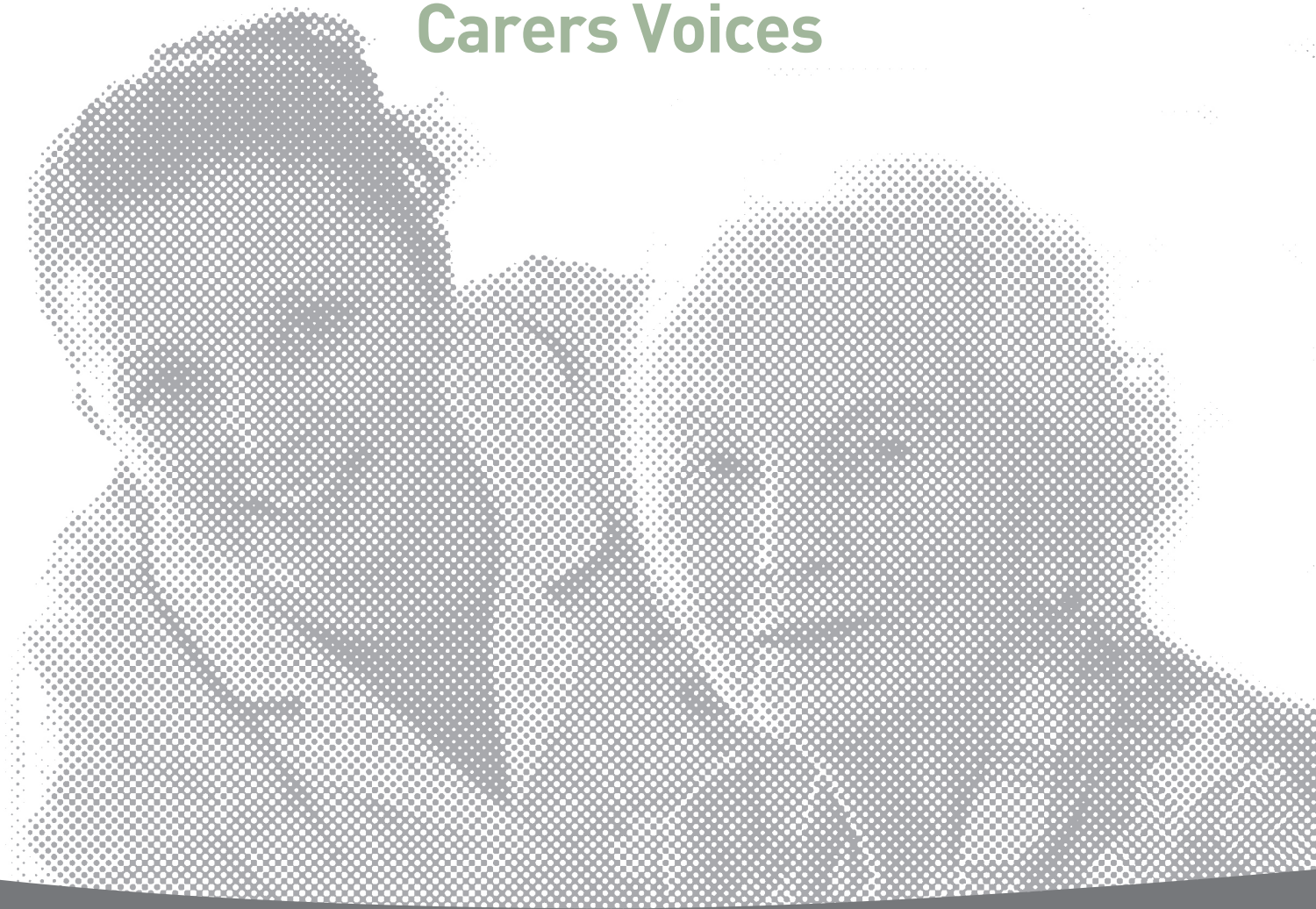
# Responding to Culturally and Linguistically Diverse Carers

## Carers Voices



**Project undertaken by**
**Multicultural Communities Council SA**
with consultants HOKJOK (Kristin Johansson and Helena Kyriazopoulos)

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MCCSA

Funded by Office for the Ageing
(Community Care Initiative Fund, Department for Families and Communities)

# FOREWORD

This consultancy is about giving carers a voice in the programs and services which affect them on a day to day basis in their caring role.

This report is about real people with real issues, and we hope this comes through clearly, however, to preserve people's privacy we agreed that all comments would be anonymous. For this reason, if we do refer to any individual, we do not directly refer to their nationality, language spoken, age or suburb.

At many of the community meetings we attended, one or more people were in tears, particularly when we asked what was hardest for them as a carer. Some people came to the meetings ready to speak and found it hard to wait until they could be heard. Many people expressed the hope that this project would lead to more help (and in some cases *any* help, as they currently receive nothing).

For some carers, simply getting to the meeting was a huge challenge, and they had to give up precious respite time to attend. For those who only have one outing a week, using it to attend a meeting was a huge commitment.

One carer who attended had not been on any kind of outing for two years. Caring for a family member who has had a stroke, this woman rushes between two households doing her best to keep both going. Most of her days are spent on personal care because of her relative's high needs. This carer was tired, emotional, glad to see people, and yet worried about the person she had left behind and how they were coping. Still grieving, whilst she wanted to speak, she was frequently in tears, and because of this and her language issues she found it hard to communicate. The community workers who know her story and stay in touch by phone spoke on her behalf. This woman was the first to leave that particular meeting.

Another carer only goes out one day a week when her husband can attend an ethno specific day care group. Our meeting was not on her day off, so she had to leave him at home in the kitchen and hope that he didn't have any '*accidents*' while she was out and that she would be '*lucky*'. Otherwise, she was going to have to clean the kitchen, the chair, wash everything

and bath him. She had tried continence products once but he wouldn't use them. When this elderly woman tried respite outings, the worker (who was considerably younger) refused to continue because the husband was too heavy to get into the car.

We are grateful to both these women and the many other carers who attended our meetings. We want to acknowledge the difficulty that some of them faced in attending, and the time and effort which many communities spent advertising the forums and assisting carers to attend. We have made every attempt to ensure that this report accurately and fairly portrays their concerns whilst still protecting their privacy.

Our thanks go as well to the many organisational stakeholders who participated in this review, with particular thanks to the members of our Advisory committee.

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# SECTION 1 EXECUTIVE SUMMARY

# EXECUTIVE SUMMARY

The SA Carers Policy, Carers Charter and Legislation form the basis of this project. The legislation enshrines the need for equitable service and resource provision. It states that it is "... *designed to ensure that carers are involved in the assessment, planning and delivery of services that impact on them and their caring role … Carers will be recognised as having a legitimate role with service providers as partners in the provision of care*".

The project's core aims are to give carers in culturally and linguistically diverse (CALD) communities a voice; to identify their needs; and to review current service responses to this sector. It also provided Office for The Ageing with information which would advise their HaCC funding priorities.

The project looked at the needs of carers in the following communities; Italian, Greek, Dutch, Vietnamese, Cambodian, Chinese, Latvian, German, Polish, Ukrainian, Hungarian, Jewish and Croatian.

Throughout the consultation process consideration has been given to identifying the most appropriate method of providing support to culturally diverse carers.

It is anticipated that the findings in this report will lead to more equitable funding arrangements for these communities.

The project methodology was based on a community development model which actively ensures that carers are involved in the assessment, planning and delivery of services that impact on them and their caring role.

An extensive consultation process was undertaken. Over 300 people attended the 20 ethno specific community meetings, 222 carer questionnaires were completed, 46 organisational stakeholders were spoken to either in individual interviews or at meetings.

The focus in the report has been on providing information in an easy to read format which will aid decsion making processes for funding and program design. For this reason the majority of the information has been tabulated or graphed so that prioirities can be easily determined.

Carers from all communities highlighted a range of issues that they found difficult to deal with. Some of the key areas were:

- emotional issues of caring
- tiredness and stress
- challenges with difficult behaviours

- the lack of community or family support
- language barriers
- the need for more respite
- the need for transport.

Many carers interviewed spoke of sheer exhaustion from caring, but would not relinquish their caring role. Carers believed that minimal intervention such as home support, Carer Allowance, carer education and group activities and just simply some respite and transport assistance would ease the burden of caring. For carers to be able to continue in their caring role these issues and others need to be addressed urgently by government and community agencies.

The process of undertaking this review and consulting carers in CALD communities has already generated a number of benefits:

- sharing of information amongst community workers
- sharing of information amongst carers attending the meetings
- increased information made available on the Carer Allowance in some communities
- establishment of a carer group in the Ukrainian community
- referrals for mental health assessments
- information on the Continence Allowance made available to two communities on request
- some carers who were not receiving assistance were sent for assessments
- carers assisted in accessing ethno specific EACH packages
- carers given details on how to access Centrelink information in their own language
- greater awareness amongst some attendees of the help which they could receive after feedback from community workers at meetings
- an opportunity for carers to be heard in a safe environment.

Carers throughout the consultation highlighted the value of receiving information, support and care in their own language as extremely important. From the questionnaire it was evident that both carers and carees levels of functional of English were quite low and this has implications for how services are delivered to CALD communities.

The range of respite issues varied from community to community and through the regional areas. Of the carers who completed the questionnaire only 27% of them indicated that they currently used respite. When all carers were asked what their preferred respite choice was, the three main ones were care at home with a carer who spoke the same language; ethno

specific community based respite; and respite for both the carer and caree at the same time. It is clear from the consultation that many carers were unclear that they were eligible for respite and that many had limited appropriate respite choices available to them.

Transport is a major issue for all communities both within the metropolitan and regional areas. For many carers they were not able to access carer support groups, and sometimes respite, as transport was not available. Many carers relied on family and friends, buses or taxis to undertake their caring duties. In one instance an elderly carer in the Riverland region, who lived outside the town, needed to walk four kilometres to buy medication.

There is a strong reliance on ethno specific agencies and bi-lingual and bi-cultural workers for providing carers and carees with the appropriate support. These agencies are not adequately resourced to do this. Some CALD communities which have been disadvantaged for over 10 years have continued to serve their ageing members on a shoe string budget. For some communities there are aged volunteers servicing the needs of the aged carer and caree. Workers with bi-lingual, bi-cultural competence are also not renumerated adequately for their skills. These community workers provide a complex and diverse range of services to carers, including assistance to help them overcome language barriers, access information/services, financial assistance and deal with a complex social system. Without these workers many carers would be extremely isolated and have limited support mechanisms.

It was clear that there needs to be an immediate injection of funds to redress the imbalance in these communities and enable the provision of adequate services.

The organisational stakeholders identified a number of key elements in a good carer support model. All stakeholders acknowledged that ethnic communities and bi-lingual, bi-cultural workers are essential elements in the delivery of CALD carer support. All respondents highlighted the exceptional work that many ethno specific communities were undertaking with their communities. They also believed that carers/communities needed to be involved in the planning of services. It was also recognised that for many ethnic communities they could not do it alone. The importance and value of appropriate collaborations and partnerships, not only with mainstream agencies but with other ethno specific communities was highlighted as was the inclusion of respite and transport in any good carer support.

It is anticipated that the following fifteen recommendations will assist CALD carers and ethno specific community groups better meet their needs. It is recommended that these be implemented as a matter of urgency and that consideration be given at a later date to the less significant issues highlighted in this report. A formal evaluation during the final stages of this funding round is considered essential, both to highlight lessons learned from implementing these recommendations and to determine whether these are satisfactorily addressing carer support needs. With each specific community, particularly the smaller ones

it needs to be born in mind that some communities will reach the end of their life cycle over the next two decades.

