carers	Number of Agencies providing services to 26-50 HACC eligible carers	Number of Agencies providing services to 51-75 HACC eligible carers	Number of Agencies providing services to 76-100 HACC eligible carers	Number of Agencies providing services to over 100 HACC eligible carers
1-10		1			1
11-20		1			1
21-30		1			
31 over			1		8

Based on survey data 21% of carers who identified as current carers but under the HACC criteria would be identified as past HACC carers were caring for a person who was receiving a package such as (CACP, EACH or EACHD) or were caring for someone who had moved to formal care. According to the agencies responding to the survey only 59% of past HACC carers received agency services after their eligibility ended with 13 % receiving services for 1 to 13 weeks, 8% receiving services for 14 to 26 weeks and 8% receiving services for 27 weeks to 1 year. Many agencies chose to support carers in a variety of ways beyond this period depending on individual needs with 17% of past HACC carers stayed with an agency between 1 to 3 years and a further 13% remained for over 3 years (Figure 24). Agencies were not asked to distinguish whether these past HACC carers were still caring, were bereaved or had stopped caring for some other reason.

Quite often agencies used alternative more flexible funding sources to assist in providing these services if they were available.

FIGURE 24: AVERAGE LENGTH OF TIME PAST HACC CARERS STAYED ON PROGRAMS



NB Respondents could select more than one response, so percentages may add up to more than 100%.

## 15.7 REASONS FOR HACC AGENCY SUPPORT TO PAST HACC CARERS

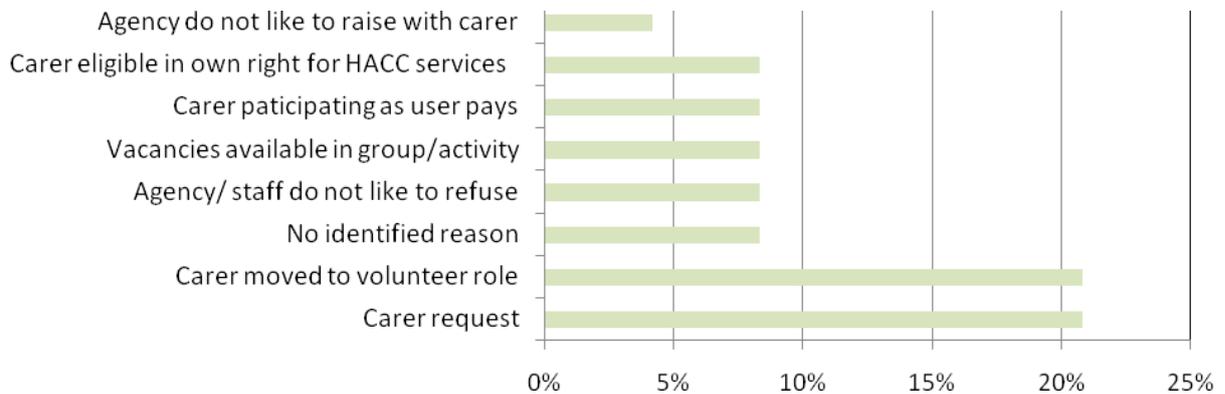
Some of the reasons agencies provided this support included:

- carer requesting to stay on the programs (21%)
- staff not wanting to refuse the carer (8%)
- vacancies available in group/activity (8%)
- carer eligible in their own right for HACC services (8%)
- agencies not wanting to raise with carer that they are no longer eligible for services (4%) (Figure 25).

Only 8% of these non eligible HACC carers were paying the full cost of the service and participating as user pays and 21% had moved to a volunteer role (Figure 25).

In some regional areas carers could not be transitioned out of the service because there were no other services available for them. Agencies in these regions needed to be creative to support these carers.

FIGURE 25: REASONS WHY HACC AGENCIES PROVIDE ONGOING SUPPORT TO NON-ELIGIBLE HACC CARERS



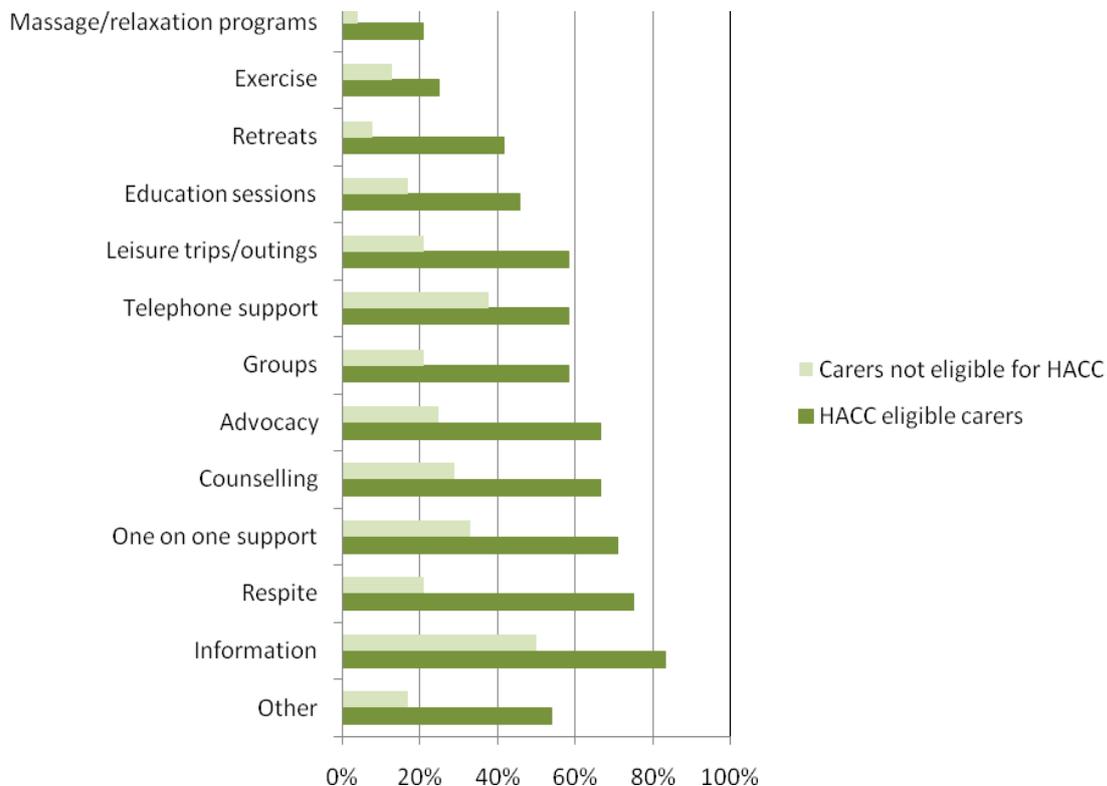
NB Respondents could select more than one response, so percentages may add up to more than 100%.

Many agencies are reluctant to move carers out immediately following the change in their caring role. HACC agencies believe that carers are most vulnerable and need additional support to get them through a very difficult time when their caring role alters, that is when their person they are caring for moves into care or passes away. Many agencies are torn between doing what is right by the carer and what they are permitted to do under their funding guidelines. Agencies with other sources of funding are 'legitimately' able to support non-eligible carers for a longer period whilst others transition carers out of their programs within 3 to 9 months.

## 15.8 TYPES OF AGENCY SUPPORT PROVIDE TO PAST HACC CARERS

HACC funded services can provide services to past HACC carers at full cost. It appears that many agencies do not do so. HACC agencies indicated that they provide the same types of support to past HACC carers as current HACC carers (Figure 26). The most common supports provided were to past HACC carers were information, telephone support and one on one support. It would be challenging to charge full fees for these services. It is worth noting that 20% of past HACC carers supported attend support groups and that in the carer survey 21% of those who identified as current carers were caring for someone who had moved to formal care or was receiving a package. (Figure 9)

FIGURE 26: TYPES OF SUPPORT PROVIDED TO HACC ELIGIBLE CARERS AND PAST HACC CARERS



NB Respondents could select more than one response, so percentages may add up to more than 100%.

Agencies tended to provide the most support to carers who had placed their family/friend into residential care or supported accommodation. It is recognised that many carers continue to be fully involved in their care recipient's life through doctor's appointments, practical and emotional support and by advocating on their behalf.

Agencies were asked to comment on how the support they provided to non-eligible HACC carers assisted them. The majority indicated that it reduced the threat of social isolation and helped carers by assisting them to:

- work through their loss and grieving process
- work through their changed role
- re-establish their links with family, friends, and community,
- navigate through the system.

The Mt Barker Community Health Service assisted a group of relinquished carers to establish the GLAD (Get a Life after Dementia) support group. This group meets independently from the HACC program and has been able to provide support to existing HACC carer support programs in the region by raising funds for HACC carer programs and also by accepting carers as they transition out of a HACC programs.

## 15.9 ORGANISATIONAL IMPACT OF PROVIDING SERVICES TO PAST HACC CARERS

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Agencies were asked to comment on the effect that service provision to non-eligible HACC carers has on their organisation. The majority of agencies spoke of the positive effects on the carers. Agencies varied in the amount of time they said this took in verbal conversations and in survey responses with some workers indicating that on occasions it could be substantial.

'the positive impact is that we see this as supporting a carer through a difficult transition and provides a continuum of care for the carer. The ongoing provision of information and telephone support has a minimal impact on resources. Counselling and referrals require dedicated staff time say 20-30 hours over the twelve months'.

Agencies struggle to report this support activity back to the funding body 'as it doesn't fit any funding parameters'. There is a greater reliance on volunteers to fill the gaps in assisting non-eligible HACC carers and one agency indicated that 'agency resources (funding/staff) are spent in managing and training volunteers (some carers) to assist the ongoing retired carers' groups/activities'.

Service providers believe that to alleviate some of this pressure which carer transition needs impose on agencies there needs to be 'an increase in staff resources/dedicated time or recognition via greater flexible funding and service agreements for this time of transition'.

Agencies indicated that an allocation of dedicated funds to supporting carers move through their caring role would have beneficial impacts for carers and agencies. Carer needs do vary and there is a group of carers who do need a transition period of between 1 to 3 years, with a smaller percentage who may require longer. Establishing time limits on the transition period was viewed as both unworkable in some instances and not needed in others because the majority of past HACC carers take up their new lives of their own accord.

## 15.10 KEY POINTS TO NOTE

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Most carers often did not absorb all the material they were provided with initially and need to be provided with information in a drip approach, rather than flooded with information early in their life as a carer.

Respite was a crucial component in enabling carers to build resilience and maintain their connectedness in their community.

Participation in broader activities is encouraged to assist carers maintain their own identity whilst in the caring role.

Agencies found that a lack of time and fatigue made it difficult for carers to maintain their links with their community, family and friends.

HACC agencies refer carers onto other supports (75%), regularly review the service and support needs (71%), inform carers when eligibility to HACC services ends (71%) and providing carers with information on how to deal with loss and grief (71%).

Nearly 60% of agencies indicated that they provided support to carers who were no longer eligible for HACC.

HACC agencies believe that carers are most vulnerable and need additional support to get them through a very difficult time when their caring role alters and the person they are caring for moves into care or passes away. At times of bereavement or the move to formal care many carers found that two or three counselling sessions were not enough to get them through such a difficult time. Agencies tended to provide the most support to past HACC carers who had placed their family/friend into residential care or supported accommodation.

The most common supports provided were to past HACC carers were information, telephone support and one on one support. It would be challenging to charge full fees for these services.

Agencies indicated that supporting past HACC carers:

- reduced the threat of social isolation
- assists them to work through their loss and grieving process
- assists them to work through their changed role
- assists them to re-establish their links with family, friends, and community
- helps them to navigate through the system.

The agency survey found that only 59% of past HACC carers received agency services after their eligibility ended with 13 % receiving services for 1 to 13 weeks, 8% receiving services for 14 to 26 weeks and 8% receiving services for 27 weeks to 1 year. Seventeen percent stayed between 1 to 3 years and a further 13% remained for over 3 years.

Establishing time limits on the transition period was viewed as both unworkable in some instances and not needed in others because the majority of past HACC carers take up their new lives of their own accord.

The primary reason given by Agencies for providing this support was carers requesting to stay on the programs (21%).

Only 8% of these past HACC carers were paying the full cost of the service and participating as user pays. Quite often agencies used alternative more flexible funding sources and volunteers to assist in providing these services.

Agencies varied in the amount of time they said they spent on support to past HACC carers. Agencies cannot report this support activity back to the funding body through MDS.

Agencies indicated that an allocation of dedicated funds to supporting carers move through their caring role would have beneficial impacts for carers and agencies.