During the consultations Centrelink issues were raised numerous times and at the request of OFTA these contributions on Australian Government issues have been included in the Appendix. In addition the carer questionnaire and the tables on what carers find the hardest include relevant information on income support and the use of residential respite. The low uptake of residential respite by CALD carers and their high unmet respite demands for other forms of respite suggest that this may be a useful area to be explored by both the State and Australian Government to find new funding mechanisms for respite. It was also clear in stakeholder discussions that many organizations are looking for maximum flexibility in packaging State and Federal funding to improve outcomes for their clients.

## RECOMMENDATIONS

1. CALD carer support programs need to be supported by a flexible approach which includes flexible respite and funding for transport.

2. Increase in basic HACC services such as cleaning, home maintenance, one-off spring cleans to be provided for all CALD carers in a flexible manner with priority being given to carers who are at risk.

3. Support carers through the development and implementation of carer education programs covering the range of carer issues which CALD carers face on a day to day basis with a particular emphasis on manual handling, dealing with continence problems, caring for a person with dementia, caring for people with complex health needs, dealing with challenging behaviour, carers wellbeing and how to access appropriate support.

4. For HACC to support carers by providing specific funding to ethno specific organisations in metropolitan Adelaide and Multicultural organisations servicing regional South Australia to enable them to educate carers about relevant subsidies, allowances and programs and to assist them where necessary in accessing the full range of assistance to which they are entitled.

5. Where carers are unable or unwilling to access support services, (for instance the provision of at home respite by mainstream providers), provide direct funding (in limited cases) to carers to enable them to buy in appropriate support.

6. For HACC to develop and fund an appropriate ongoing, carer awareness program for CALD communities which is delivered through the information channels most preferred by CALD carers.

7. For HACC to increase direct funding to CALD communities/ethno specific agencies to expand current or implement new carer support services and build the capacity of the communities to support their carers in a flexible manner taking into consideration cultural and linguistic needs.

8. Increase remuneration, training and support for bi-lingual, bi-cultural workers who are delivering a complex and diverse range of culturally and linguistically appropriate services.

9. For the OFTA CALD team to initiate and lead opportunities for carer support workers to meet six monthly to share information, develop skills, strengthen networks and plan shared activities.

10. For HACC to provide funding to organisations which have demonstrated a capacity to effectively support and mentor ethno specific organisations to, build capacity and, where appropriate, deliver complementary services including training, general information, carer support, respite and key worker mentoring.

11. For HACC to fund where necessary, specific Access and Equity positions within core mainstream and multicultural agencies and larger ethno specific community organisations that can build and strengthen collaborations and partnerships ; act as a bridge to ethno specific communities; develop networks and culturally and linguistically appropriate services targeting priority communities.

12. For HACC to provide funding for dedicated multicultural workers in key rural centres, and adequately resource them to build capacity at the regional level, and form appropriate links with all relevant metropolitan organisations, so that appropriate carer support services can be provided to regional South Australia,

13. For HACC to review funding arrangements with all agencies that have a responsibility to deliver services to all carers (including CALD carers) to ensure that, at a minimum, a pro rata percentage of their funding is spent on the provision of services for CALD carers. Where this does not occur consideration should be given to redirecting the funding to other organisations.

14. At the end of the second year of the triennial funding undertake a formal evaluation of work undertaken by HACC in relation to CALD carers and CALD carer support services over the intervening period.

15. During this round of triennial funding identify other CALD communities which are ageing and have carer support needs, for instance the Filipino community.

# SECTION 2 PROJECT OVERVIEW

## SECTION 2:1 PROJECT OUTLINE

The SA Carers Policy Charter and Legislation forms the basis of this project. This legislation enshrines the need for equitable service and resource provision. It states that it is "*... designed to ensure that carers are involved in the assessment, planning and delivery of services that impact on them and their caring role … Carers will be recognised as having a legitimate role with service providers as partners in the provision of care*".

The project's core aims are to give carers in culturally and linguistically diverse (CALD) communities a voice; to identify their needs; and to review current service responses to carers from culturally and linguistically diverse backgrounds.

The designated target groups for this project were carers in the following communities: Italian, Greek, Dutch, Vietnamese, Cambodian, Chinese, Latvian, German and Polish. The project was extended to four additional groups: Ukrainian, Hungarian, Jewish and Croatian because:

- they all receive HaCC funding for Aged/Volunteer projects
- their populations fall predominantly within the Aged Community.

Previous planned responses to the care needs of the above communities have not usually included responses to carers, and preliminary consultations by Office for the Ageing (OFTA) indicated that carers' support services require immediate development and need to be specifically tailored to meet the individual communities' needs. Throughout the consultation process consideration has been given to identifying the most appropriate method of providing support to culturally diverse carers.

It is anticipated that the findings in this report will lead to more equitable funding arrangements for these communities.

## SECTION2:2 METHODOLOGY

The project methodology was based on a community development model which actively ensures that carers are involved in the assessment, planning and delivery of services that impact on them and their caring role.

An extensive consultation process was undertaken. This included:

- focus interviews
- a range of stakeholder meetings
- five advisory group meetings
- ethno specific meetings with carers in metropolitan Adelaide and Whyalla, Mt Gambier and Renmark
- a 30 item carer questionnaire
- an organisational stakeholder questionnaire
- a forum with ethno specific organisational stakeholders
- regular meetings with Office for the Ageing (OFTA).

Community meetings were advertised in a variety of ways, dependent on the community, by radio segments, flyers, newsletter articles and direct contact from community workers.

The focus in the report has been on providing information in an an easy to read format which will aid decision making processes for funding and program design. For this reason the majority of the information has been tabulated or graphed so that priorities can be easily determined.

The carer questionnaire results provide all key results in graphs with a limited amount of text. There were 222 questionnaire responses from 212 carers (10 carers cared for more than one person). The information referring to demographic characteristics of carers, income, etc has been adjusted to avoid counting twice.

The community carer tables give the breadth of issues within communities. The number of sub issues associated with core issues and the more detailed tables give an indication of the

complexity of the issues communities are facing. The text on ‘carers’ voices’ highlights particular themes we felt needed attention drawn to them, either because of the frequency of their occurrence or because carers were at higher risk.

The tables on how carers access information provide a useful overview for future communications with these communities.

In total 46 organisational stakeholders were spoken to directly either in individual interviews or at group meetings. The stakeholder questionnaire was sent to a broad regional and metropolitan mix of fifty organisations.

## SECTION 2:3 PROJECT BENEFITS TO DATE

The process of undertaking this review and consulting carers in CALD communities has already generated a number of benefits:

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- an opportunity for carers to be heard in a safe environment.

# SECTION 3 CALD CARERS HAVE THEIR SAY

## SECTION 3:1 CARER QUESTIONNAIRE RESULTS

### NOTES ON RESULTS

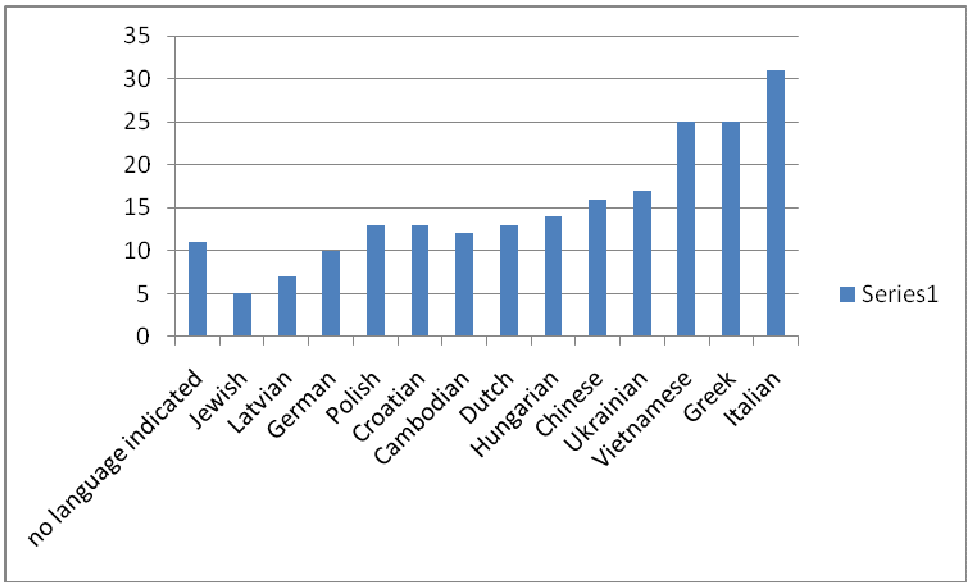
A 30 item questionnaire was administered to carers at the community meetings in metropolitan and regional meetings. (see Appendix: Carer Questionnaire). In addition some carers completed the questionnaires outside of these meetings and they were forwarded to the consultants.

In total 222 questionnaire responses were received from 212 carers. Responses from relinquished carers have not been included. Ten carers were carers of two or more people and completed multiple questionnaires. Where appropriate data has been adjusted to ensure nothing has been counted twice.

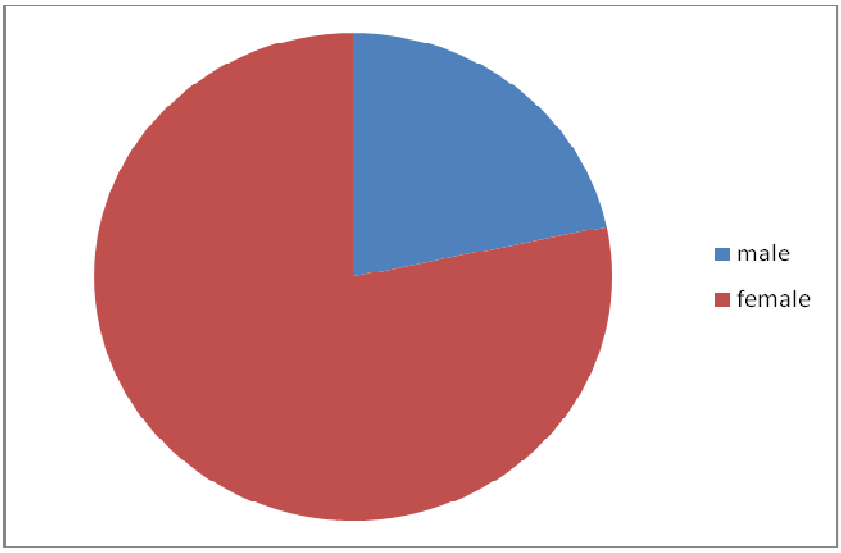
The response to question 7 was excluded from analysis because it was clear from looking at the data that some people had misinterpreted this question and were referring to time spent in the caring role rather than time spent working (in paid or volunteer work) or studying.

If a particular question had no responses from one or more of the participants and this affected the interpretation of the data, this has been noted.

### FIGURE 1: NUMBER OF CARERS WHO RESPONDED FROM EACH COMMUNITY

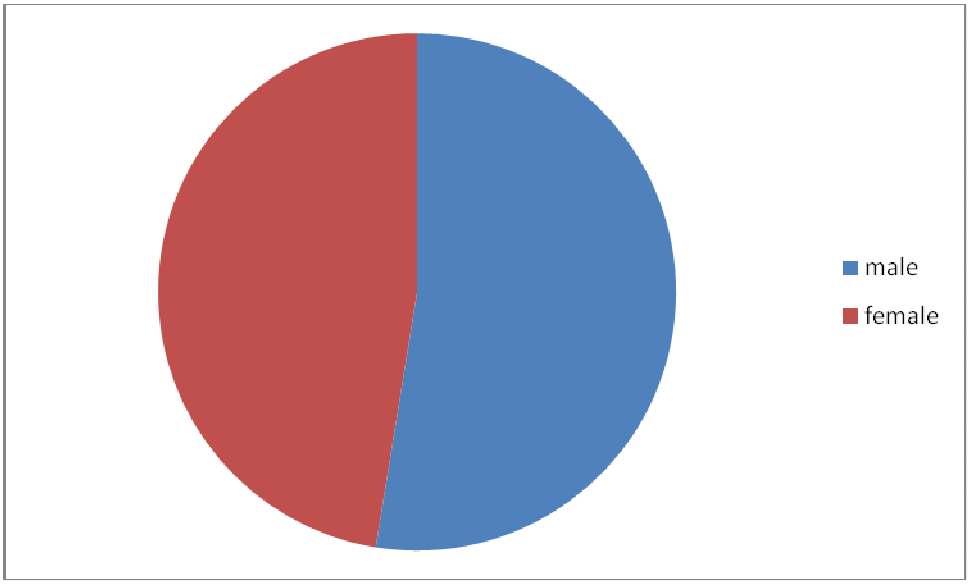


## FIGURE 2: CARER GENDER



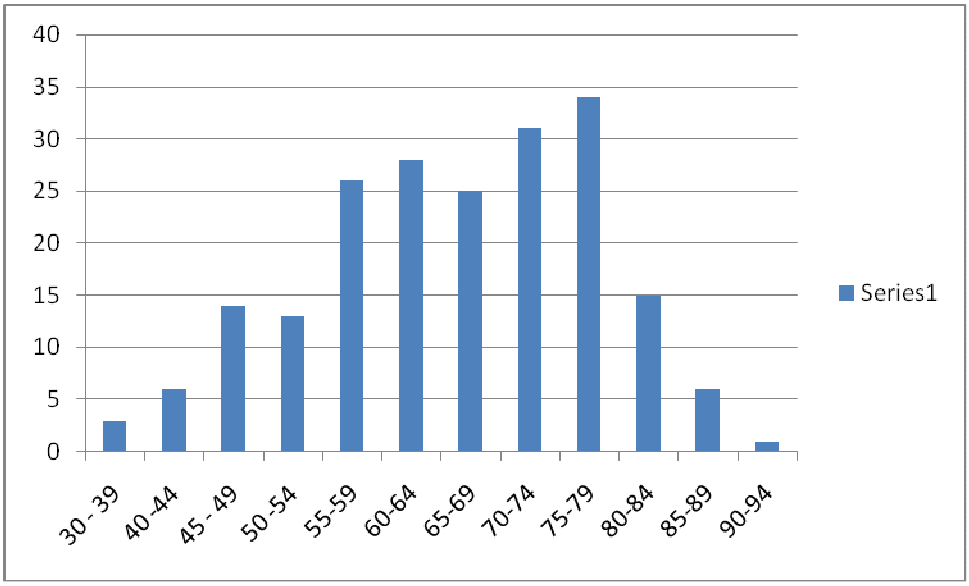

Carers were predominantly female, with 78% (165) female carers and 22 % (46) male carers. One carer did not nominate gender.

## FIGURE 3: CAREE GENDER



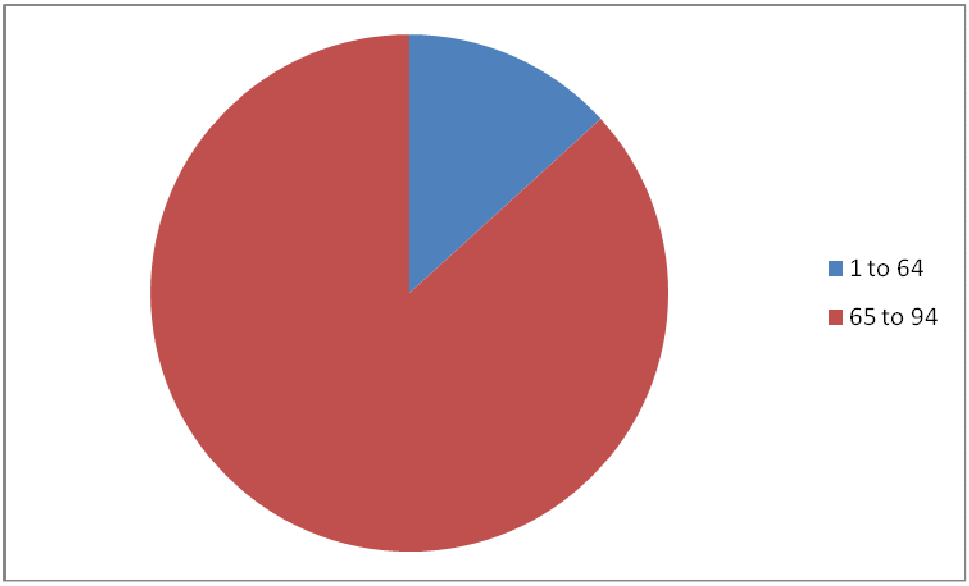

There were approximately even numbers of male and female carees, with slightly more men.

## FIGURE 4: AGE OF CARERS



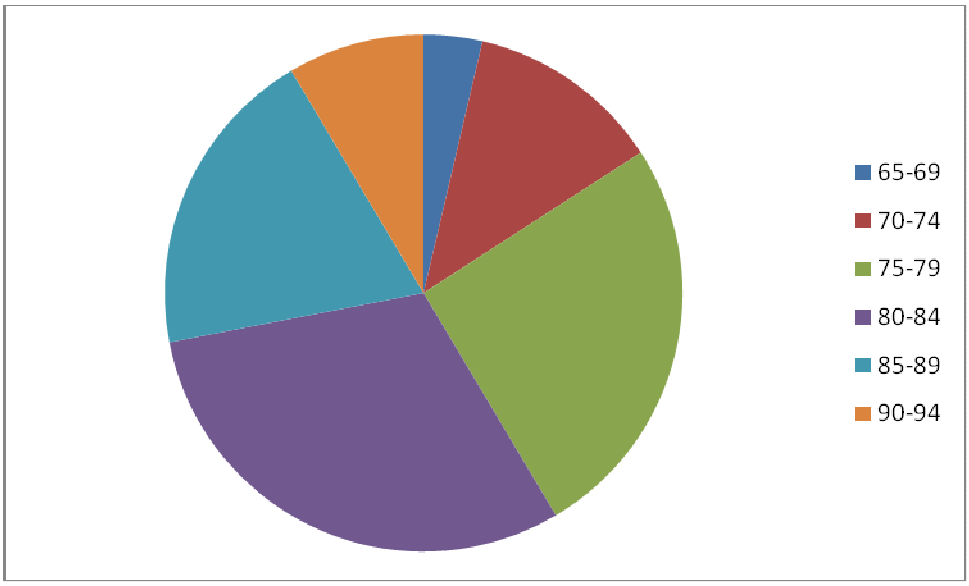

Only 191 carers nominated their age. Average age of the 191 carers was 69 years, 112 were aged 65 and over. The average age of 65+ carers was 74. Twenty two carers were aged 80 and over.

## FIGURE 5: AGE OF CAREES



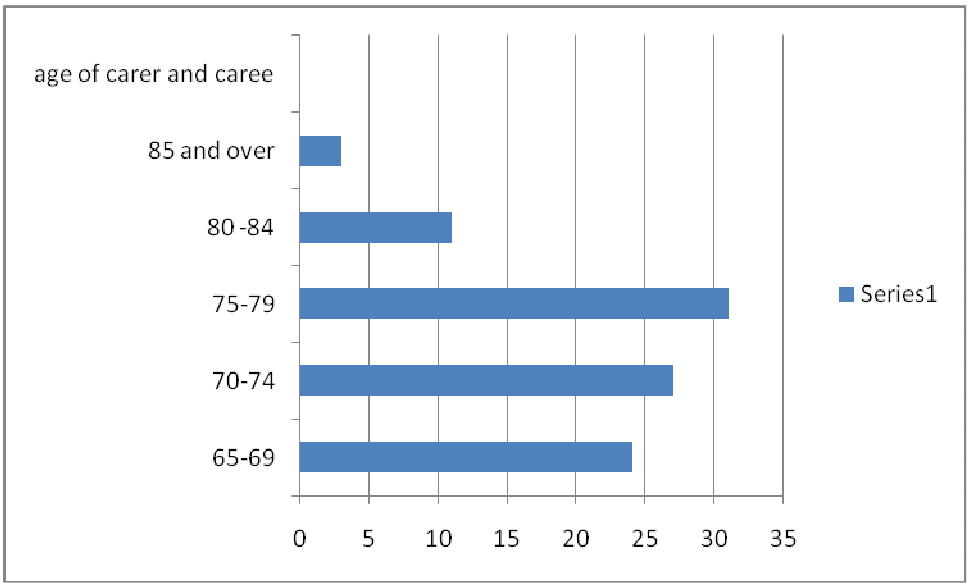

There were 189 responses and 33 did not respond to this question. Eighty seven percent of carees (164) who responded were aged 65 and over. Of those in this age range 50% were aged 80 and over.

FIGURE 6:1 ELDERLY LOOKING AFTER THE ELDERLY




There were 92 carers (44%) aged 65 and over caring for carees who were also aged 65 and over. The average of these carers was 74 and four cared for more than one person. The average age of those they care for was 79.

FIGURE 6:2 ELDERLY LOOKING AFTER THE ELDERLY




In 92 cases both the carer and the caree were aged 65 and over.

The ten carers in this category came from the following communities: Cambodian, Dutch, Greek, Italian and Ukrainian. Eight were female and two were male. Their ages ranged between 34 and 77, with 4 carers aged 65 and over.

Four carers said that their caring role was 24/7 and five said it was twenty hours or less. Four drove themselves, three used family and friends and three caught buses or taxis. Only one carer in this group did any paid work, however, four said they did volunteer work.

All of them spoke the same language as the carees. Three of these carees were unable to write English and three could only read limited English. They were the sole carer in eleven instances, and in four instances they shared the load with other carers for one of their carees. Only three carers said that they used any respite, and in two of these instances the respite was provided by family members.

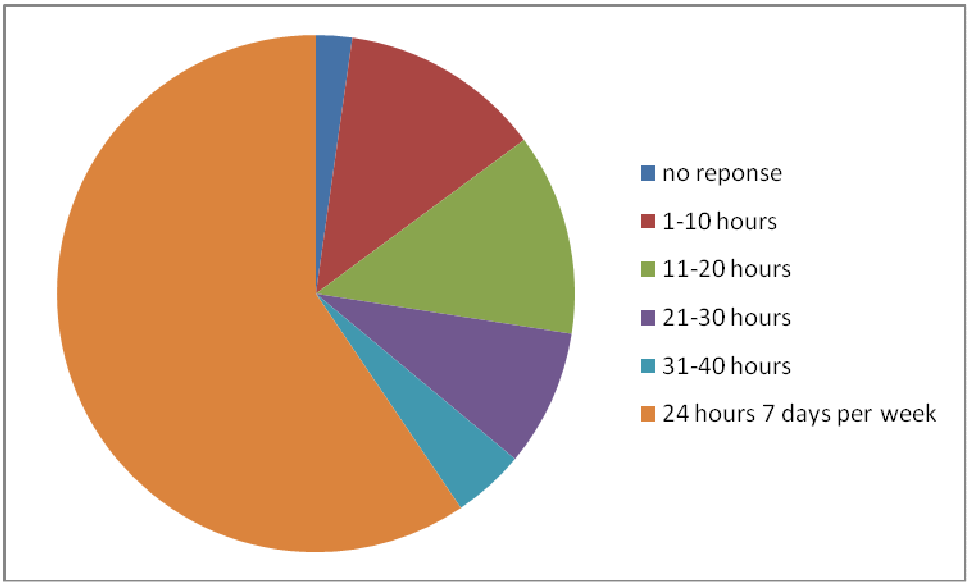
Only three carers received the Carer Allowance and four received the Australian Pension. Fifty percent of them indicated that they received assistance in caring from paid helpers and fifty percent also said they had assistance from family. One carer said she received no assistance and had no one to turn to for help. The following were only nominated once: friends, community and organization.