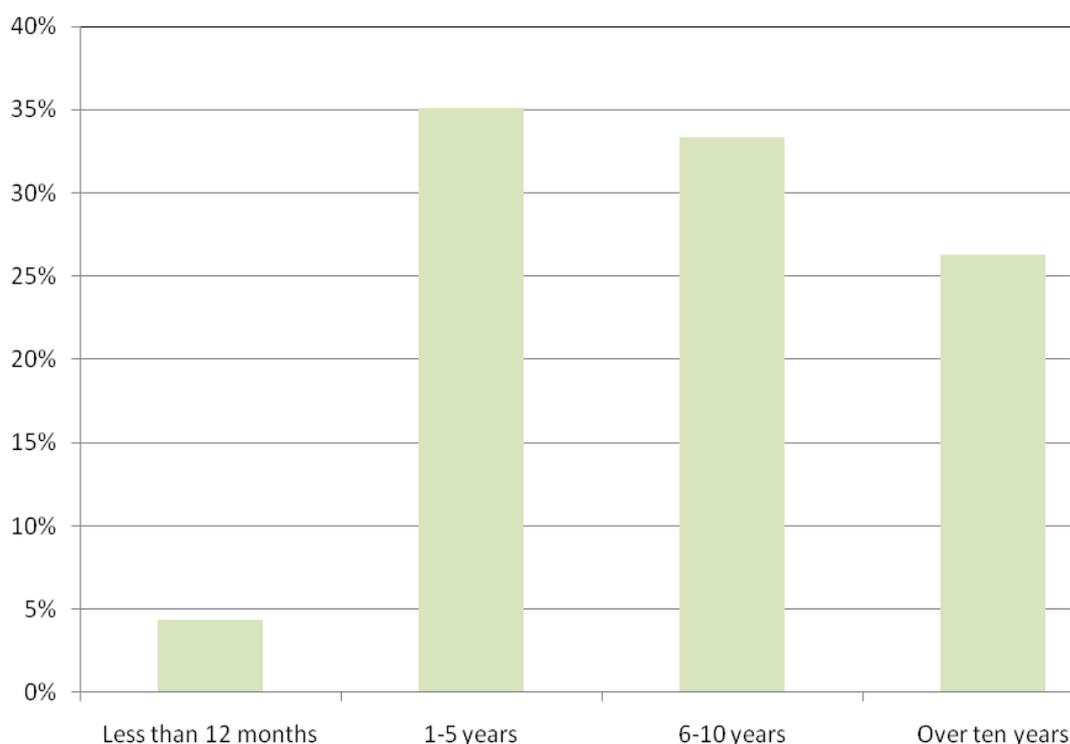
## 16 CARERS IN TRANSITION: CONSULTATION FINDINGS

### 16.1 TIME SPENT IN THE CARING ROLE

The length of the caring role varied substantially amongst survey respondents who identified as past carers. As Figure 27 illustrates, 4 distinct groups of past carers responded to the survey. Over 60% of all past carers cared for 6 years or more.

Meeting attendees who said that they had been caring for over 10 years tended to be carers of children with a disability.

FIGURE 27: TIME SPENT IN THE CARING ROLE BY PAST CARERS



## 16.2 CARE RECIPIENTS RELOCATING TO RESIDENTIAL CARE OR SUPPORTED ACCOMMODATION

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*‘Support from family or friends is important for less stress and more sanity.’*

Past carers indicated that the types of support they found the most helpful when the person they were caring for moved to either residential or supported accommodation were:

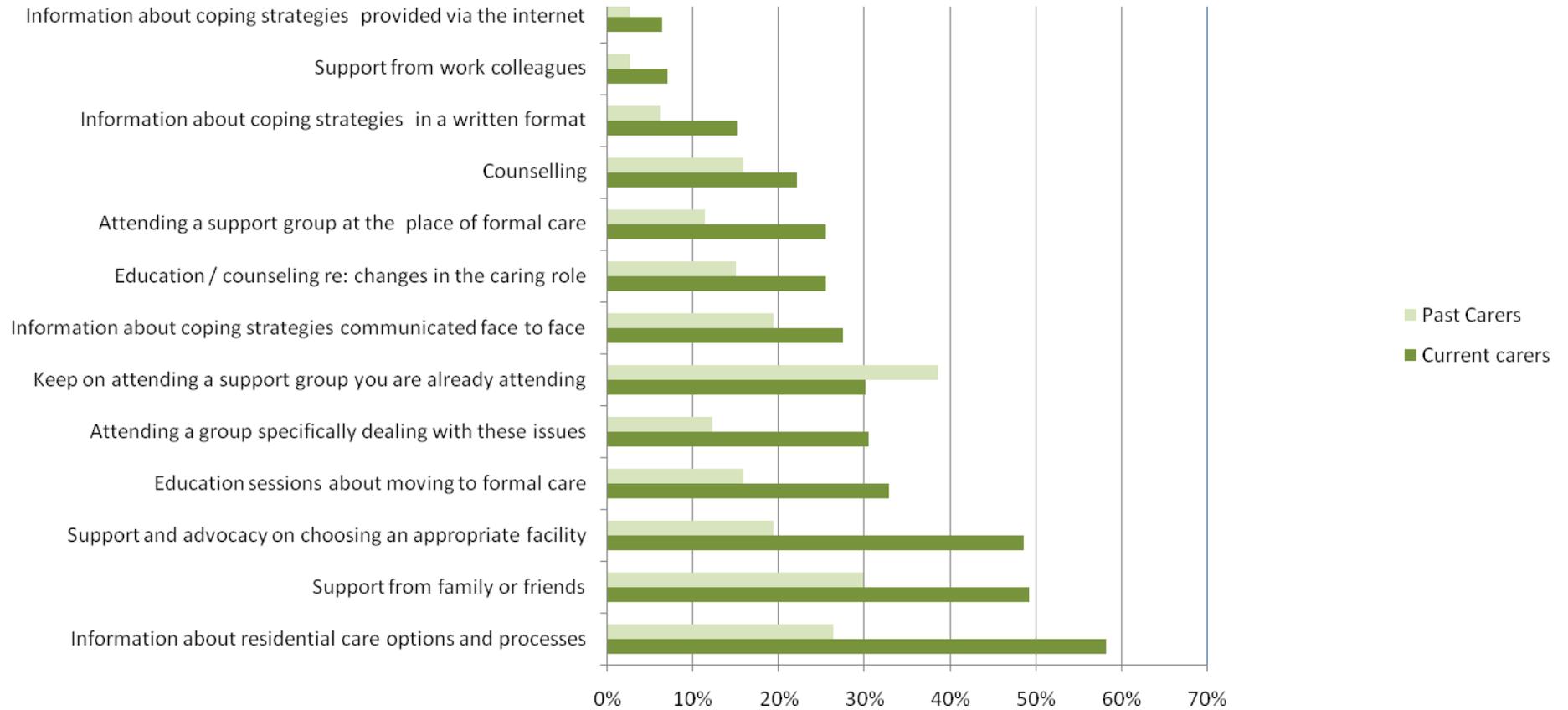
- continuing to attend a support group which they are already attending (39%)
- friends and family (30%)
- information about residential care options (26%) (Figure 28).

This transition time is emotionally difficult for carers and this is supported by the research findings outlined in Section 13, agency feedback in Sections 14 and 15, and carers’ comments.

Whilst a number of past carers indicated that they found information about coping strategies helpful there were clear differences in their views depending on the form of presentation with 19% finding face to face information helpful, versus written (6%) and via the internet (3%) (Figure 28). Agency workers also indicated that past carers were phoning for support.

Current carers were more focused on the process and the ‘how to’ of managing the move to formal care with 58% nominating information about residential care options and processes and 48% nominating support and advocacy in choosing an appropriate facility as the types of help they anticipated would be helpful. As with past carers support from family and friends was anticipated to be the second most useful type of support with 49% indicating that they would find this helpful (Figure 28).

FIGURE 28: TYPES OF SUPPORT FOUND OR ANTICIPATED TO BE HELPFUL IF THE CARE RECIPIENT MOVES TO FORMAL CARE



NB Respondents could select more than one response, so percentages may add up to more than 100%.

Several carers indicated that their family were not helpful at this time either because of conflicts or because there were limited family members.

Carers also indicated that they would find the following support helpful at this time:

- information before the transition event occurred
- support and information located in one place
- information about Aboriginal specific services
- information about specific CALD services
- support from a broker
- a less complex process
- support in visiting residential facilities.

In addition one carer wanted *'Support groups that are able to re-introduce bereaved carers to a 'normal life''*.

One carer indicated that there was a difference in visiting expectations between Government and private facilities and said that *'government funded aged care facility encouraged me to take time out, not visit too regularly etc. Private facility expected regular visits straight away, they needed to be more understanding of carers'*.

There was one response about a neighbour who had difficulties trying to facilitate this move *'neighbour is Jewish and has pretty specific needs. The ACAT assessment does not seem to recognise the mental difficulties someone has unless they have been hospitalised for their mental issue'*.

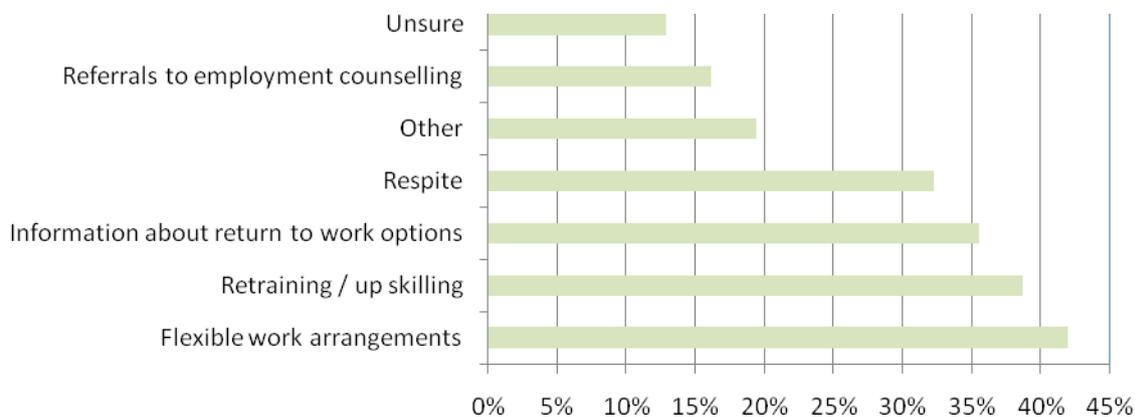
Carers who worked in the aged care sector said they found it easier to access HACC services and to understand the *'system'* for formal care. Another carer indicated that none of the options listed (Figure 18) were helpful.

### 16.3 CARERS LOOKING TO RETURN TO WORK OR STUDY

Less than 40% of the current carers who responded to the survey were aged under 65 years and only 11% were aged under 50 years (Appendix 3 Figure 34 for more information). Of the 116 survey respondents aged 25 to 64 who are current carers, 16 people (14%) wanted to access a return to work program. Two respondents aged between 65 and 79 also indicated that they wanted to access a return to work program (Figure 29).

Only 26% of current carers aged 25-64 (31 people) indicated what types of assistance might help them to return to work. Of these 31 carers over 30% indicated that they believed that respite, information about return to work options, retraining/up skilling and flexible work arrangements would assist them.

FIGURE 29: TYPES OF ASSISTANCE WHICH CARERS BELIEVED WOULD HELP PREPARE THEM FOR FUTURE RETURN TO WORK OPPORTUNITIES



NB Respondents could select more than one response, percentages may add up to more than 100%

Some carers indicated other types of assistance which they believed might assist including;

- basic computer skills
- free training program in their chosen career
- training, information of job vacancies
- managing time to deal with conflict and stress.

*'Carers should be entitled to free access to support and to any training program they feel best suited to them without red tape. Transition from unpaid job to paid job must be seamless.'*

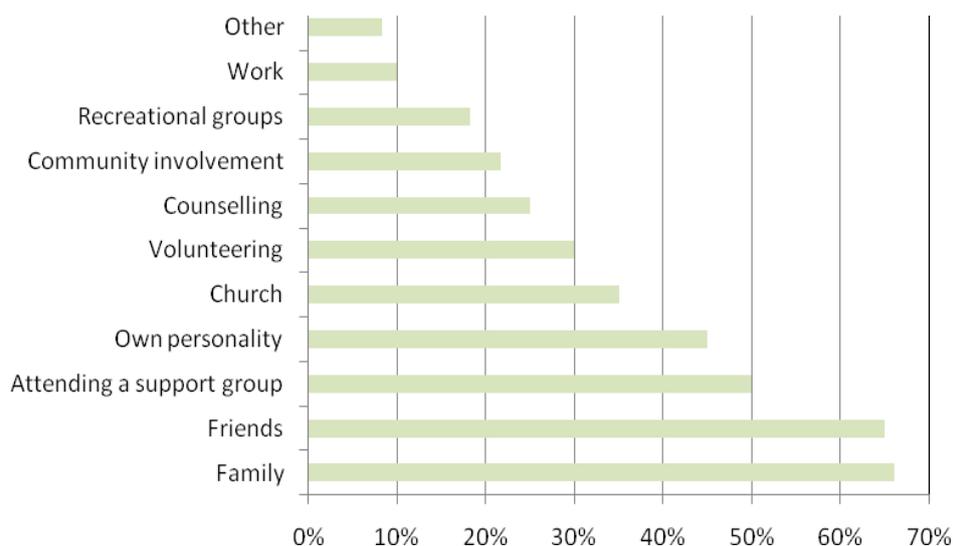
Some carers who had been out of the workforce for some time expressed fear and apprehension about reentering the workforce. One carer said they had purposefully take a small part-time job to get back in *'in a less scary way'*.

## 16.4 BEREAVED CARERS

Bereaved carers use multiple sources of support to help them through the grieving process. Two thirds of all carers found family and friends the biggest source of support in helping them deal with bereavement (Figure 30). As mentioned previously a distinction was not made in the survey between friendships formed prior to the caring role and friendships formed at support groups and retreats. Based on the consultations it appears that many carers were turning to friends from support groups for support.

Attending a support group was also significant with 50% of bereaved carers saying they found it helped them to deal with their loss. Those who had been told they were no longer eligible to attend a group expressed anger. There was a consistent view that people needed the comfort and support of their support group the most at times of bereavement and when the care recipient entered supported accommodation.

FIGURE 30: TYPES OF HELP WHICH BEREAVED CARERS FOUND HELPED THEM DEAL WITH THEIR LOSS



NB Respondents could select more than one response, so percentages may add up to more than 100%.

*'Have to rebuild relationships and manage loneliness. On-going dealing with grieving'*

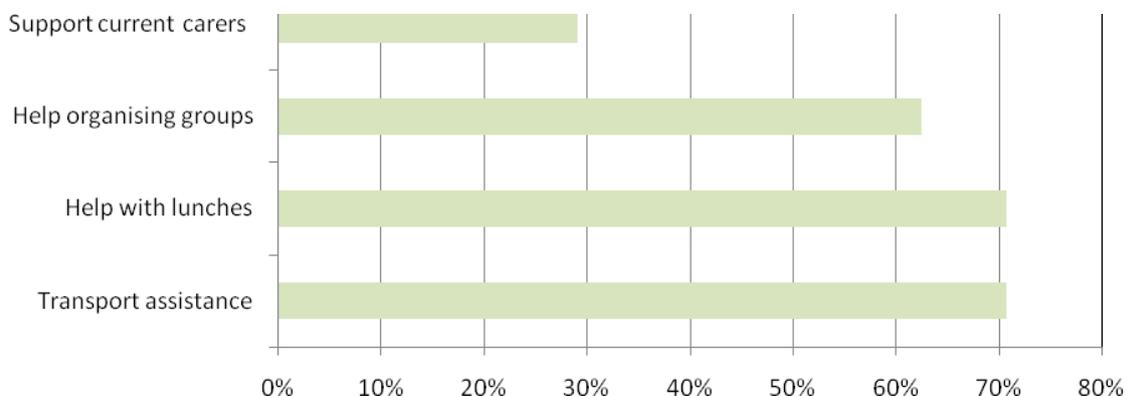
## 16.5 CARERS WHO BECOME VOLUNTEERS

Volunteers may be past or current carers, students, retired people and interested citizens. Volunteering helped 30% of bereaved carer survey respondents deal with their loss (Figure 20 above).

Volunteers are *'treasured and valued'* in all HACC agencies as they are an added resource which agencies could not do without. Volunteers in some small HACC funded agencies are the *'backbone'* of the organisation and many could not survive without their assistance. One agency consulted stated that *'60 volunteers provided up to 20,000 hours of support per year'*

For many volunteers it is their way of giving back to the community and/or the agency which supported them. They assist with a range of roles predominantly transport assistance, lunches and assistance with organising groups (Figure 31). They also volunteer time to undertake office administration, phone support, gardening, car washing and maintenance, second-hand shops, home visits, events fundraising activities, newsletter collation/distribution and social support programs.

FIGURE 31: VOLUNTEER ROLES IN AGENCIES



NB Respondents could select more than one response, so percentages may add up to more than 100%.

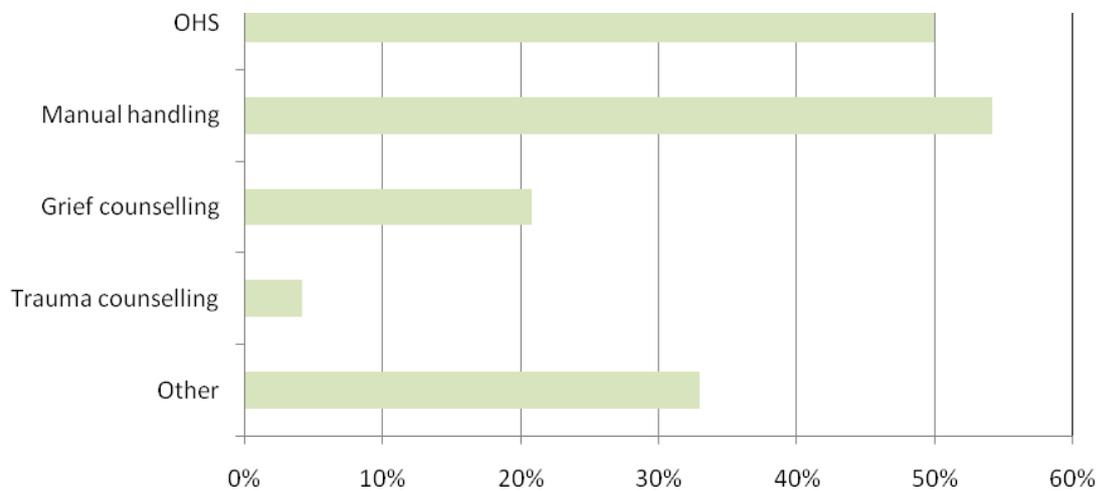
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## 16.5.1 VOLUNTEER TRAINING

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It is clear that agencies recognize the value of volunteers and are putting time and resources into training them with 71% of agencies providing a range of volunteer training. Half the agencies provided occupational health and safety training, 54% manual handling training and 21% grief counselling training. (Figure 32)

FIGURE 32: TRAINING PROVIDED TO STAFF AND VOLUNTEERS



NB Respondents could select more than one response, so percentages may add up to more than 100%.

In addition 33% of agencies reported that volunteers are provided with additional training in one or more of the following areas:

- service policy and procedures
- confidentiality
- privacy
- mandatory notification
- child safe environment
- first aid training
- mental health first aid
- food hygiene

- risk management
- behaviour management
- cultural awareness
- disability awareness
- bus driving/transport issues
- phone and administration
- carer support model
- training in assisting with groups and retreats.
- support training so that volunteers can phone carers and listen to their needs, advise of outings and groups (also volunteers are trained by sitting in on carer groups)
- initial counselling
- counselling
- accidental counselor
- advocacy.

## 16.6 KEY POINTS TO NOTE

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Over 60% of all past carers cared for 6 years or more.

Past carers found:

- continuing to attend a support group which they are already attending (39%)
- friends and family (30%)
- information about residential care options (26%)

the most helpful types of support when the person they were caring for moved to either residential or supported accommodation.

This transition time is emotionally difficult for carers. Carers varied in how they preferred to be provided with information.

Current carers were more focused on the process and the 'how to' of managing the move to formal care with 58% nominating information about residential care options and processes and 48% nominating support and advocacy in choosing an appropriate facility as the types of help they anticipated would be helpful. As with past carers support from family and friends was anticipated to be the second most useful type of support with 49% indicating that they would find this helpful.

26% of current carers aged 25-64 indicated that respite, information about return to work options, retraining/up skilling and flexible work arrangements would assist them to return to work. and 14% wanted to access a return to work program. Two carers over 65 also wanted to access a return to work program.

Some carers who had been out of the workforce for some time expressed fear and apprehension about reentering the workforce.

## 17 A FRAMEWORK FOR CARERS

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### 17.1 CONTEXT FOR THE FRAMEWORK

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In recent years there has been an increasing amount of primary research focused on the needs of carers, which adds to the evidence base on which policy and programs can be designed. Although carers are united as a group by the role they perform, the impact of this responsibility, and their capacity to manage the challenges associated with being a caregiver, varies from one individual to another.

As this project's research has found, many carers face varying levels of disconnection from their family, friends, communities and interests. Whilst the level of disconnect varies depending on the length and intensity of the caring role, the carers own health, financial resources, existing networks, proximity to sources of support and the level of formal and informal support that they receive one of the primary reasons for the disconnect appears to be the caring role per se. The research showed that formal support has a valuable role to play in helping carers stay connected.

A major challenge facing those developing policies and programs to support carers is to achieve service provision that is:

- flexible
- accessible
- responsive to carers of different ages, different cultural backgrounds, at different life and caregiving stages and living in a range of locations
- able to maximise carers connections to their family, friends, community, interests and existing social networks
- able to prepare carers to successfully navigate major transitions in their caring role and assist them as they do so.

Of particular concern are the demands associated with:

- younger carers undertaking the caring role
- carers of people with dementia (particularly younger onset)
- carers who are caring for extended periods, sometimes several decades
- carers who are caring for over 40 hours per week
- carers who are caring for people with high needs who are either receiving HACC services or without any formal assistance
- carers whose care recipient will not utilise respite and/or allow formal services to come into the home
- carers who are at critical transition points (times known to bring significant vulnerability):
  - when the carer first becomes aware of the need for them to undertake a caring role and committing to the changed role, i.e.. *'recognizing the need'* and *'taking it on'* .
  - During the caring journey there will be times when the level of need and caring role change, i.e. *'working through it'*
  - entry of the care recipient into full time formal care *'reaching the end'*
  - bereavement.
- carers who are entering the workforce, returning to work, increasing their paid work or trying to balance existing work and care arrangements.

It is only relatively recently that research has highlighted the need to support carers at key transition times. There is a lack of transition programs to assist carers during these times.

## 17.2 KEY POLICY LINKAGES FOR THE FRAMEWORK

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The Framework has been designed to resonate with current policy direction relating to carers. Nationally, the Australian Government's National Carer Strategy 2011<sup>1</sup>, in conjunction with the Carer Recognition Act 2010, forms part of the Australian Government's National Carer Recognition Framework. This is guided by an overall vision of ensuring that '*... society values and respects carers and to ensure they have rights, choices, opportunities and capabilities to participate in economic, social and community life.*' The five goals of the National Strategy complement the Principles and directions of South Australian carer initiatives.

Goal 1: Better recognition for carers

Goal 2: Better support to help carers work

Goal 3: Better information and support for carers

Goal 4: Better education and training for carers

Goal 5: Better health and wellbeing for carers.

The aim of the National Strategy is of particular relevance –

*'To respond to the diverse and changing needs of carers with services and supports that are coordinated, flexible, appropriate, affordable, inclusive, and sustainable.'* (Appendix 5)

In South Australia the South Australian Carers Plan 2009 complements and builds on the South Australian Government's commitment to support carers through the South Australian Carers Recognition Act 2005, South Australian Carers Charter and South Australian Carers Policy 2006. The Plan sets the vision and key priorities for the Department for Communities and Social Inclusion to support and respond to carers in South Australia. The South Australian Carers Policy – Supporting Carers

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[http://www.fahcsia.gov.au/sa/carers/pubs/national\\_carer\\_strategy/Documents/national\\_carer\\_strategy.pdf](http://www.fahcsia.gov.au/sa/carers/pubs/national_carer_strategy/Documents/national_carer_strategy.pdf)

(2006) reflects the seven Principles of the Charter and identifies how these can be reflected in government policies and services.

Principles 1, 2, 4, 6 and 7 of the SA Carers Charter are of direct relevance to the Framework.

#### **SA Carers Charter Principles**

- Principle 1 - Carers have choices within their caring role
- Principle 2 - Carer's health and well-being are critical to the community
- Principle 3 - Carers play a critical role in maintaining the fabric of society
- Principle 4 - Service providers work in partnership with carers
- Principle 5 - Carers in Aboriginal and Torres Strait Islander communities need special consideration
- Principle 6 - All children and young people have the right to enjoy life and reach their potential
- Principle 7 - Resources are available to provide timely, appropriate and adequate assistance to carers

The framework also needs to reflect the South Australian HACC Service Principles and the Community Care Common Standards.

#### **South Australian HACC Service Principles**

- Principle 1 - Promote each person's opportunity to maximise his or her capacity and quality of life.
- Principle 2 - Provide services tailored to the unique circumstances and cultural preferences of each person, their family and carers.
- Principle 3 - Ensure choice and control are optimized for each person their carers and families.
- Principle 4 - Emphasise responsive service provision for an agreed time period to be reviewed as agreed.
- Principle 5 - Support community and civic participation that provide valued roles, a sense of purpose and personal confidence.
- Principle 6 - Provide appropriate workforce training and development.

### **Community Care Common Standards**

**Standard 1 - Effective Management.**

The service provider demonstrates effective management processes based on a continuous improvement approach to service management, planning and delivery.

**Standard 2 - Appropriate Access and Service Delivery.**

Each service user (and prospective service user) has access to services and service users receive appropriate services that are planned, delivered and evaluated in partnership with themselves and/or their representatives.

**Standard 3 - Service User Rights and Responsibilities.**

Each service user (and/or their representative) is provided with information to assist them to make service choices and has the right (and responsibility) to be consulted and respected. Service users (and/or their representative) have access to complaints and advocacy information and processes and their privacy and confidentiality and right to independence is respected.

### 17.3 SOURCES INFORMING THE FRAMEWORK

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The Framework has been informed by the combined findings of the following:

- face to face consultations and surveys with current and past carers which
  - examined the impact of caring on current and past carers
  - identified activity levels of current and past carers
  - identified sources of formal and informal support utilised by current and past carers
  - identified which sources of support were the most helpful in:
    - helping carers to live their own lives
    - supporting carers to stay connected to their communities
    - maintaining and strengthening friendships
    - maintaining their interests and employment
    - maintaining a sense of self worth and what is important to them to undertake their caring role
  - reviewed carers understanding of HACC and the purpose of HACC carer supports
  - identified sources of support which were most helpful during periods of transition.
- a survey of service providers providing HACC carer support
- a brief literature review which looked at Australian and international literature focusing on transition issues for carers, as well as key policy directions in relation to carers.