Six said that when they wanted to talk to someone they would turn to family, five said their doctor and four said their friends. Community worker and social worker were each nominated once.

Fifty percent said they participated in most of the social activities listed, two indicated no participation, two only participated in community functions and one nominated church functions as their social activity.

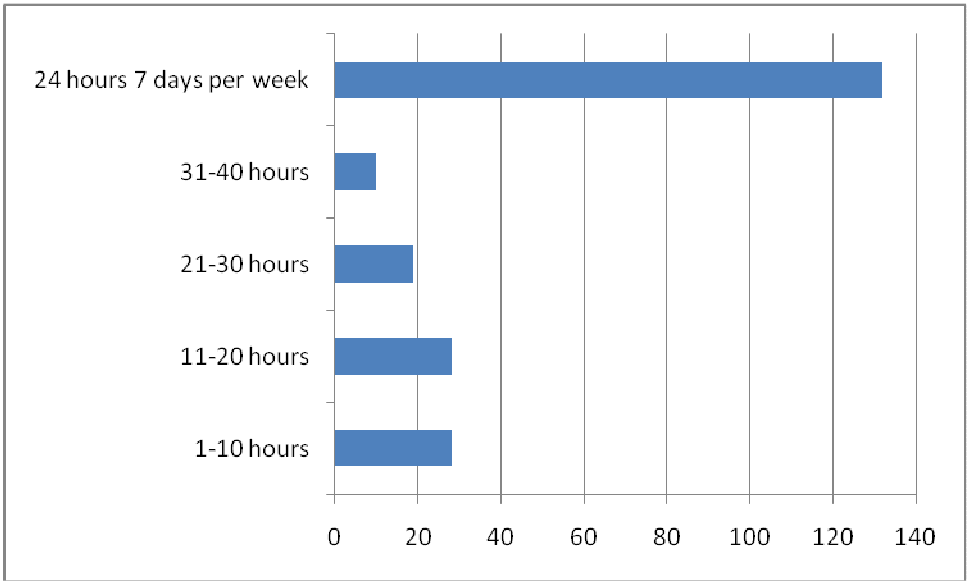
Six of the carers had a plan in place in case of emergencies or accidents.

## FIGURE 7:1 HOURS SPENT CARING



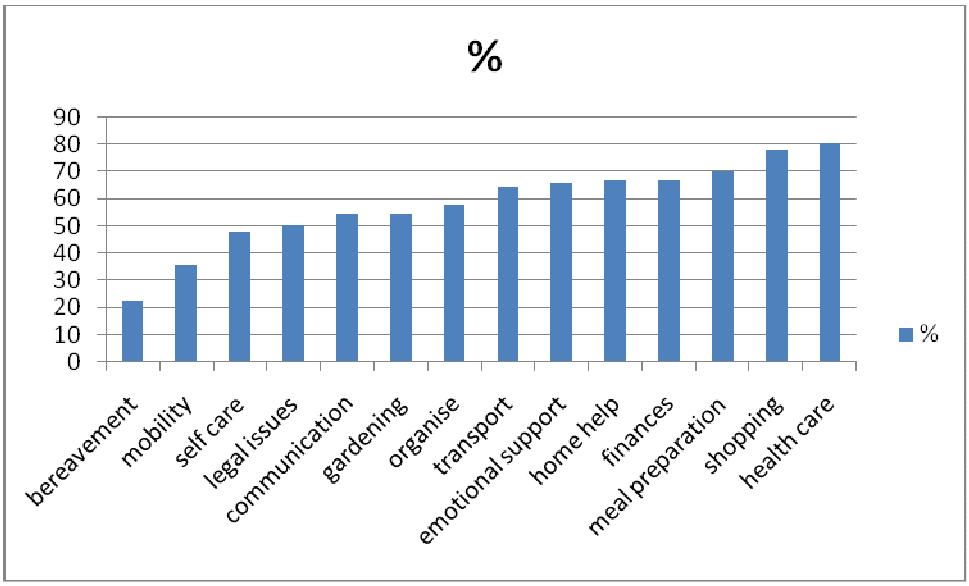

Nearly sixty percent of carers said their caring role was24/7 and 72.6 % said they spent 20 hours or more per week caring.

## FIGURE 7:2 HOURS SPENT CARING




Of the 132 carers who said that they care 24/7, 112 also said they were sole carers and 35 of these sole carers are caring for people with dementia.

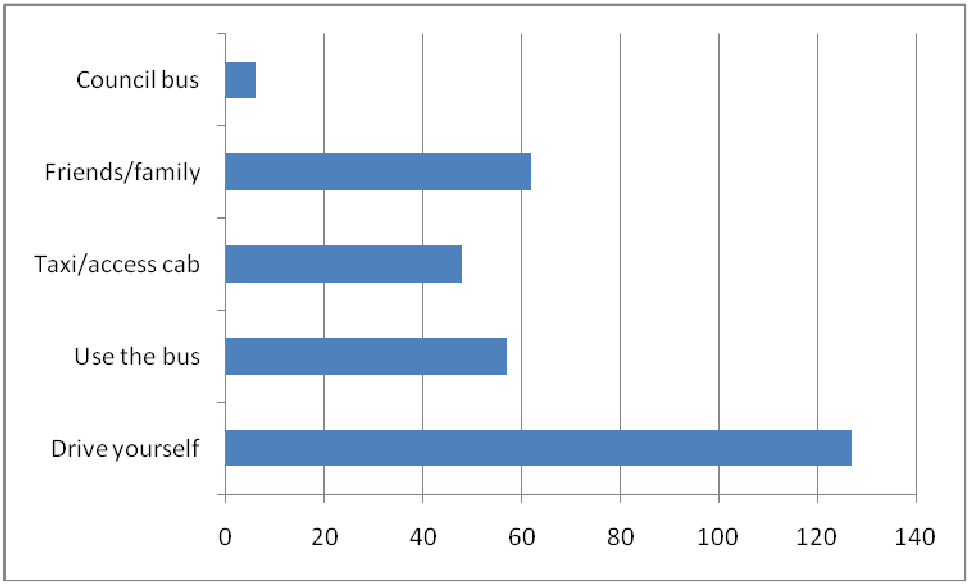
## FIGURE 8 ACTIVITIES WHICH CARERS SAID THEY HELP CAREES WITH




## OTHER WORK

Relatively low numbers of the carers who responded said that they worked: 41 carers do paid work and 61 do volunteer work.

## FIGURE 9 TRANSPORT USED BY CARERS




Some carers nominated more than one transport option.

## FIGURE 10 CARERS' ENGLISH SKILLS

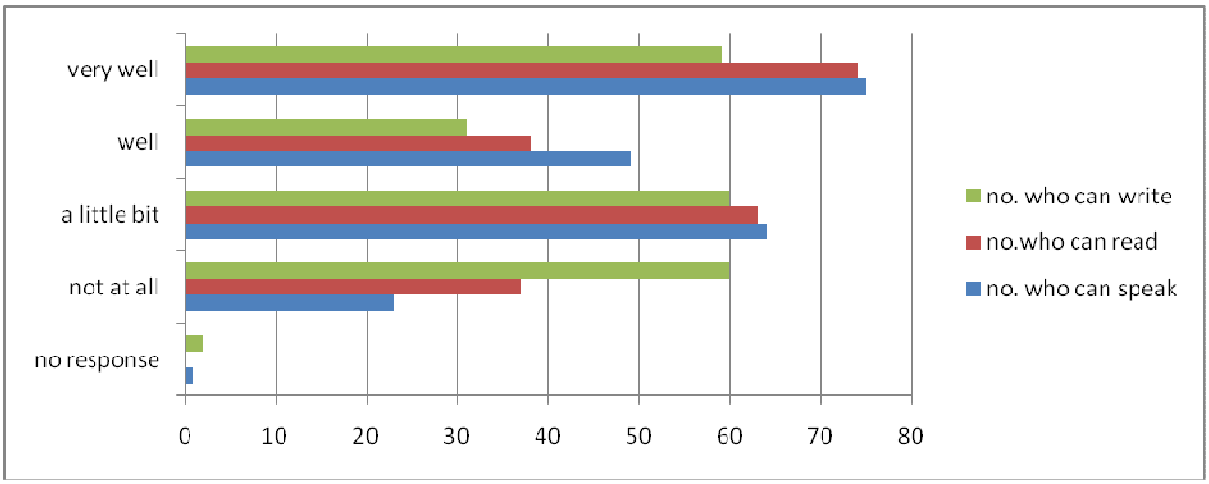


FIGURE 11 CAREES' ENGLISH SKILLS

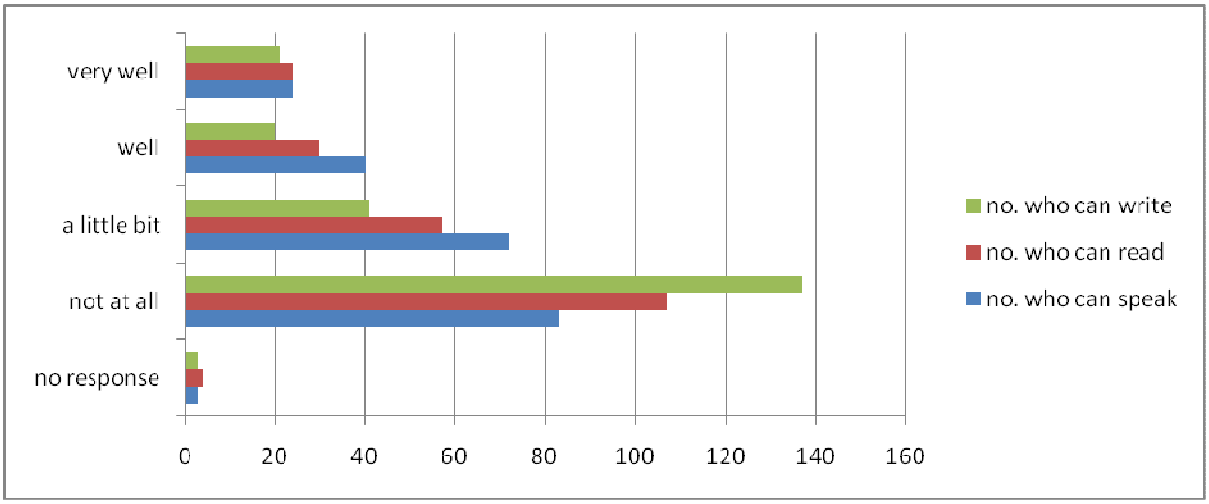
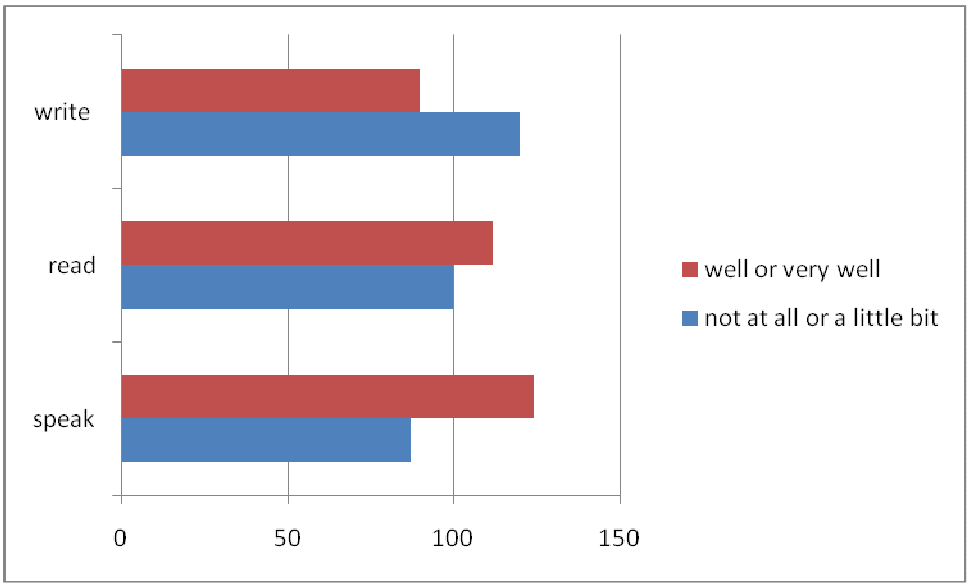
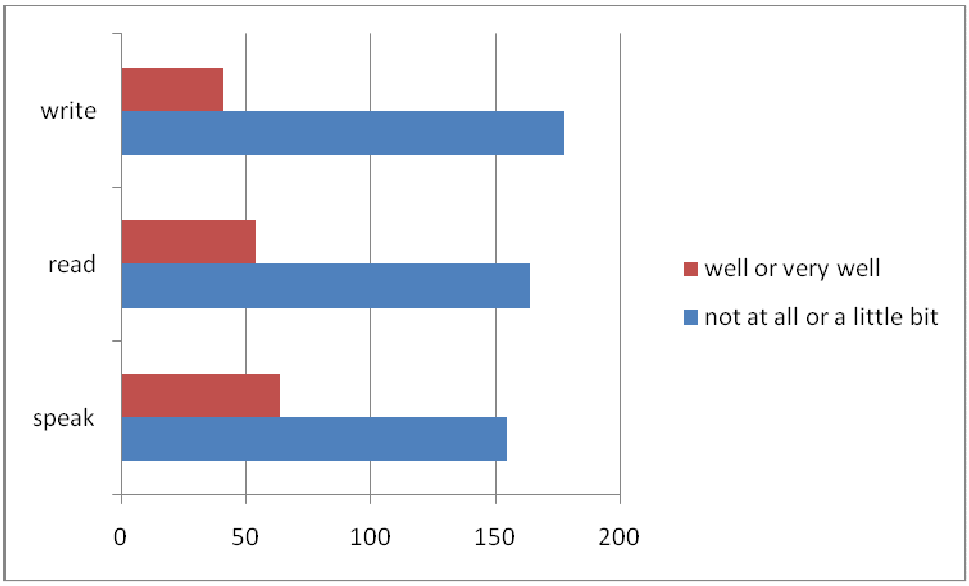



FIGURE 12 CARERS' FUNCTIONAL LEVELS OF ENGLISH




This indicates that a significant number of CALD carers face some difficulties speaking, reading or writing English. (**This has implications for how information and services are delivered).**

## FIGURE 13 CAREES' FUNCTIONAL LEVELS OF ENGLISH




Seventy percent of carees can only speak English 'a little bit or not at all' and 37% of carees cannot speak any English. **(This has significant implications for respite).**

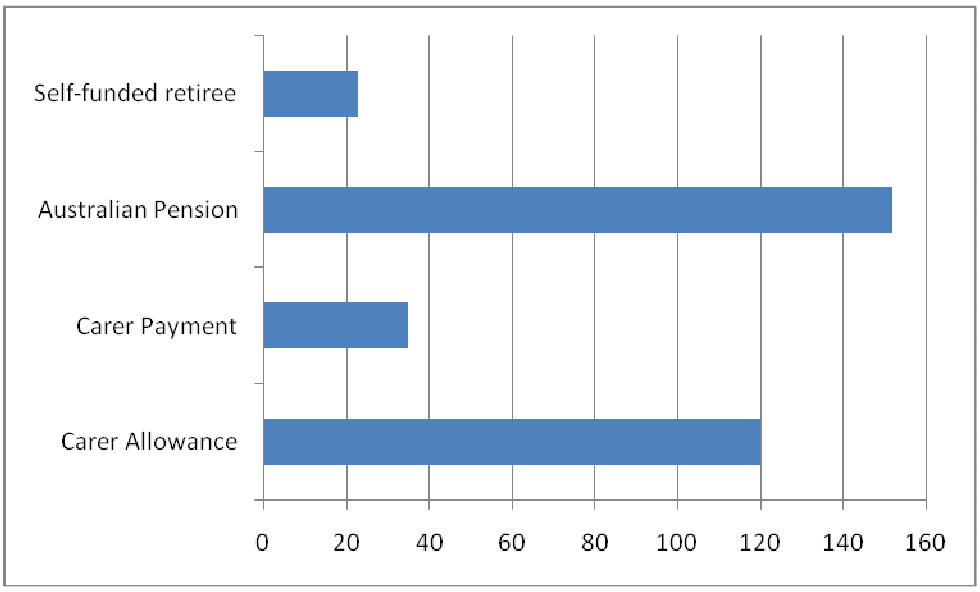
## LANGUAGE COMPATIBILITY OF CARER AND CAREE

The majority of carers (97%) spoke the same language as the caree.

## RESIDENCY STATUS

Ninety eight percent of carees either are permanent residents or Australian citizens.

## FIGURE 14 CARERS' INCOME SOURCES

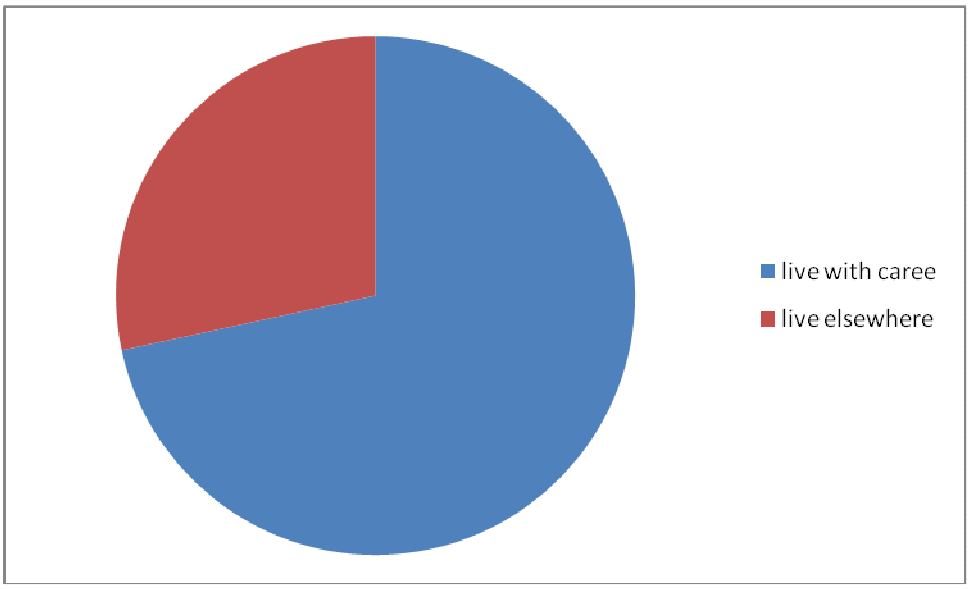



The Carer Allowance was received by 57% of carers while 16% were receiving a Carer Payment and 72% an Australian pension.

## FIGURE 15 GEOGRAPHIC LOCATION OF CARERS AND CAREES

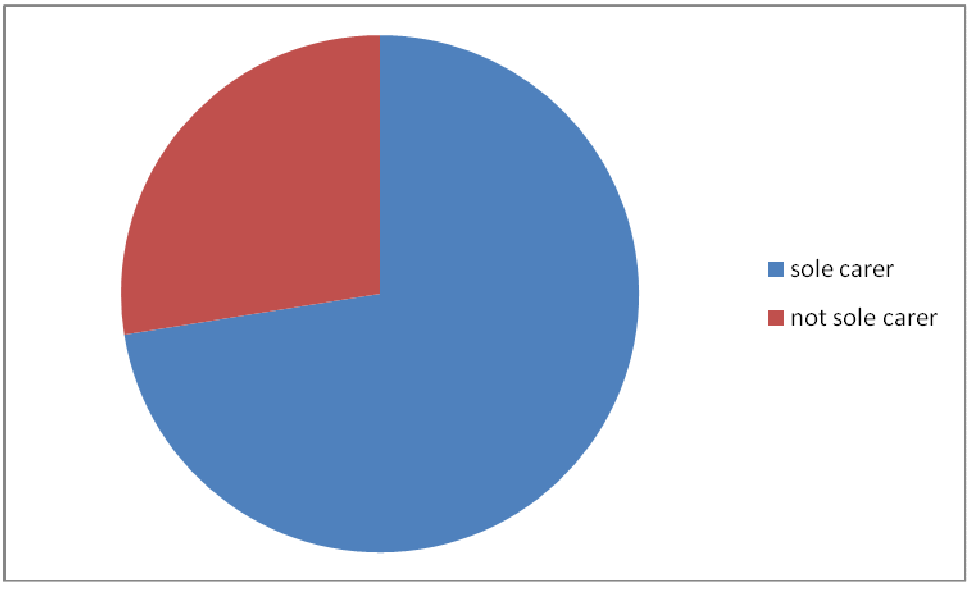
| Postcode | No. of Carers | No. of Carees | Postcode | No.of Carers | No. of Carees | Postcode | No. of Carers | No. of Carees |
|---|---|---|---|---|---|---|---|---|
| 5007 | 2 | 3 | 5043 | 6 | 7 | 5091 | 0 | 1 |
| 5008 | 3 | 4 | 5045 | 7 | 7 | 5092 | 2 | 3 |
| 5009 | 2 | 2 | 5047 | 0 | 1 | 5093 | 4 | 3 |
| 5010 | 7 | 7 | 5049 | 1 | 0 | 5095 | 7 | 7 |
| 5011 | 2 | 2 | 5051 | 1 | 0 | 5107 | 3 | 4 |
| 5012 | 5 | 5 | 5052 | 2 | 1 | 5108 | 7 | 8 |
| 5013 | 4 | 5 | 5063 | 2 | 1 | 5109 | 3 | 7 |
| 5014 | 1 | 6 | 5064 | 1 | 1 | 5112 | 1 | 1 |
| 5015 | 1 | 0 | 5065 | 2 | 1 | 5113 | 1 | 2 |
| 5016 | 1 | 1 | 5066 | 2 | 2 | 5114 | 1 | 0 |
| 5017 | 1 | 1 | 5067 | 4 | 4 | 5125 | 2 | 1 |
| 5019 | 1 | 1 | 5068 | 0 | 1 | 5158 | 1 | 1 |
| 5022 | 2 | 1 | 5069 | 2 | 2 | 5159 | 4 | 2 |
| 5023 | 12 | 12 | 5070 | 6 | 6 | 5161 | 0 | 1 |
| 5024 | 1 | 2 | 5072 | 1 | 3 | 5162 | 1 | 0 |
| 5031 | 5 | 8 | 5073 | 4 | 3 | 5234 | 1 | 0 |
| 5032 | 6 | 4 | 5074 | 3 | 3 | 5280 | 1 | 1 |
| 5033 | 1 | 1 | 5076 | 1 | 1 | 5290 | 3 | 4 |
| 5034 | 2 | 2 | 5082 | 3 | 4 | 5341 | 6 | 6 |
| 5035 | 1 | 2 | 5083 | 0 | 2 | 5342 | 1 | 1 |
| 5037 | 4 | 2 | 5084 | 6 | 6 | 5343 | 1 | 1 |
| 5038 | 3 | 3 | 5085 | 8 | 6 | 5345 | 1 | 1 |
| 5039 | 2 | 2 | 5086 | 6 | 7 | 5600 | 12 | 13 |
| 5040 | 2 | 1 | 5087 | 3 | 2 | 5608 | 6 | 5 |
| 5042 | 1 | 1 | 5088 | 1 | 1 | 5621 | 0 | 1 |