## 17.4 KEY ISSUES IMPACTING ON CARERS

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Findings from both the consultation process and the literature review have been consistent and mutually reinforcing about the key issues facing carers. Whilst caregiving has been found to bring a number of positive outcomes for carers, these are outweighed by the negative impacts, some of which can be ameliorated by service interventions.

Negative impacts are united by a theme of loss, which carers have described as:

- isolation arising from reduced ability to spend time with friends, family or in paid work
- reduced social networks (less time available for socialization, fatigue and/or they have limited access to respite, which may be related to family and friends distancing themselves)
- loss of time for oneself, to undertake daily living activities, and to attend to one's own health needs
- reduced financial security due to reduced paid work involvement and/or the costs associated with caregiving
- losing work-related skills and career development opportunities due to the need to leave paid work or reduce to part time work. Over time the carer becomes less skilled, less employable and less confident about their ability to engage in paid work and most face significant challenges in either returning to paid employment when their caring role is complete or entering the workforce for the first time
- these losses are often described by carers as creating a sense of loss of control over one's own life, loss of freedom, loss of independence, loss of a future and loss of a sense of self.

The impact of these losses is cushioned by the amount of formal and informal support the carer receives and exacerbated by the absence or inadequacy of those support sources. Carers also face a range of challenges to do with the caring role which can be assisted by the timely provision of information on self-care, respite and other supports (Section 12.6 Figure 19).

For carers in transition, particularly those at the end of the caregiving journey, a perceived significant issue is the lack of recognition by policy and by program eligibility criteria of the need for continued contact with services they have been using (often for many years), the need for continued support, information, linkage to other services (such as employment and training) and time to adjust to the transition and to manage the impact of cumulative loss.

## 17.5 SUPPORTING CARERS TO STAY CONNECTED, MAINTAIN INTERESTS AND SELF WORTH

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Carers identified a range of supports which helped carers them stay connected to their community, family and friends. The 5 top forms of support were:

- assistance and visits from family, friends and neighbours (47%)
- support groups (44%)
- respite (33%)
- phone (30%)
- assistance from community organisations (25%). (Section 12.3 Figure 18).

Carers indicated that retreats, respite, support groups and counselling were formal sources of support which assisted them to care for themselves. Carers indicated that respite and support groups assisted them to maintain their interests and that flexible respite assisted them to continue working whilst caring.

Carers found that information on managing stress and preventing and/or dealing with depression was useful in their caring role as was information on dealing with loss and grief. Support groups played an important role in maintaining carers sense of self-worth as carers were able to connect with others in similar situations and understand that other carers were also facing similar problems. The support groups reduced carers' sense of loneliness, provided strong connections and by accelerating formal and informal learning strengthened carers ability to successfully undertake the caring role.

For some carers the current formal sources of support did not address their needs and they would have preferred access to funds to address their socialisation needs and their desire to maintain their current networks. Some carers wanted the capacity to go overseas or interstate to visit relatives (who would assist with respite) to have interstate and/or overseas phone calls, to have access to the internet or to have financial assistance with petrol and car costs.

## 17.6 SUPPORTING CARERS IN TRANSITION

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Eligibility for carer support services reflects an assumption that carers no longer need those services once their caregiving role has ceased – either through the admission of the person into formal care, or through bereavement. It is clear from previous research findings and consultations undertaken for this project, that this assumption is flawed. Therefore, specific programs and funding which reflect carers levels of need are required. The changing, and often increasing needs of carers should be included in the development of the HACC and disability levels of service approach.

One of the formal services which carers rate as being critically important to assisting their adjustment to transitions, as well as to managing their caregiving role, is the carer support group. Being able to continue with a group that has been important to a carer, often over many years, is seen by some carers as critical to preventing isolation as well as to providing much needed support. Significant numbers of past carers (39%) indicated in the survey that attending the same support group was the most useful form of support when the person they were caring for moved to formal care. This was higher than all other support options (Section 16.2 Figure 28). Half of the bereaved carers who responded indicated that attending a support group helped them to deal with their loss (Section 16.4 Figure 30). There is also scope to develop support services specifically tailored to bereaved carers, or to carers adjusting to the admission to formal care of their care recipient (Section 16.2 and 16.4).

Carers also value information and education services, and there is scope to add to specialised services designed to support carers in transition. This could include information related to the formal care setting, as well as to adjusting to a change in carer roles and circumstances. It is essential that such information and education is also timely, accessible and culturally appropriate.

Current carers wanted information, support and advocacy assistance to help them select an appropriate formal care facility. Parents of adult children with disabilities expressed this as a key concern. A significant group of bereaved carers found that volunteering helped them to deal with their loss and in some instances required training to facilitate this.

In order to assist carers to return to work, there is a need for linkages to retraining and training opportunities, careers advice and employment related services that are tailored to the needs of carers who have been out of the workforce, as well as for young carers who are beginning their higher education and/or training and ultimately employment. This requires cross sector linkage at policy level, between the aged care sector and the higher education, vocational education and training (VET) and employment sectors.

Carers also need to be further supported to combine caring and work, so that their re-entry/entry is facilitated to paid work following the cessation of their care giving role. Strategies are needed that support carers to combine caring and work, including mechanisms that promote family friendly practices in the workplace and the provision of flexible services to support working carers. For young carers, strategies are needed that support them to combining caring with work and with study, and which address their specific social and emotional well-being. Again, this requires cross sector linkage at policy level.

A regular review of service and support needs was identified by carers as a key type of assistance which would be helpful for carers whilst in the caring role.

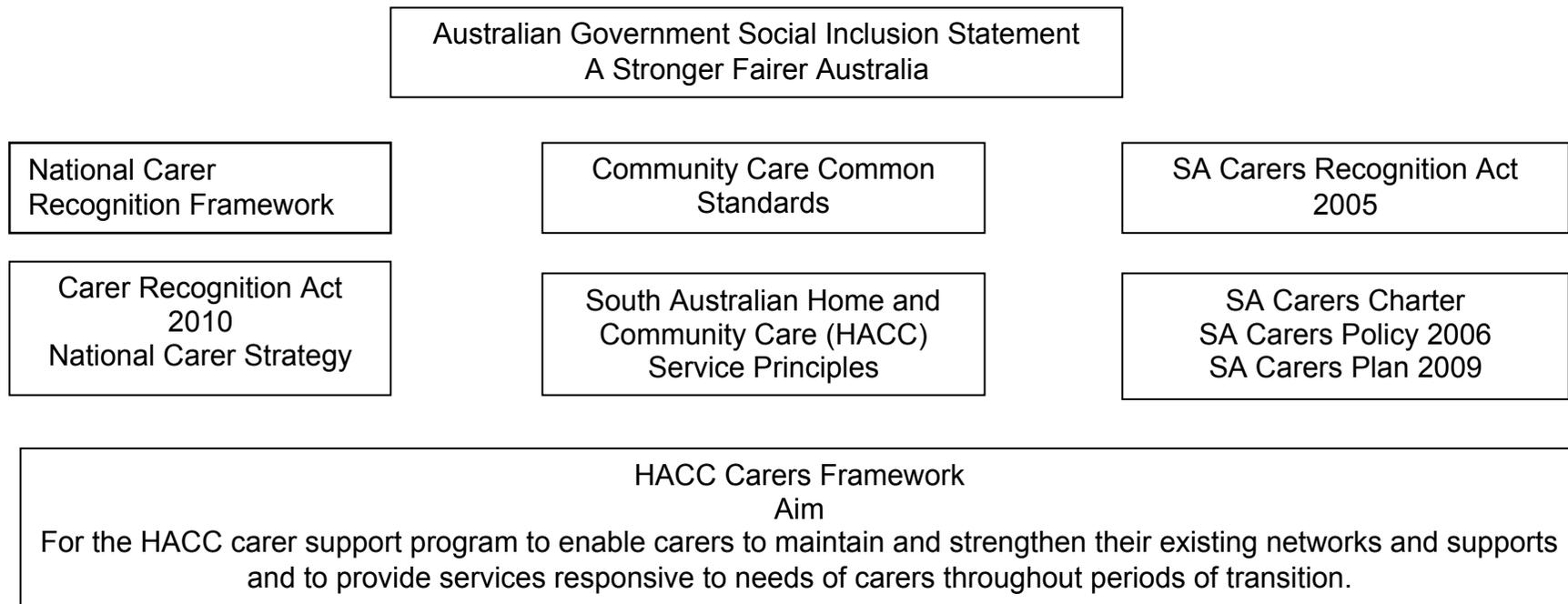
Given the impact of long term caregiving on the health and wellbeing of carers, it is also important to develop strategies to assist carers in transition. This could include access to regular medical checkups supported with respite care, as well as post-caregiving role medical assessment and linkage to specific services that may be needed.

Specific programs and funding are required to meet carers varying levels of need.

## 17.7 CARER PRACTICE FRAMEWORK

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The Framework reflects both the feedback from carers and carer support agencies (via surveys and face to face consultations) and the findings of the literature review. They link to the seven Principles of the South Australian Carers Charter, the six South Australian HACC Service Principles as well as to the National Carer Recognition Framework and the Community Care Common Standards. The proposed Carer Practice Principles which follow add a further dimension to the current policy directions, underpinning principles and goals that are relevant and appropriate for carers and support recent moves to consumer directed support (that is, the tailoring of services and supports to individual need, and increasing the control by consumers of their own support).



## Carer Practice Principles

1. Services and support should be individualised to reflect the fact that carers' needs differ according to their cultural and linguistic background, language spoken, health status, age, gender, location, formal and informal support networks, community connections, employment status, time spent caring, nature of caring role, care recipient needs and their ability to utilise respite.
2. Agencies should adopt a holistic approach to providing services including exploring the availability of formal and informal supports, interacting with other agencies and the broader community and/or utilising multiple funding sources to meet carers' individual needs.
3. Carer services and support should be sufficiently flexible, responsive, timely and accessible across the caregiving journey, including the period following the cessation of caregiving responsibilities.
4. As carers' needs change across the caregiving journey and the process of change differs from one carer to another, regular reviews of carers' needs should be undertaken and support and information provided to reflect changes in the caring role and prepare carers for upcoming transitions.
5. Services and supports for carers should play a critical proactive role to prevent and/or address the negative impacts of caring, including poor physical and mental health outcomes, loss of earning and career development opportunities, and loss of social, and sometimes, family relationships.
6. Carer support services should be well publicised and easy to access with clear communication to carers about eligibility criteria and what a particular service can and cannot provide.

7. Information should be provided to carers:
  - at the beginning of the caring role to increase their awareness of what assistance is available and to navigate the service system
  - in a variety of mediums and in a format requested by the carer
  - that is timely to prepare and support carers through transitions
  - about community support and short and long term formal care options for frail older people and younger people with a disability if the carer is unable to continue caring.
  
8. The impacts of the caregiving role are profound and enduring and service policies and guidelines should reflect the fact that carers' need for support does not necessarily end with the death of the care recipient or the care recipient's entry in to full time formal care. Agencies should take a supportive approach to prepare carers for periods of transition by linking to counselling and other options that will assist carers to:
  - increase their resilience
  - work through their loss and grieving process
  - work through their changed role
  - re-establish their links with family, friends, and community
  - navigate through the system.
  
9. Agencies should adopt a flexible approach to providing respite services and should explore the provision of non-traditional forms of respite, for example, internet access, driving lessons, and assistance to maintain interests.
  
10. Agencies should develop programs and prioritise the provision of carer respite to enable carers to lead a balanced life by maintaining their interests, connections with the community and to family and friends, their social networks and employment.
  
11. Agencies should offer some carer support services outside of working hours so that working carers have the ability to access them.
  
12. Agencies should develop a policy to support their employees who undertake a caring role, and where possible offer flexible working arrangements and the ability to work from home.

## 18 RECOMMENDATIONS

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The following recommendations are based on the findings of the consultation process and the literature review. A number of carers who participated in the consultation were no longer eligible for HACC services and a number also spoke about services that affect them outside the scope of the HACC program. As a result, a number of these recommendations fall outside the scope of the HACC program, however they are included as they are important for both State and Commonwealth governments and service providers to consider for delivering services for carers in the future.

1. It is recommended that HACC funded agencies and other agencies that support carers adopt the Carer Practice Principles outlined in the Carer Practice Framework.
2. It is recommended a review is undertaken within the next three years to evaluate the uptake of the Carer Practice Principles and HACC Carers Project recommendations to ascertain the impact of their adoption on the lives of carers and their success in keeping carers connected to their community.
3. It is recommended that a level of service approach is developed and applied to carers including programs to reflect that carers' needs change across the caregiving journey and the process of change will differ from one carer to another.

4. It is recommended that information sessions and/or support groups are established specifically for carers whose care recipient is entering residential care or supported accommodation (both at the places of formal care and independent of these) which as part of its role:
  - meets some of the information needs of carers during this period
  - provides support in this transition stage
  - assists carers to reconnect with their interests, the community, family, friends and employment (depending on their age).
5. It is recommended that information sessions and/or support groups are established for bereaved carers which:
  - assist with grief, loss and guilt
  - assist carer to transition from the caring role and reconnect with their interests, the community, family, friends and employment (depending on their age).
6. It is recommended that support group members are informed how they could establish a past carer support group, some of the activities which existing groups undertake and what formal assistance might be available to them.
7. It is recommended that other support options such as ongoing engagement in existing support groups, counselling, visits from former carers and volunteers and membership of established groups of past carers such as the Barossa group and the Mt Barker group are also explored.
8. It is recommended an evaluation is undertaken within the next three years to review the various benefits of new carer support groups (Recommendations 4, 5, 6 and 7) versus and/or in conjunction with other transition supports.
9. It is recommended that the Commonwealth Government undertake research into extending the Carers Payment for a period of time to carers who are under the Aged Pension age to enable them to recover from the caring period before transitioning to Newstart payments or employment.