## FIGURE 16 CO-LOCATION OF CAREE WITH CARER



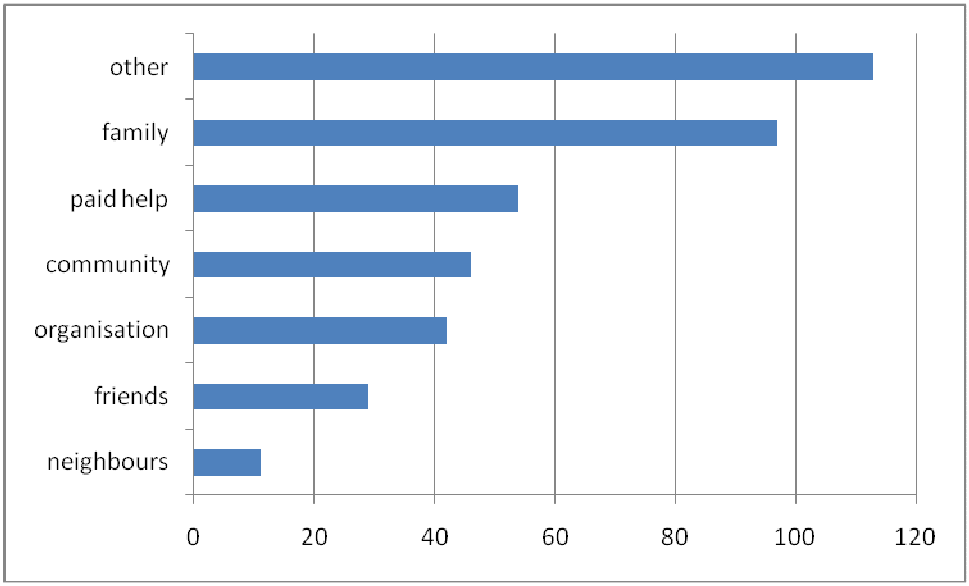

Seventy two percent of carers (159) said that they live with the person that they are caring for.

## FIGURE 17 SOLE CARERS




Seventy one percent of carers (158) said that they are the sole carer for that particular caree.

## FIGURE 18 SOURCES OF ASSISTANCE IN CARING

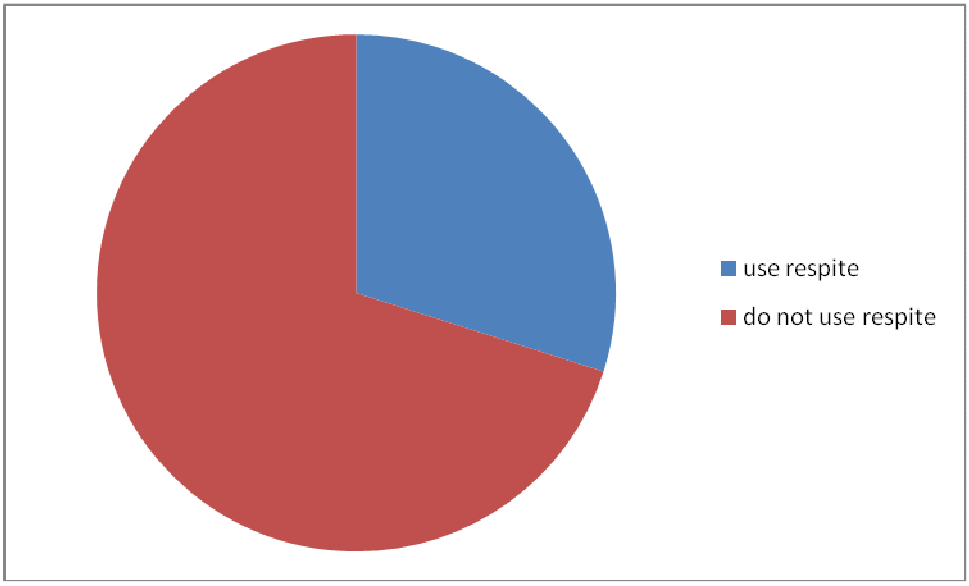



There appears to have been some misunderstanding with this question.

From some of the notes written on the questionnaires it appears that some carers may not have understood the term 'organisation' and used 'other' to cover organisations such as ACH or Metropolitan Domiciliary Care etc. and possibly some community organisations.

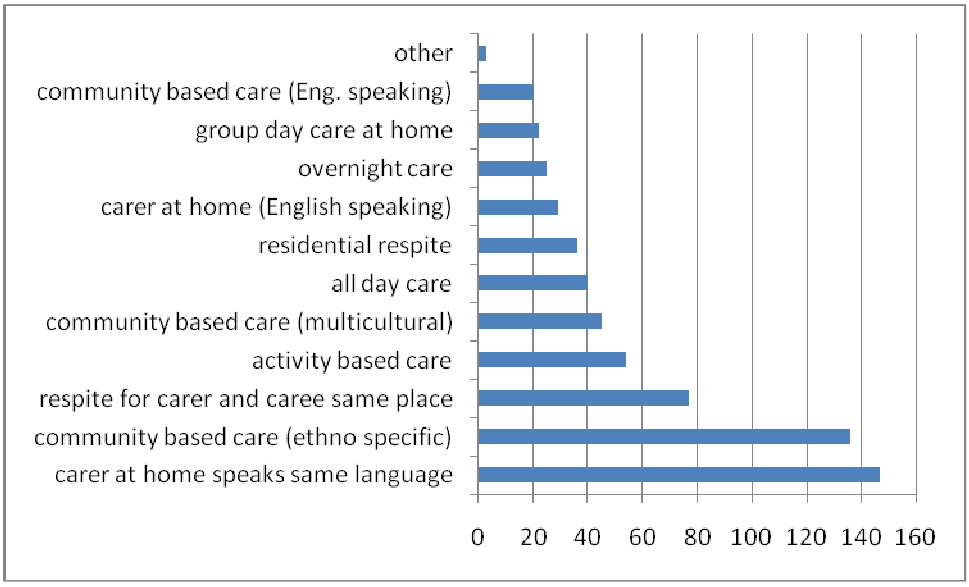
Some carers noted during the forums that they receive assistance from their church and from volunteers.

FIGURE 19 CURRENT USE OF RESPITE SERVICES



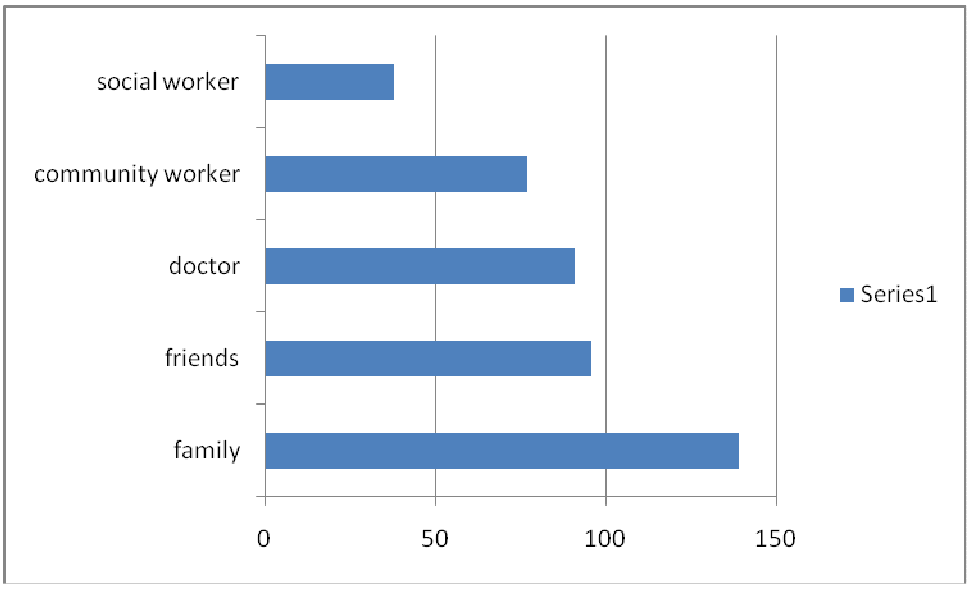

Seventeen carers did not respond to this question, which may indicate their unfamiliarity with the term ‘respite’. Of the respondents, only 61 (27%) currently use respite services.

## FIGURE 20 PREFERRED RESPITE CHOICES




On a ranking scale of 1 to 5 (where 5 is most preferred) the data above represents choices 4 and 5 as the 'preferred choice'. The two most popular choices are home or community respite with a carer who speaks the same language.

## FIGURE 21 CARERS' SUPPORT NETWORKS




Family was the greatest source of support when carers needed to speak to someone.

In several instances, when they had no family in Australia carers mentioned regularly calling relatives overseas.