10. It is recommended that carers are encouraged to develop emergency care plans and these are updated as part of a regular review of carer needs to reflect the changing needs of both the carer and care recipient.

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### WORKING CARERS

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11. It is recommended that carers who want to remain working or to enter or re-enter the workplace are provided with a range of support options to assist them to balance work and care. This could include development of a program of support offering counselling, respite, assistance to explore training or education and support to negotiate flexible working arrangements.

12. It is recommended that further research is undertaken into the needs of working carers including respite and flexible working arrangements and based on this research a three year pilot program is developed and implemented.

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### SUPPORTING CARERS

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13. It is recommended a Carer Advocacy Service is established and further exploration is undertaken to explore its role, scope and the benefits.

14. It is recommended a subsidy scheme for carers which utilises a discount card scheme to enable carers to access discounts from Government services and businesses (similar to Seniors card) is established.

15. It is recommended that further research be undertaken to explore how family and friends can support carers in their caring role and how shared care arrangements can be supported.

16. It is recommended that further research into a holistic approach to carer support be undertaken for carers who have difficulty utilising respite, attending retreats and/or support groups. As a result, a pilot program should be developed and trialed.
17. It is recommended that future research is undertaken on the carer support needs of high need carers including those caring for more than one person, sequential carers, long term carers and young carers.
18. It is recommended that research is undertaken to develop programs to reduce the financial impact of caring. Consideration for Recommendations 9, 14, 22 and 27 should be included in this research.

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#### STAYING CONNECTED

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19. It is recommended there is a renewed focus on the development of flexible respite for evening, weekend and occasional longer periods of respite based on carers individual needs.
20. It is recommended that a strategic approach to the development of programs trialing non-traditional forms of respite based on carer feedback is established, for example internet access and driving lessons for carers.
21. It is recommended that activity-based meaningful respite programs are explored and further developed to encourage care recipients to utilise respite programs and allow carers to have a break from the demands of caring. Priority should be given to programs for carers of people with dementia and younger people with a disability past school age.

22. It is recommended that additional respite is provided for carers of:
- younger onset dementia care recipients as their needs and behavioural issues increase
  - children with a disability to assist carers access education and work
  - younger carers to assist them to access work and education programs.
23. It is recommended that there is further research into transport assistance for carers which takes into account the fact that carers often have reduced financial capability. This research should explore options such as the multiple use of SATSS vouchers for a single taxi trip and petrol subsidies and approaches for carers without access to alternative means of transport.

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#### MAINTAINING CARERS WELLBEING

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24. It is recommended a national program of free preventative health checks, home and community based exercise programs, relaxation and stress management programs for carers is developed. This could include the use of massage to reduce carer stress.
25. It is recommended that the National Carer Counselling Service is expanded to provide regular counselling if required, access to counselling at key transitions (including bereavement, entry of the care recipient into formal care and return to work) and that past carers should remain eligible for 12 months after their caring role ceases.
26. It is recommended carers are supported to focus on their personal wellbeing. This could include programs to support carers to develop time management skills to schedule breaks for themselves which they can utilise for exercise, relaxation, stress management or recreational activities such as hobbies or gardening.

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## YOUNGER CARERS

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27. It is recommended that a specific program of support for young carers to support them to meet their development needs is developed in conjunction with FaHCSIA and other appropriate agencies. It would include:

- more socialisation
- information and support in formats utilised by youth
- training and information pertinent to the caring role and household tasks if necessary
- access to regular counselling and mentoring
- advocacy support
- internet access
- study subsidies
- a pilot on line support group
- respite to access work and study programs
- transport assistance to attend group activities
- specific youth positions
- early intervention strategies and programs.

28. It is recommended that there is an automatic fee waiver for young carers.

29. It is recommended that the needs of young carers are reassessed in three years' time following the implementation recommendation 26 and 27.

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## FUNDING

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30. It is recommended that additional flexible funding is provided for early intervention and proactive programs to ensure carers are supported to stay connected to their community and to prepare for periods of transition.

31. It is recommended that a mechanism is established which will enable agencies to report on transition support and support for past carers.

## APPENDIX 1    ADVISORY COMMITTEE

---

Peter Sparrow	Carer Support
Rosemary Warmington	Carers SA
Maria Ross	Northern Carers Network
Jenny Potter	Carer
Moss Politis	MALSSA Inc.
Gary Vogt	CarersLink, Barossa and Districts
Graham Aitken	Aboriginal Home Care
Joseph Bayer	CARITAS, Hungarian community
Marcia Fisher	Flora McDonald Lodge, Residential
Amy Weckert	Department for Communities and Social Inclusion
Jan Gaskin	Department for Communities and Social Inclusion
Annette Doonan	Department for Communities and Social Inclusion
Rosie Mangan	Office for Carers
Marie Farley	Office for Carers
Kira Kudinoff	FaHCSIA
Kleo Pope	Department of Health and Ageing
Alison Prior	Department of Health and Ageing
Erica Tyler	Centrelink
Darcy Kanaris	Centrelink
Kristin Johansson	HOKJOK
Helena Kyriazopoulos	HOKJOK

## APPENDIX 2 COMMUNITY AND STAKEHOLDER LIST

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We would like to thank all those who helped to facilitate the consultation process.

Anne Gawen	CarersSA
Bronwyn Filsell	Men's Shed Pt. Augusta
Carol Lyson	Domiciliary Care Pt. Augusta
Carolanne Zimmerman	Community Health Loxton
Claire Beard	Alzheimer's Australia SA
Colleen Moore	Carers SA (South East)
Don Haywood	Zebra Finch Aboriginal Men's Group
Gary Vogt	CarersLink, Barossa and Districts
Graham Aitken	Metro Mob (Auspiced by Aboriginal Home Care)
Ian Amey	Parkinson SA Support Group
Italia Mignone	Italian Benevolent Foundation
James Girvan	Carer Support
Jenni Colebeck	CarersSA (Loxton)
Jenny Potter	Younger Onset Dementia Group
Joseph Bayer	CARITAS, Hungarian Community
Julie Brand	Community Health Riverland
Kam Chu	Chinese Welfare Services
Karen Miller	Barmera Health Service
Kathy Millinch	Helping Hand
Katrina Beere	CarersSA (West)
Lianne Brewin	CarersSA (Loxton)
Louise Monument	Northern Carer's Network
Lyn Walsh	Port Pirie Aboriginal HACC Coordinator
Lyndall Fowler	Adelaide Hills Community Health Service
Maria Ross	Northern Carer's Network
Mary Graham	Gawler Health Service

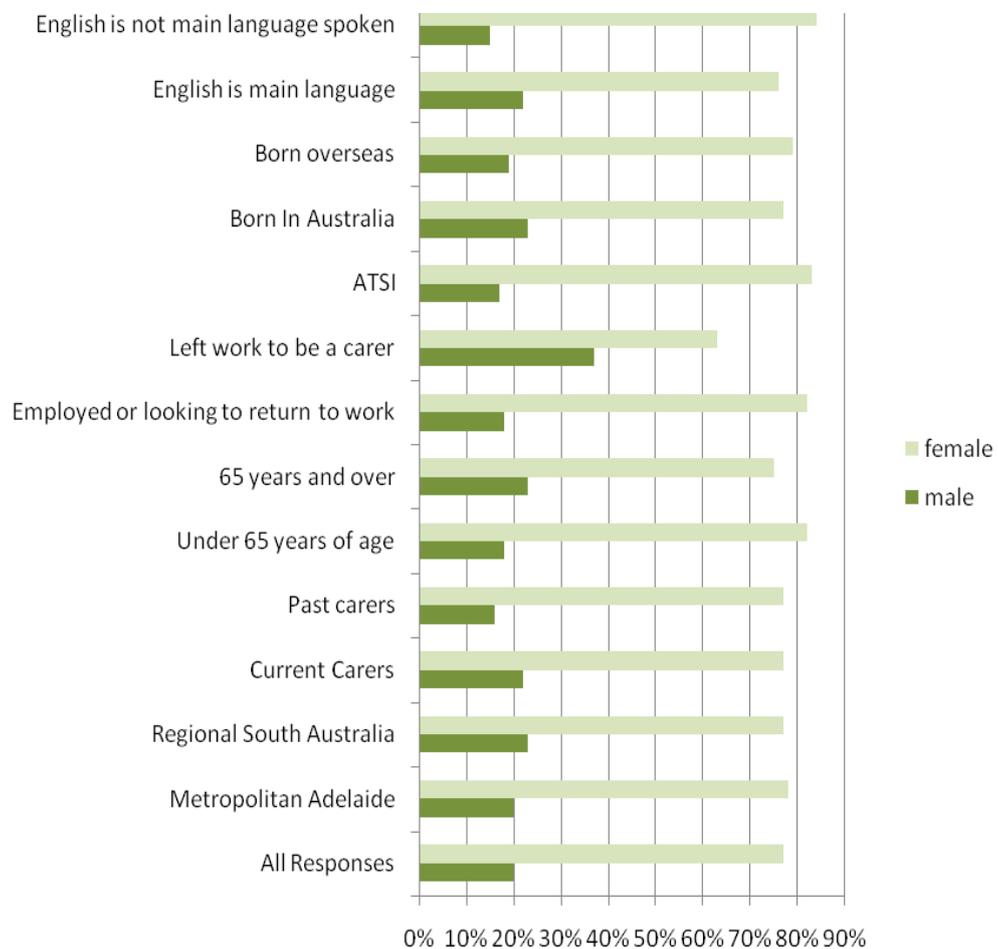
Merilyn Little	Carers SA (Port Augusta)
Moss Politis	MALSSA Inc
Peter Sparrow	Carer Support
Rosemary Warmington	CarersSA
Rita McCechnie	Younger Onset Dementia Group
Ros Franklin	Health Focus Port Augusta
Sharon Hoffman	Northern Carer's Network
Sue Castledine	Kura Yerlo, HACC program Coordinator
Thuy Nguyen	Vietnamese Women's Association SA Inc
Tommy Hung	Chinese Welfare Services

## APPENDIX 3 DEMOGRAPHICS OF CURRENT AND PAST CARERS WHO RESPONDED TO SURVEY

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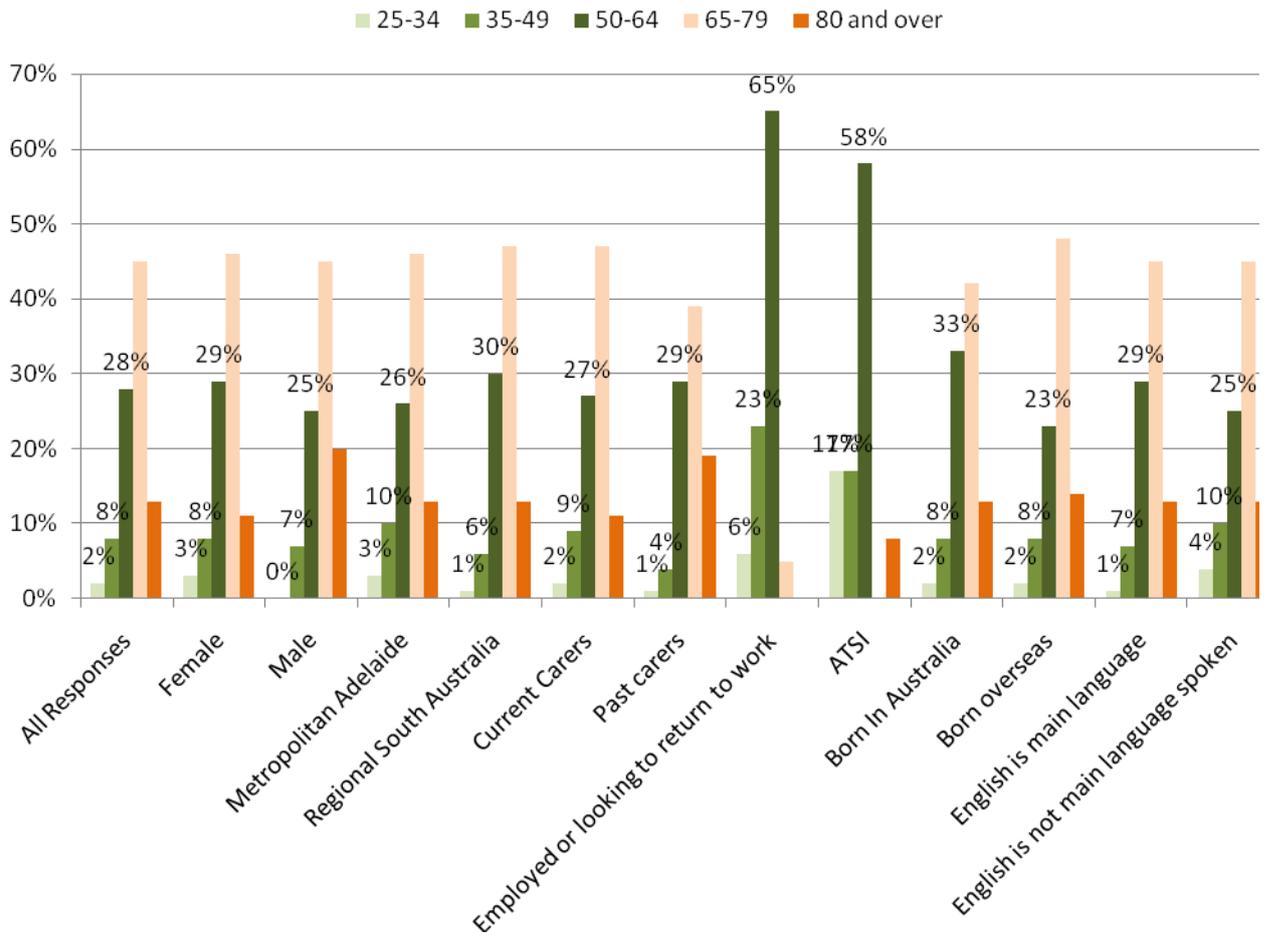
### GENDER

FIGURE 33: GENDER BREAKDOWN OF CURRENT AND PAST CARER SURVEY RESPONDENTS



## AGE OF SURVEY RESPONDENTS

FIGURE 34: AGE IN YEARS OF CURRENT AND PAST CARER SURVEY RESPONDENT



## GEOGRAPHIC LOCATION OF SURVEY RESPONDENTS

FIGURE 35: LOCATION OF SURVEY RESPONDENTS

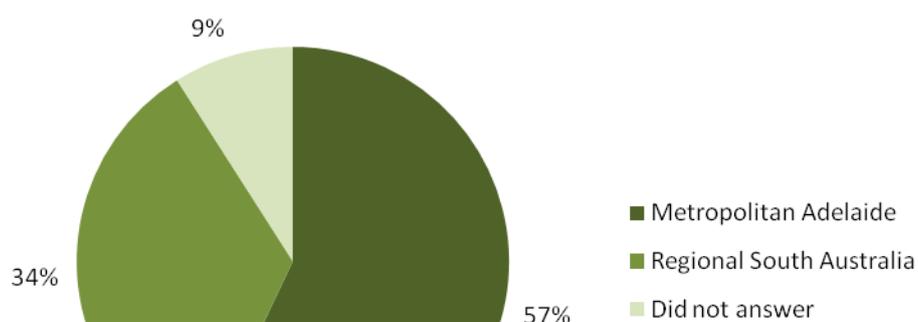
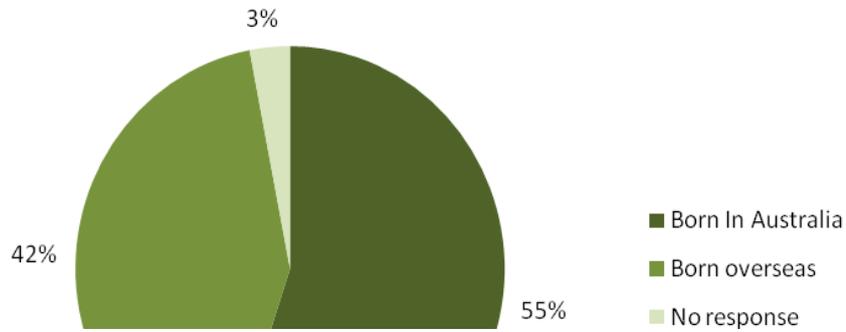


TABLE 8: LOCATION OF SURVEY RESPONDENTS IN MORE DETAIL

Adelaide	Goolwa Beach	Murray Bridge	Reynella East
Angaston	Goolwa North	Newton	Royal Park
Ardrossan	Gumeracha	Noarlunga Centre	Salisbury East
Arthurton	Hackham West	Normanville	Salisbury Heights
Beaumont	Hallett Cove	Norwood	Salt Creek
Bridgewater	Happy Valley	Nurioopta	Seacliff
Brighton	Hindmarsh	Oakden	Semaphore South
Broadview	Ingle Farm	Onkaparinga	Somerton Park
Cape Jervois	Kangaroo Island	Onkaparinga Hills	Strathalbyn
Christies Beach	Kingscote	Paradise	Surrey Downs
City of Tea Tree Gully	Lameroo	Para Hills	Victor Harbor
Edithburgh	Littlehampton	Parafield Gardens	Virginia
Elizabeth	Loxton	Penneshaw KI	Vista
Elizabeth Downs	Maitland	Plympton Park	Walkerville
Encounter Bay	Mannum	Pooraka	Whyalla
Findon	Middleton	Port Clinton	Wynn Vale
Fulham Gardens	Millswood	Port Augusta	Yankalilla
Gilles Plains	Minlaton	Port Lincoln	
Glenelg	Moonta Bay	Pt. Pirie	
Glenelg North	Mount Barker	Renmark	

## BIRTHPLACE OF SURVEY RESPONDENTS

FIGURE 36: BIRTHPLACE OF SURVEY RESPONDENTS



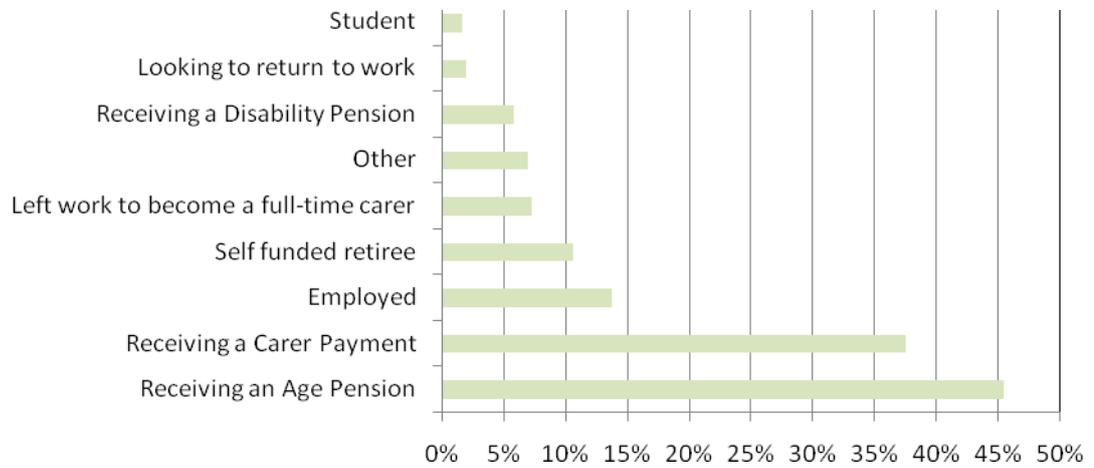
## LANGUAGE SPOKEN BY RESPONDENTS WHOSE MAIN LANGUAGE AT HOME WAS NOT ENGLISH

TABLE 9: NON ENGLISH LANGUAGE SPEAKERS RESPONDING TO CARERS' SURVEY

Adynamathana	German	Mandarin	Tagalog (Filipino)
Arabic	Greek	Narrunga, Kurna	Ukrainian
Cantonese	Italian	Polish	Vietnamese
Croatian	Lithuanian	Russian	
Dutch	Macedonian	Serbian	
Hungarian	Maltese	Slavic	

## EMPLOYMENT AND BENEFITS

FIGURE 37: EMPLOYMENT STATUS OF SURVEY RESPONDENTS AND GOVERNMENT BENEFITS



**NB Respondents could select more than one response, so percentages may add up to more than 100%.**

## APPENDIX 4 CARERS COMMENTS

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Many carers wanted to have their say both at the meetings and in the survey. Whilst pertinent issues are discussed throughout the report this Appendix contains direct quotes from carers. Carers gave permission for their quotes to be used in the HACC Carers Project Report.

### APPENDIX 4.1 CARERS TALKING ABOUT THE IMPACT OF CARING

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‘Caring has been a process of feeling quite disempowered to empowered. In the beginning it was all panic stations to try and figure out how we were going to care for mum in our home when we were both undertaking full-time activities. The initial few weeks were hell! We didn't have support and when carers were put into place there was time to be able to breathe again. Very stressful in the beginning! Family ties have been affected due to the unbalanced way of a caring situation. The healing process for mum and also us as carers began to happen when everyone took responsibility for their role. Through encouragement mum started improving and becoming more independent. I sought counselling as I could feel I was allowing my life to be dominated by the caring role. Through strategies to improve my own self esteem I could then be stronger with decisions and make time for myself and ask for appropriate help. It has made me a stronger person and what an amazing learning experience. Mum is in control of her life and happy (with my assistance) and I'm happy that we have a very stable relationship again that is joyful, encouraging and loving.’

---

‘Huge Impact. It was an honour and a privilege to care for my mother in her twilight years. Despite all the drama, the isolation, the stress, the demands, the difficulties, it was a once in a lifetime opportunity I will never, ever, regret. Wouldn't have missed it for quid's.’

'I went through a stage where I was angry and frustrated. After a while I knew nothing would change and it was only me who could help myself. I started to make time to do things and from that moment things changed and it all didn't look as bad. Now I enjoy my life and see that we are lucky compared with people who have it much more difficult than us.'

---

'It has been rewarding to know that good caring has maintained my husband's health, but it is also very draining. I believe it has made me a more tolerant, compassionate person, but it is also very frustrating at times. It has made me less selfish but at times I need my own needs met.'

---

'My life has been put on hold. I gave up a job I had just acquired after two years of searching I gave up my home for 12 months, my studies. Gave up most things in my life to care. In this, I was able to make my mother's last year's enjoyable by spending time with her and making her my priority.'

---

'I have missed the easy ability to be able to visit our four children who all live interstate, however we do receive regular phone contact from all of them (travel for travel sake is not a concern).

The companionship of a partner to partake in 'evenings out' i.e. dining out, sporting fixtures etc. The problem of learning to change my role. i.e. household role of cooking, washing, cleaning, etc. that my wife always understood as a stay at home wife and mother.'

---

'I have been caring for my mother for 7 years and up until only recently I have been pleased to give her this gift of my time and to help her recover from her stroke. I have enjoyed spending time with her and getting to know her more.

But I am only 53 years old and too young to retire from paid work. I want to continue to contribute to society through active engagement in paid work and other community activities. I also want to finish my PhD and in recent months it has been impossible to get the time to do that.'

'While I initially shared the caring with my brother, I always did more, but over the last few years that load has increased to a point where I feel I have lost myself. Also I don't like the way my mother treats me now, I am her carer not her daughter and because I am a woman, single with no children she seems to think I should be always available to her. I am becoming very resentful of her attitude and I don't like this about our situation.'

---

'The impact has been huge. We lost our future plans, our financial future, some of our friends and also some family members. As a carer for 9 years the toll on me has been huge and I feel that my health has been compromised. I have absolutely no time for myself (we are near the end of me being able to care at home and am waiting permanent placement - this is very different than in early and middle stages).'

---

'Positive - we have met new very special friends whom I believe will become lifelong friends. The first 7 years were good and travelled and did things now rather than later. I have had a lifetime of information and experience in 9 years!'

---

'Complete change of my lifestyle and for the first 7 years became a recluse with a lot of struggle/stress to manage a new routine and caring work especially. Not knowing how to access more respite. However it made me physically, mentally and emotionally stronger and these have remained with me even now when my mother has died (even managing to sleep less than 8 hrs a day!!) In the later years of my caring, I got to know the Northern Carers and the Tea Tree Gully support service and life became much easier with the great help given by these lovely people especially in arranging respite care. It allowed me to get out of the house and start to have a life outside caring and this has helped to overcome grieving when my mother died.'

---

'Positive: getting to know my mother on an entirely different level.  
Negative: It has been very energetically draining and the responsibility has sometimes overwhelmed to the point that I felt I wasn't coping and that I was going under trying to keep up with my work responsibilities/my pets/try and start a new relationship - new man in my life - there wasn't much time or energy left for him. I find it very difficult trying to maintain friendships when mum is demanding my time.'

---

'It has taken over my life. My life is no longer my own. I have to think about how my life will fit around my husband who comes first. If he is comfortable and content I am too. I have met some wonderful friends. I have found that I am not alone with my problems. However, I have lost my best friend, my carer and my lover. We cannot have conversations, discussions and share things together or travel on holiday together. I feel guilty doing things for myself or when I put my husband in overnight respite.'

---

'As a family we have cared for 3 foster children with high health care needs. One child is still with us after 19yrs. I would not change my life or wish it had been different but we, my husband 2 children and I are all different because of it. The work load is enormous you are always time poor. The social isolation at times is very obvious. Much of society does not understand.'

---

'I have been caring for my daughter for the last 8 years as she has mental and physical problems. I also am a carer for her daughter who is 13. I organise everything in my daughter's life for her (meals, dropping granddaughter off at school/pick-up, getting her out of bed in the morning, pay her bills, tend to her garden, organise doctors' visits).'

---

'Built a closer relationship with the one cared for and family. Some relationships have become more distant. Increased housekeeping skills and appreciation of the role of a housekeeper. Better understanding of human nature, relationships and brain function. Decreased social, sporting entertainment and travel involvement. Greater exposure to elements of the media in trying to bring about a better understanding of memory impairment and its implications.'