FIGURE 22 CARERS' PARTICIPATION IN SOCIAL ACTIVITIES

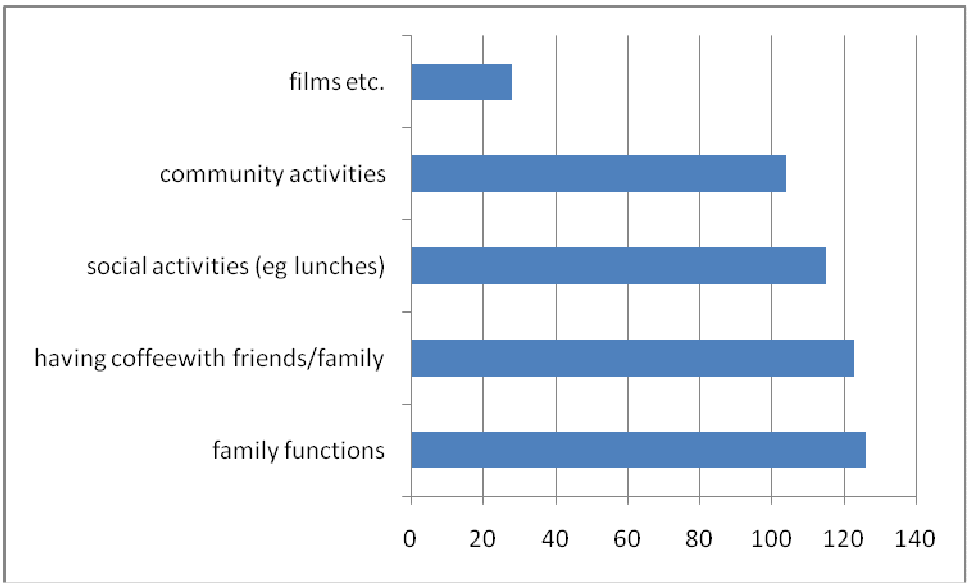
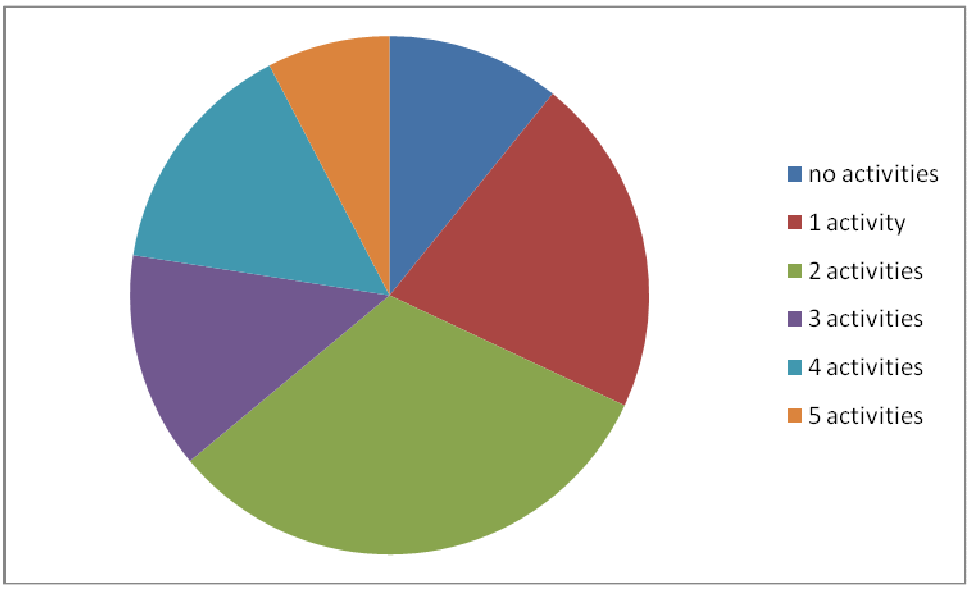
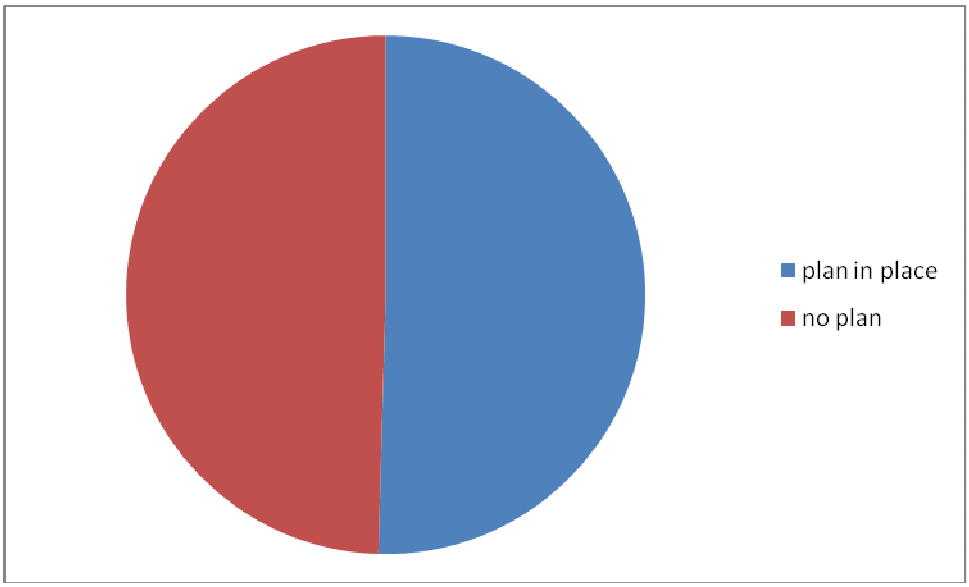



FIGURE 23 NUMBER OF SOCIAL ACTIVITIES WHICH CARERS PARTICIPATED IN



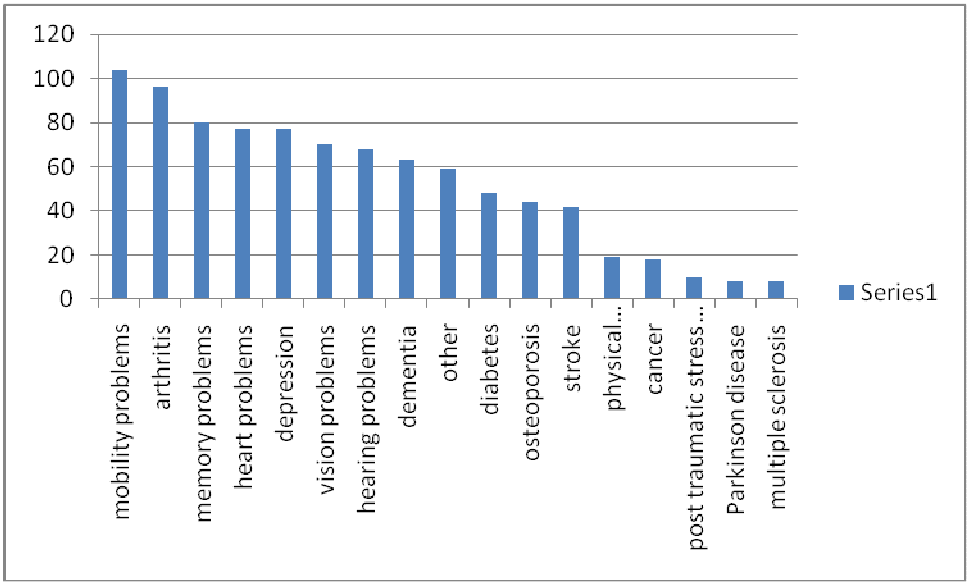

Thirty two percent of carers nominated two of the activities listed above which they participated in. Eleven percent of carers said that they did not participate in any of these activities.

FIGURE 24 EMERGENCY PLAN IN CASE OF ILLNESS, ACCIDENT OR EMERGENCY



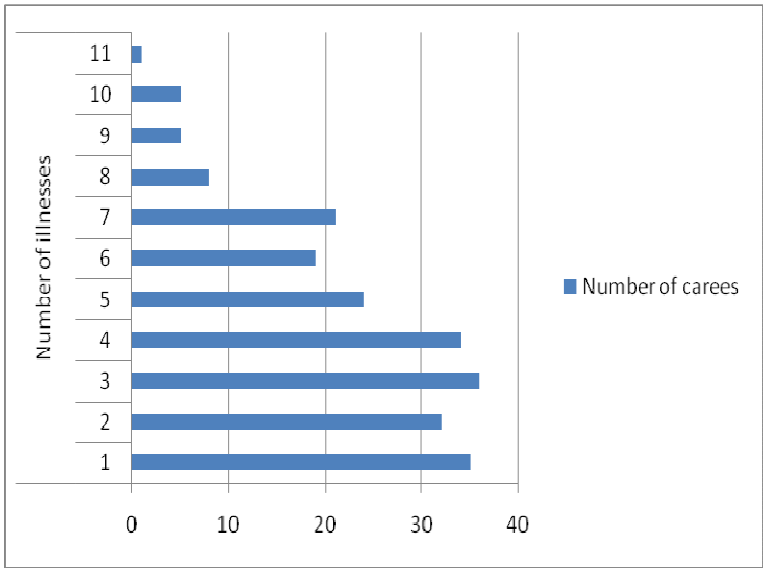

At the forums, quite a number of carers mentioned that their plan was to call the ambulance service. Some mentioned their church and others mentioned family. Only a couple referred to a formal plan.

FIGURE 25 CAREE HEALTH CONDITIONS




The top five health issues for carees were mobility problems, arthritis, memory problems, heart problems and depression. Many carees had more than one condition which would have exacerbated the caring load.

FIGURE 26 NUMBER OF ILLNESSES PER CAREE




On average each caree had 3.9 illnesses.

## SECTION 3.2 COMMUNITY CONSULTATIONS

### NOTES ON FINDINGS

Over three hundred people attended the twenty community meetings. The numbers attending each meeting varied, and when reviewing all results readers should take into consideration the fact that ethno specific representation varied. (refer Figure 1 for more information).

The following issues also need to be taken into account:

- the forum discussion was based on four open questions and in some instances a current issue would dominate part of the discussion and or carers who replied extensively to the question about what they found the hardest would then not respond to the question about what help they needed. For this reason tables of expressed need (either indirectly or directly expressed ) have been compiled.
- carers ability to articulate in English varied and where English language skills were poorer interpretation took longer.
- in some instances, the greater the language difficulty, the more likely it was that carers gave short responses without elaboration
- in some communities, the community worker or interpreter included their own thoughts when giving feedback on community-wide issues. These have not been tabulated as carers' views but have been included under stakeholder issues
- carers were underrepresented at the Mt. Gambier meeting

## KEY FINDINGS SUMMARISED

### TABLE 1:1 EXPRESSED NEEDS

This table was compiled from carers' answers to what was hardest and what they most needed help with, as, in many instances, those who expressed what was hardest did not speak up again and indicate what help they needed. Sixteen communities (13 metropolitan and three rural are each represented by an *)

| EXPRESSED NEEDS (DIRECT & INDIRECT) | CALD COMMUNITIES IN WHICH CARERS STATED THAT THEY NEEDED THIS HELP |
|---|---|
| Respite (including flexible & residential)<br><br>Transport | ********** |
| Financial issues/assistance<br><br>Support: community/family/emotional | ********** |
| Relief from tiredness and stress | ********** |
| Carer education and assistance dealing with challenges with difficult behaviours | ********** |
| Home support<br><br>Help in accessing: services/information/financial assistance | ********** |
| Carer support groups/carer activities<br><br>Personal needs/time for self<br><br>Bilingual workers | ********** |
| Increased funding for community sector<br><br>Language assistance<br><br>Medical issues | ********** |
| Isolation/home<br><br>Work related issues and caring | ********** |

| TABLE 1.1 EXPRESSED NEEDS (DIRECT & INDIRECT) CONT. | CALD COMMUNITIES IN WHICH CARERS STATED THAT THEY NEEDED THIS HELP |
|---|---|
| Problems in dealing with system<br><br>Relinquish care or extended respite | ******* |
| Older carers caring for elderly | ****** |
| 'Carer' label<br><br>Ethno specific meals | ***** |
| Cultural sensitivity/appropriate skills of staff<br><br>Sector-wide improvements | **** |
| More volunteer assistance | *** |
| Accepting services | ** |

## TABLE 1:2 EXPRESSED NEEDS

This table was compiled from carers' answers to what was hardest and what they most needed help with, as in many instances, those who expressed what was hardest did not speak up again and indicate what help they needed.