---

'Being able to help someone makes me feel wanted and needed, this has resulted in my life being about someone else and I sometimes feel that I want it to be about me. As a mother I don't mind having someone need me, but I need them to understand that I sometimes have needs too.'

---

'I don't feel it has impacted on my life, it has been a gradual process, and I deal with it as needs must. Age also contributes. But, we are still here, coping with each day as it comes, and still lots to be thankful for!'

---

'The most impact was knowing that there was no medical thing that could be done, no medication as the disease was so rare, and nothing I could do to help him but love and care. The most positive thing was the help I received from the Carers Association in SA and the Mt Barker Community Health, HACC, CACP, CWCA Hills. Until he went into aged care, someone from HACC would call and visit and then report to the doctor once a month. He was in aged care for 14 months before he died and they made it possible for me to take him out in a motorised chair every day. The meetings with Carers SA after helped fill the void it caused when he went. It was also a great loss as we worked together every day and caring took up all my time so I lost all social contacts for a while.'

---

#### APPENDIX 4.2 POSITIVE IMPACTS OF CARING

---

'A positive life and love over 56 years of marriage, great children and grandchildren we are reaping what we have sown and know that they love us greatly. We know that further help is there if needed from both children and grandchildren.'

---

'I believe the three years spent as a carer has made me more patient and understanding person than I previously. I have had to help deal with the mental and physical issues of another person in a situation that was never really planned for. I also have no regrets and would do it again because I feel I have given something back to the family.'

---

'Even though times have been challenging we have turned out better people because of our situation.'

---

'Caring for a loved one taught me a lot of valuable insights in valuing life. That regardless of what situation I am in, I must learn to be grateful that I am alive and well, rather be a carer than a care recipient. Values of patience, sacrificial living for the benefit of others strengthened me to a high degree. Living outside my comfort zone taught me how to become resourceful and self reliant. At times painstaking but you endure. Learn to look after yourself more as you do not wish the weight you are carrying to be heavier. One thing you wish for that you do not wish to be cared for because of what you have, experience as a carer.'

---

'Learn to live and enjoy life one day at a time and be grateful that you had another day.'

---

'Learning to understand my own capabilities. Learning to communicate with other carers. Learning to accept life as it comes.'

---

'Providing live in care for my mother for dementia has enabled us to share many special times. I have thoroughly enjoyed hearing stories of her life and our family previously unknown to me as her long term memory has been very good. As we pop out for coffee or to the shops, a favorite saying of my mother's is 'I just love living with you - I never know what I am going to do next! It makes me realise how isolated she had become as she aged.'

---

'Relationship with father has developed where it was very shallow before my caring role began - rewarding.'

---

'I developed a much stronger relationship with the person I cared for, I did it for love not monetary compensation, and my family understood the sacrifice without any resentment.'

---

'At the time of my wife's diagnosis of dementia there was quite a stigma attached so we decided together to tell everybody, family, friends, neighbours, we encountered not one negative reaction rather the reverse, this heartened us and formed a base for a relationship with others in a similar situation plus we loved each other dearly

and our children knew this - which has the effect of drawing us closer together as a family and is ongoing. Beryl died in 2006.'

---

'It is a rewarding role and I appreciate the opportunity to give back to my Mum for all the hardships she endured to raise her family as a single Aboriginal mother in time of overt racism.'

---

'... did not think I would ever do it. I am proud of what I did for 10 years.'

---

'The positive impact is that mum is happy and far better off living with me than any alternative.'

---

'On the bright side - being a volunteer has helped me to get my mind off the situation at home and has taught me that there is always someone worse off than you.'

---

#### APPENDIX 4.3 CHALLENGES AND NEGATIVE IMPACTS OF CARING

---

'Life is on hold (permanently).'

---

'It has reduced my life - I am now not able to participate in many activities that I used to, this has impacted on my health and it has impacted on my family's well being as I have young children. It also impacts financially and unfortunately the only positive I can see is that the person still lives at home and is with his children.'

---

'Severely restricted me from fulfilling my expectations re: retirement. Am stuck at home with no holidays/down time etc. Job from a demanding patient who I love dearly.'

---

'No longer being an individual. Nothing is fun or joy any more. Forever 'on call' and 'on duty' 24/7.'

---

'Loss of independence and freedom to just pop out and do something on my own. Having someone following me or looking for me continually. Having to spend hours

filling in forms, organising appointments, providing all transport and having to try and keep my loved one content as he just loves going out and so much needs to be done around the home. It is a 24 hour job being a carer - if they are at home a carer really doesn't have a life of their own - not even to shower.'

---

'Loss of freedom and independence. Guilt, low self-esteem, putting the cared for first. Having a breakdown, feeling overwhelmed.'

---

'Resigned from 4 volunteer organisations as well as bushwalking club of 27 years when husband was placed in care under the Mental Health Act. His medication was \$260 per month. We were spending \$90 per week above our income (no outings or presents - they were no longer an option.) So I sold our home and bought a unit near his residential care. He died 4 months later. I had been receiving 2 hours weekly respite (to maintain our garden) when I was entitled to 8, but there was no-one available. 16 months after my husband died I received a letter telling me more help was now available! Now have back pain from having cared for an 84kg man.'

---

'Going from full time employee to full time 'home-body' was a shock to the system and took a bit of getting used to, especially the drop in income.'

---

'When you are a full time carer, the impact is quite simple....you don't have a life. As your life has to revolve and fit in with the person that you are caring for, even when you are ill, you still have to get on with it. You can feel quite isolated at time and wonder to yourself how much longer can you go on. It is like you are on a merry go round and you would like it to stop, so you can get off and take a deep breath and be able to do what ordinary families do just once, book a holiday to the gold coast that would be nice, but our son won't fly and he won't go on boats.

He becomes very aggressive he is 6' 10' tall and weighs 13 stone, so some people would say don't take him then put him in respite. There is no respite ever available when I need it. If you want to go out for a meal, he puts on a tantrum, as he doesn't like crowded places. If you go out to the shops with him, he doesn't stop grabbing things off the shelves and becomes aggressive when asked to put things back.

Some people I am sure have no idea what carers have to deal with everyday and put up with. All my answers have come from my heart as this is how I feel. I hope that some things are going to change as a result of this survey.'

---

'I never got over the thought that my having to care for my wife robbed me of the last years of my retirement. That sounds selfish I know but it did not stop me from putting my best into the caring role.'

---

'At Victor Harbor I was a volunteer teacher who taught computing to seniors. I had to give this up when we found out that my husband was suffering from Dementia. I also had to give up golf and going on outings with my husband. After 48 years of living with my husband it is very depressing to be living alone. Moving from Victor Harbor to Mt Barker to be closer to support networks and leaving friends was hard as well as at 67 having to make completely new friends was daunting.'

---

'Leaving the city and going back to the country was a massive change in life style'

---

'The financial implication of caring puts a strain on budget with all the little extras including transport, appointments, losing benefits e.g. discounts on services for those on a pension (as we are not eligible).'

---

'This has had an enormous effect on my financial earnings and has placed me in an unfortunate low finance place.'

---

'Financial problems, not being able to do the things we had planned, maintenance required around the home, trying to keep a balance on life and home calmness rather than too much happening.. If too much going on can cause agitation.'

---

'Challenges - maintaining a normal and healthy lifestyle and relationship with my partner. Loss of constant income has been the biggest impact. Opportunities to participate in community activities have also been reduced. Transport an issue at times and a large financial burden for medical assistance. '

---

'Being a carer is a miserable existence!!!'

---

'Fear of the unknown. anger at the medical profession for lack of understanding. Stress leading to breakdown. Lack of information. Struggling to find balance in life. Loneliness. Insomnia.'

---

More stress and not knowing what to do. Not able to do all the things that we would like to do because we are home a lot.

---

'To see the person you care for in so much pain 24/7 when nothing seems to fix it, having diabetes one thing heals and then something else happens, It's just continuous and never ending. The feeling of helplessness.'

---

'I lost the ability to travel and see my family overseas and interstate, this makes me sad'.

---

'Caring for husband is a challenge with the mood swings you don't know which way he will go. There are good days and bad days, with Alzheimer's. It gets very frustrating.'

---

'Caring is a very one sided affair and affects you in many ways. All our friends cannot understand what you are experiencing - usually they don't ask as they don't know how to respond. Financially it can be very taxing.'

---

'Caring for and bringing up my grandchildren has at times been challenging - my grandson having been in trouble with the law. It has been at times stressful and has impacted on my health. I love my grandchildren and I love my family. I have no regrets and would do it all again'.

---

'I have taken on to bring up the grandchildren - two. To make sure they get a good life. I do sacrifice a lot to do this. My grandson has a disability, he is violent, has ADHD and because of this I can't take him to many places. This is a challenge and impacts on our family life. But I am prepared to take him on and give him an opportunity of a good life'.

---

‘There is very little carer support for those with children, where one or both are under 65. Disappointment.’

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‘We have found that our life has changed due to not having time for each other or friends and always having our son at home 24/7. It is hard to deal with everyday stress that at times doesn’t change when we get home. I envy families with healthy normal children and sometimes wish that people who judge us or our son can experience what we have been through.’

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‘Toilet training, dealing with constant sickness as a young child. Dealing with professionals that tell you there’s nothing wrong with your child. Dealing with obsessive compulsive behaviours. Having to keep school hours even though our son is 35 we have to have him up early in the mornings. Never being able to leave him unsupervised. There are many more issues and challenges we deal with every day. The one thing I would really like is peace of mind about where our son will go when we are no longer able to care for him.’

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‘The greatest impact is the adjustments all family members have to make, siblings growing up with a brother that was not socially accepted. Seeing your other children and their children reluctant to bring friends home or being seen as a family unit.’

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‘I have only been a carer for just over a year and we have had to deal with quite a lot of emergencies in that time - the dialysis, also unrelated problems severe hernia pain that lead to surgery.’

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‘My services were from Resthaven and they were good. In my long experience the hassle I got from government departments was something I could have done without, they offer no help and they should.’

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‘When they are happy, I can be happy and relaxed. When they are grumpy I have to put up with a lot of stress.’

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'Feelings of being trapped, not being able to cope with the anger and temper from the person I am caring for. Not knowing too much about my role as carer.'

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'Worry, stress, disagreements with partner; hospitalisation trauma on us and loved one; can't talk to loved one; 'loss' of the 'normal' son we once had; depletion of family unit; Christmas without our loved one; depression.'

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'Making the physical distance from my family - in two different states - feel greater and insurmountable.'

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'Before I was caring I was a worker in a family business a member of the local CFS and progress association and a member of Friends of Deep Creek. All were very busy active fulfilling roles. I now do none of them.'

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'I have cared over the past 16 years for my mother, husband, step-father and now daughter. It is an emotional, draining experience leaving me stressed with medical problems. More money should be allocated to give carers 'a life' after all, we have saved governments millions of dollars.'

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'Reduction in the type of community contacts that I value personally.'

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'Difficult to juggle caring for my wife, children and extended family responsibilities. I have older parents who also rely on me. I am the only child and the burden falls on me.'

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'At first the lack of information or supports of any kind apart from special schooling made available and that was long distance travel while needing to get myself to work and daughter to local school (no car). Major impact was caring 'forever' and fitting in needs between caring, job, being a mother and sleep. Having no extended family and difficult personal situations (marriages and divorce.) the improvement of supports in the late 1980s helped a great deal.'

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'Negative - loss of self, worry if I get ill who will look after partner or what will happen to him, envy my friends and their partners out enjoying each other's company,

having to think of two people constantly, we don't get invited out with friends as a couple nowadays because they can't be bothered with my husband.'

---

'Major concern: what happens to my son when I die?

It has been a never ending journey so far 37 years. I would like him settled in a suitable 'home' so that I can take a break. Worries about the future when I may not be able to continue my caring role.'

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'Despite having a nursing background I was unprepared for the impact that dementia would have on our lives. What can prepare one to live with a beloved stranger? I feel that early support groups, where carers with experience can console and understand the daily grind, become a buddy by telephone maybe??'

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'No one cares/d for me I have cared for my son for 45 years for the past 5 years he has been living at Karra but I still visit him almost on a daily basis, taking two buses there and two buses back home, I am exhausted. I also now have to care for my husband who has heart problems and issues with his knees. He does not drive any more so we are restricted as to where we go. MALSSA has been my strength, they have advocated on my behalf for over 12 years.'

'Fatigue from constantly being at someone's beck and call, and attending to their medical appointments and medications etc. The stress sometimes gets too much and I sometimes feel that I am not always nice to be around. I have spoken to my GP and am taking antidepressants.'

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'Tiring  
takes energy both physically and mentally.  
Emotionally draining  
Frustration  
When things don't go to plan → guilt → anger → depression.'

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'Also, I get exhausted trying to juggle both roles and full time employment and find myself getting short tempered and overwhelmed, I just keep hoping that next week will be better.'

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'This has led to a horrible state of hyper vigilance a combination of fear, anxiety, exhaustion, depression and loneliness to top it all off.'

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Health and physical deterioration, due to vastly reduced exercise routine.

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'Stress, depression, marriage difficulties, not able to travel, difficult to go on a holiday, loss of friendships, embarrassment, having to cancel gym at last minute.'

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'P.T.S.D, Fibromyalgia, herniated disc, occurred while making child's bed, anxiety, now coeliac, severe stress has done that. Can't cope with prescription meds, now alternative meds and more expensive.'

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'I felt overwhelmed as the time went by suffered from stress, depression and didn't want to mix or talk to people. I was put on anti depressants by my GP and I still continue to take them. The feeling of exhaustion mentally - from working out and accessing suitable services and groups - these are all wonderful but a minefield to

work through and to choose the ones best suited to our situation. I felt so confused and tired a lot of time.'

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#### APPENDIX 4.5 HELPING CARERS CARE FOR THEMSELVES

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'My husband recently spoke to our GP about spending some time in hospital to give me a break at home. It is having time at home alone that I feel I need. I have a computer at home and have managed to teach my husband how to use facebook and play some games. This has taken some pressure off me, but what do I do if my computer needs to be replaced, The cost of being on the internet and replacing a computer can be prohibitive.'

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'I always tried to do something for myself while he was in respite. Either to see a movie, get my hair done or have a massage or sometimes just have a day where all I did was watch DVDs or read a book. these things kept me sane.'

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'Having respite for a few hours or overnight. To go to doctors on my own, out alone with friends, go to my exercise class.'

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'Keeping positive, this is easier for some people than others by human nature some people a more flexible and can adjust to different situations in life. Looking after someone you love and watching them deteriorate is difficult but it does not help you or them if you continually get upset. Letting go of things that you realize are not important anyway (like the wheelchair scraping the paint off the door frames- it can be repainted - one day - after a while you do not even notice it).'

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'Counselling and talking to people has helped me.'

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'Try to engage in regular exercise and maintain a healthy diet. Try to maintain a positive outlook, which can be challenging.'

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'Not a great deal all the carer services seemed to be supporting older carers looking after kids, there is little specifically for those who have children and a parent to care

for and where the person you are caring for does not want anyone else engaged. My children suffer too, where is the support for them ????????

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'Frankly, God has been the source of my strength in all the things that I do, caring for my family, myself and others.'

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'Regular home cleaning where no age barrier applies and regardless of my state of health. Too many doctors' appointments 15-25 per month'

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'More multi-faceted services and direct help. Eg. relocation of home through Housing SA will alleviate all issues, but due to borrowing it will cost more money for family and for the government and leave elderly feeling isolated for no good reason. It was a real help to have a lady to clean the house as there was so many things to do for my husband for so long.'

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'Having help with cleaning.'

---

'Occasional home help.'

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'My own determination.'

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'Belief in self - can/must do. Again, past experience having only self to rely on from age 12 (orphan and institutionalised). Married at 18 years and mother by 21. Success from own efforts re-inforced 'can do' 'will do' attitude necessary.'

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'The love and compassion and understanding of my sweetheart, close family and very old close friends.'

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'Support, understanding and a sense of humour.'

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'Close friends, personal knowledge of how important it is to care for myself.'

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'More outing at weekend, family members taking more responsibility.'

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'Mostly my friends and my husband who has to listen to me carry on sometimes.'

---

'family/friends/support group/carers support organisations.'

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'Friendships keeping me sane.'

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'Managing time logically. Asking assistance from other family members to avoid pressure.'

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'Having my sport. Advantage to meet friends for coffee as my patient doesn't always like to socialise.'

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'Try to maintain a 2xweekly exercise program. I go out for coffee breaks when possible. Keeping in contact with family and friends who care and understand. Joining the SA carers support groups and activities when I can.'

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'Friends - carers association.'

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'Stay organised, eat well, get out in the garden to potter around as much as possible. Try to keep everyone positive, try and dwell on what we can do not what we can't do. Taught ourselves the internet usage, can now stay in touch with family overseas, pay bills, research.'

---

'Regular respite, information on stress management.'

---

'Awareness of all the help and support available.'

---

'Recovering from a breakdown and waking up to myself. This would not have happened without the actions of Carers SA workshops.'

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'information, knowledge of self care.'

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'More respite time.'

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‘Being able to keep up with my friends on respite days and Bowling Tuesday am and Thursday match day and mixing with the girls at the club.’

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‘More respite available when I would get overwhelmed.’

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‘Outings, respite, retreats.’

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‘Accessing respite, although I had marvellous support from CS&R. I am an only child so time was very precious - and my Mum did not attend many occasions /outings and we all ( my family) stayed home because of this.’

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‘Respite to be able to do things like exercise, fishing etc.’

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‘If we want to go on a holiday I would like it to be easier to get respite for a period more than a week. It is harder than pulling teeth.’

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‘Keep on getting carer help and respite without that life would be very stressful.’

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‘I am not sure. I need respite but when I have it I must not crowd it with all the tasks I ought to have done.’

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‘Having time to myself (retreats away)  
Day trip away.’

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‘Being able to have time out either for a couple of hours right through to weekly breaks. Retreats and pampering days and daily outings.’

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‘Someone to listen to my concerns.’

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‘Someone to talk to and listen and understand some of my frustrations. Just having someone listen and care would be nice. Don't like to burden family and friends with my woes. I can't help but wonder who will take care of me when I am sick.’

---

'A phone call at times as I get very lonely and miss being able to get in the car and choof off!'

---

'Phone contact with friends. Loneliness is an issue.'

---

'Chatting about 'chores' and trying to laugh about 'how things have changed' with friends.'

---

'Having someone to talk to who can appreciate your problems.'

---

'Discussions with a psychologist helped by advising me to do other pleasurable thing for myself each day and practicing deep breathing when feeling stressed.'

---

'To know that there is someone who cares and is willing to just listen or provide assistance when I need it.'

---

'Mostly my friends and my husband who has to listen to me carry on sometimes just my group for carers – Croatian.'

---

'Being involved with 'Carers Link' in the area I live. Maintaining friendships. Involvement with my hobbies. Trying to maintain self-image and esteem.'

---

'Support from those who understand my caring role and those who understand the effects of stroke.'

---

'I learned a lot from others in the Early Onset support group which I linked with on a regular basis. I had to look after myself otherwise I couldn't keep my husband at home. Learned to ask for help and to reach out to others, and to take time for myself. Massage at a pampering day for carers helped me realise how much stress i was bringing into my body and the importance of massage/exercise. Prayed a lot.'

---

'Support groups and good humour  
Good social support carer workers in the VWA.'

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'Support group is good (male). Council has assisted in improving our house environment, making it safer and providing an area we know our daughter is safe.'

---

'Faith.'

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'More time and ongoing employment.'

---

'More money.'

---

'Respite, transport, financial assistance and information.'

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'Good diet, caring medical help. Struggling to keep paying for health cover.'

---

'more time for myself.'

---

'Time out to relax, enjoy friends, having a sleep in.'

---

'A regular massage and time out!'

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'Time to read a book or two!'

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'Having more time to do the things I'd like to do not the things I have to do'

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'A holiday just for myself.'

---

'Time out while they are asleep.'

---

'Time out - shopping

volunteering

laughter therapy

Northern Carers Network - support groups - Salisbury Women's, stroke group.'

---

'Having me time and not feeling guilty about it.'

---

'more time off.'

---

'I try to keep walking and does some gym work. I have not kept up with friends other than carers.'

---

'I take the time to relax when my husband has a sleep in the afternoon or we will go for a short walk. At times I have taken him out in the wheelchair (not shopping) and we have just gone and sat somewhere in the park or elsewhere, just to get out of the house or go and have a coffee somewhere.'

---

'Massages. talking to friends would help. Every 3 months a couple of days away in a 'spa resort' getting pampered for free.'

---

'Massage/exercise specific to my needs medically, classes at Alwyndor very good for seniors but often full up.'

---

'Realisation that I needed time out to do something totally about me. Eg movies .Acknowledging that I can't do everything myself.'

---

'The odd massage and days out helps a lot.'

---

'Relaxation and massage sessions.'

---

'Ensuring I maintain exercise and fitness.'

---

'used to play bowls.'

---

'Eating well and keeping in good health.'

---

'Going for long walks.'

---

'We have developed shared interests that engage us and/or provide therapy, when physically able - painting, aqua aerobics, massage, continuing education (Holdfast Seniors College, Glenelg, singing, writing.'

---

'Take myself out and treating myself to things and have my nails done, being pampered once a month.'

---

'I think a little time could be spent concentrating on the information re carers self-worth ie Hair, skin and some small indulgence!'

---

'My volunteering duties.'

---

'Work.'

---

'Working. I love to be out helping others who can't help themselves.'

---

'Counselling, more respite, higher level care package (CACP, EACH)  
Support at work was really great. getting support from my family would have been helpful, but for them it was just all too hard, so I am angry with them now, so the stress of the role and their inaction has fractured family relationships significantly.'

---

'Having a retreat every year (if only locally for three days and a few pampering days. I would love to go away for longer (see family overseas) but know my husband would not want to go into respite. The other area is finance. Just won't happen but I can dream.'

---

'Having respite for a few hours or overnight just makes the world of difference to be being able to carry on caring. Just to be able to go to the doctors on my own, go out with friends or out to my exercise class.'

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'Anxiety Management has helped, this is a good course for Carers.  
Time out is the best even if it is to veg out on the lounge in front of the TV  
Time away with others.'

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'All my life I have always been involved in doing community work on a voluntary basis. I get personal satisfaction in helping others, especially the aged in our community.'

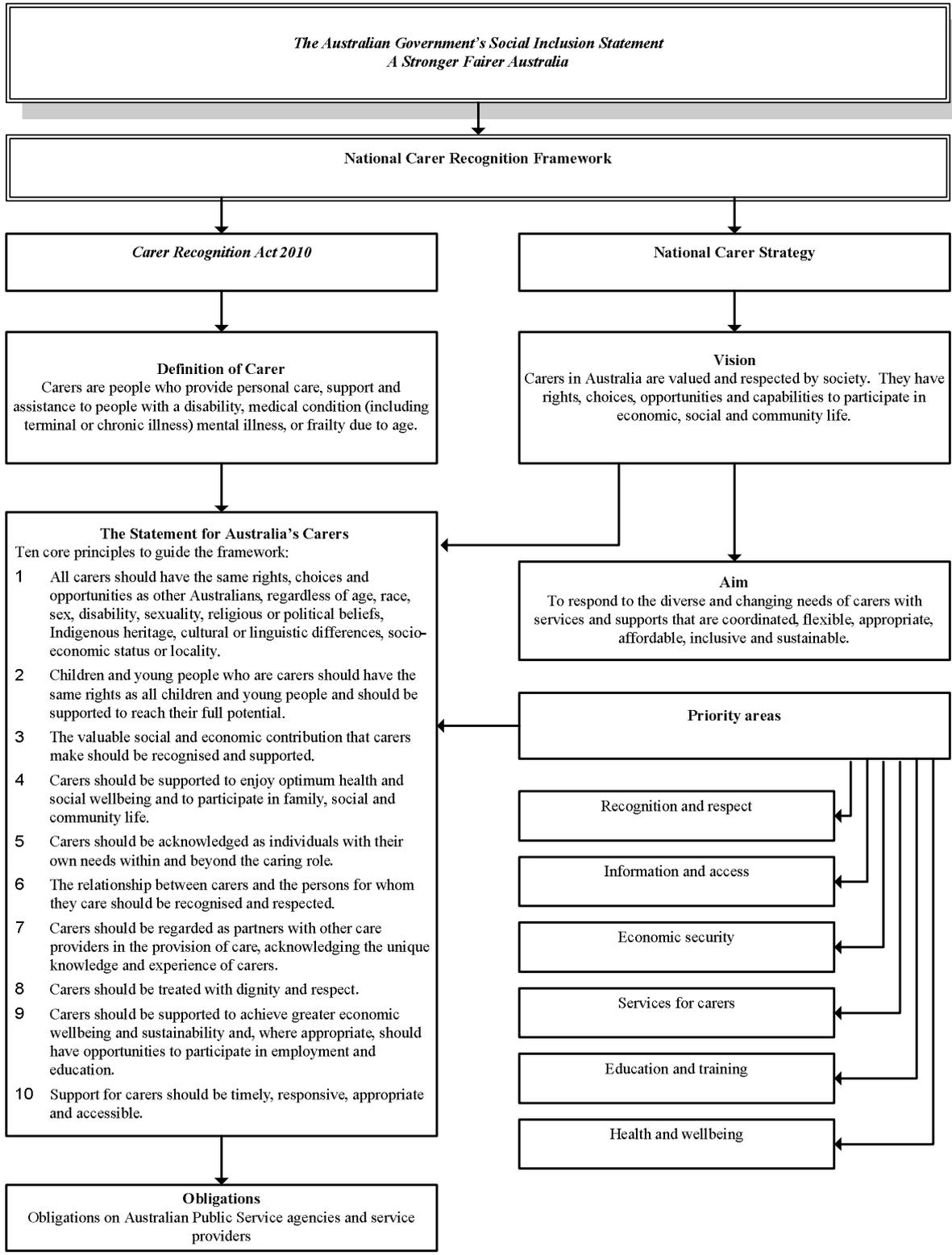
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'I now keep in touch with my sisters interstate with the phone, my bills are very expensive but it is worth it.'

---

'Coping with everything on my own. (e.g. gardening, attending doctors visits / prescriptions, shopping, respite transport). I appreciate the respite days and help of a gentleman who stays with my husband so I can play bowls. On respite days it allows me to catch up with my friends and catch up with keeping things under control.'

Appendix 5 The Australian Government's Social Inclusion Statement: A stronger fairer Australia



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