| EXPRESSED NEEDS (DIRECT & INDIRECT) | | CALD COMMUNITIES IN WHICH CARERS STATED THEY NEEDED THIS HELP BY COMMUNITY AND LEVEL OF SUB-ISSUES |
|---|---|---|
| *Each * refers to number of sub issues raised*<br>******more than 10*<br>*****7-10*<br>**** 4-6*<br>*** 2-3*<br>** 1* | | |
| Respite including flexible and residential | ******* | Italian |
| | ****** | Hungarian, Vietnamese |
| | ***** | Chinese, Croatian |
| | **** | Cambodian, Dutch, Greek |
| | *** | German, Jewish, Latvian, Polish |
| | ** | Ukrainian, Regional: Mt Gambier, Whyalla |
| | * | Regional: Riverland |

| TABLE 1.2 EXPRESSED NEEDS (DIRECT & INDIRECT) CONT. | | CALD COMMUNITIES IN WHICH CARERS STATED THEY NEEDED THIS HELP BY COMMUNITY AND LEVEL OF SUB-ISSUES |
|---|---|---|
| Transport | *** | Cambodian, German, Greek, Italian |
| | ** | Chinese, Croatian, Dutch, Hungarian, Latvian, Polish, Ukrainian, Vietnamese, Regional: Mt Gambier, Riverland, Whyalla |
| | * | Jewish |
| Financial issues/assistance | *** | Cambodian, German, Greek, Hungarian, Italian, Vietnamese, Regional: Riverland |
| | ** | Chinese, Croatian, Jewish, Latvian, Ukrainian |
| | * | Dutch, Polish; Regional: Mt Gambier |
| Support community/family/emotional | **** | Croatian, Dutch, German; Greek, Hungarian, Italian, Latvian, Vietnamese Ukrainian, Regional: Whyalla |
| | *** | Cambodian |
| | ** | Chinese, Polish, Jewish, Regional: Mt Gambier |
| | * | Riverland |
| Carer tiredness and stress | **** | Cambodian, Dutch, Italian |
| | *** | Chinese, Croatian, Greek, Hungarian, Latvian |
| | ** | Jewish, Ukrainian, Vietnamese, Regional: Mt Gambier, Whyalla |
| | * | Polish |

| TABLE 1.2 EXPRESSED NEEDS (DIRECT & INDIRECT) CONT. | | CALD COMMUNITIES IN WHICH CARERS STATED THEY NEEDED THIS HELP BY COMMUNITY AND LEVEL OF SUB-ISSUES |
|---|---|---|
| Carer education and assistance dealing with challenges with difficult behaviours & carer education | **** | Cambodian, Italian, Polish |
| | *** | Dutch, Ukrainian, Vietnamese |
| | ** | Croatian, Hungarian, Latvian, Regional: Whyalla |
| | * | Chinese, Greek, Jewish |
| Home support | **** | Italian, Latvian, Regional: Riverland |
| | *** | Croatian, Dutch, Greek, Ukrainian |
| | ** | Cambodian, Chinese, Polish, Vietnamese, Regional: Mt Gambier |
| Help in accessing services/information/financial assistance | *** | Regional: Whyalla |
| | ** | Chinese, Dutch, Latvian, Regional: Riverland |
| | * | Cambodian, German, Hungarian, Italian, Ukrainian, Vietnamese, Regional: Mt Gambier |
| Carer support groups/carer activities | **** | Chinese, Hungarian |
| | *** | Greek, Polish, Vietnamese |
| | ** | Croatian, Dutch, Jewish, Ukrainian |
| | * | Regional: Mt Gambier, Riverland |

| TABLE 1.2 EXPRESSED NEEDS (DIRECT & INDIRECT) CONT. | | CALD COMMUNITIES IN WHICH CARERS STATED THEY NEEDED THIS HELP BY COMMUNITY AND LEVEL OF SUB-ISSUES |
|---|---|---|
| Personal needs/time for self | *** | Cambodian, Dutch, Italian |
| | ** | Chinese, Croatian, Greek, Vietnamese |
| | * | German, Hungarian, Polish, Regional: Whyalla |
| Bilingual workers | ** | Italian, Vietnamese |
| | * | Chinese, Croatian, German, Greek; Hungarian, Latvian, Polish, Ukrainian, Regional: Mt Gambier |
| Increased funding for community sector | ** | Croatian, Regional: Riverland |
| | * | Cambodian, Chinese, German, Hungarian, Italian, Latvian, Vietnamese, Regional: Whyalla |
| Language barrier/assistance | ** | Chinese, German, Italian, Polish, Ukrainian, Vietnamese, Regional: Whyalla |
| | * | Dutch, Hungarian, Latvian |
| Medical issues | **** | Cambodian |
| | *** | Dutch |
| | ** | Polish, Regional: Mt Gambier |
| | * | Chinese, Croatian, Italian, Latvian, Vietnamese, Regional: Riverland |

| TABLE 1.2 EXPRESSED NEEDS (DIRECT & INDIRECT) CONT. | | CALD COMMUNITIES IN WHICH CARERS STATED THEY NEEDED THIS HELP BY COMMUNITY AND LEVEL OF SUB-ISSUES |
|---|---|---|
| Isolation/home | ** | Cambodian, Croatian, Dutch, Polish |
| | * | German, Greek, Hungarian, Jewish, Latvian |
| Work related issues and caring | ** | Greek, Jewish |
| | * | Cambodian, Croatian, Dutch, German, Polish, Regional: Riverland, Whyalla |
| Problems in dealing with system | ** | Italian, Latvian, Regional: Whyalla |
| | * | Dutch, German, Hungarian |
| Relinquish care or extended respite | ** | Dutch |
| | * | Croatian, Hungarian, Italian, Vietnamese |
| Older carers caring for elderly | ** | Greek, Hungarian, Italian, Ukrainian, Vietnamese |
| | * | Latvian |
| Carer label | ** | Italian |
| | * | Croatian, Hungarian, Latvian, Vietnamese |
| Ethno specific meals | ** | Regional: Mt Gambier, Riverland |
| | * | Chinese; Dutch; Latvian; |
| Lack of cultural sensitivity of staff/appropriate skills of staff | **** | Italian |
| | *** | Regional: Whyalla |
| | * | Croatian, Regional: Riverland |

| TABLE 1.2 EXPRESSED NEEDS (DIRECT & INDIRECT) CONT. | | CALD COMMUNITIES IN WHICH CARERS STATED THEY NEEDED THIS HELP BY COMMUNITY AND LEVEL OF SUB-ISSUES |
|---|---|---|
| Sector wide improvements | ** | Italian |
| | * | Hungarian, two communities not identified |
| More volunteer assistance | * | Croatian, Vietnamese, Regional: Whyalla |
| Accepting services | ** | Regional: Riverland |
| | * | Regional: Whyalla |

## TABLE 2:1 OVERVIEW OF ISSUES WHICH CALD COMMUNITIES FOUND THE HARDEST TO DEAL WITH

| HARDEST THING FOR CARERS: OVERVIEW | CALD COMMUNITY |
|---|---|
| Tired and stressed<br>Transport | ********** |
| Challenges with difficult behaviors<br>Lack of community/family support | ********** |
| Respite and breaks | ********** |
| Confined within the home<br>Financial issues<br>Home duties | ********** |
| Emotional impact on carer<br>Language as a barrier<br>Loneliness and not enough social support | ********** |
| Overloaded (too much to do)<br>Work related issues and caring | ********** |
| Problems in dealing with the system<br>Time for self | ******** |
| Medical issues | ******* |
| Older carers caring for elderly | ****** |
| 'Carer' label | ***** |

| TABLE 2.1 HARDEST THING FOR CARERS:OVERVIEW CONT. | CALD COMMUNITY |
|---|---|
| Accepting services<br><br>Staff in residential facilities<br><br>Reliance on family | ** |
| Lack of cultural sensitivity | * |

## TABLE 2:2 OVERVIEW OF ISSUES WHICH CALD COMMUNITIES FOUND THE HARDEST TO DEAL WITH BY COMMUNITY AND LEVEL OF SUB-ISSUES

| HARDEST THING FOR CARERS | | CALD COMMUNITY |
|---|---|---|
| *Each * refers to number of sub issues raised*<br>******more than 10*<br>*****7-10*<br>**** 4-6*<br>*** 2-3*<br>** 1* | | |
| Tired and stressed | **** | Polish |
| | *** | Chinese, Croatian, Hungarian, Italian, Latvian, Vietnamese |
| | ** | Greek, Jewish, Ukrainian, Regional: Mt Gambier, Whyalla |
| | * | Cambodian, Dutch |
| Transport | ** | Cambodian, Croatian, Italian |
| | * | Chinese, Dutch, Greek, Hungarian, Latvian, Polish, Ukrainian, Vietnamese, Regional: Mt Gambier, Riverland, Whyalla |
| Challenges with difficult behaviours | *** | Cambodian, Dutch, Italian, Polish, Ukrainian, Vietnamese |
| | ** | Croatian, Hungarian, Latvian, Regional: Whyalla |
| | * | Chinese, Greek, Jewish |
| Lack of community/family support | *** | Croatian, Hungarian, Italian, Latvian |
| | ** | Cambodian, Greek, Ukrainian, Vietnamese, Regional: Whyalla |
| | * | Dutch, German, Jewish, Regional: Mt Gambier |

| TABLE 2.2 HARDEST THING FOR CARERS CONT. | | CALD COMMUNITY |
|---|---|---|
| Respite and breaks | *** | Dutch, Hungarian, Italian |
| | ** | Cambodian, Croatian, Latvian, Polish, Ukrainian, Vietnamese, Regional: Whyalla |
| | * | Chinese, Regional: Mt Gambier |
| Confined within the home | ** | Cambodian, Croatian, Dutch, Polish, Vietnamese |
| | * | German, Greek, Hungarian, Jewish, Latvian, Ukrainian |
| Financial issues | ** | Cambodian, Hungarian, Jewish, Latvian, Ukrainian, Vietnamese |
| | * | Dutch, German, Greek, Regional: Mt Gambier, Riverland |
| Home duties | *** | Italian |
| | ** | Cambodian, Chinese, Greek, Ukrainian, Regional: Riverland |
| | * | Croatian, Dutch, Latvian, Polish, Regional: Mt. Gambier |
| Emotional impact on carer | *** | Dutch, Hungarian, Italian |
| | ** | Cambodian, Greek, Ukrainian, Regional: Whyalla |
| | * | Croatian, Latvian, Regional: Mt Gambier |
| Language as a barrier | ** | German, Italian, Polish |
| | * | Chinese, Dutch, Hungarian, Latvian, Vietnamese, Regional: Whyalla |

| TABLE 2.2 HARDEST THING FOR CARERS CONT. | | CALD COMMUNITY |
|---|---|---|
| Loneliness and not enough social support | ** | Dutch, Greek, Italian, Jewish, Ukrainian, Vietnamese |
| | * | Croatian, Latvian, Polish, Regional: Whyalla, |
| Overloaded (too much to do) | *** | Italian |
| | ** | Dutch, Greek, Ukrainian |
| | * | Cambodian, Hungarian, Jewish, Latvian, Regional: Whyalla |
| Work related issues and caring | ** | Greek, Jewish |
| | * | Cambodian, Croatian, Dutch, German, Polish, Regional: Riverland; Whyalla |
| Problems in dealing with the system | ** | Italian, Latvian, Regional: Whyalla |
| | * | Dutch, German, Hungarian, Vietnamese, Regional: Riverland |
| Time for self | ** | Cambodian, Dutch, Greek, Italian, Vietnamese |
| | * | Chinese, German, Regional: Whyalla |
| Medical issues | ** | Cambodian |
| | * | Croatian, Dutch, Polish, Vietnamese, Regional: Mt Gambier, Whyalla |
| Older carers caring for elderly | ** | Greek, Hungarian, Italian, Ukrainian, Vietnamese |
| | * | Latvian |
| 'Carer' label | ** | Italian |
| | * | Croatian, Hungarian, Latvian, Vietnamese |

| TABLE 2.2 HARDEST THING FOR CARERS CONT. | | CALD COMMUNITY |
|---|---|---|
| Accepting services | ** | Regional: Riverland |
| | * | Regional: Whyalla |
| Reliance on family | * | Greek, Regional: Riverland |
| Staff in residential facilities | ** | Italian |
| | * | Regional: Whyalla |
| Lack of cultural sensitivity | ** | Regional: Whyalla |

## TABLE 2:3 HARDEST ISSUES FOR CALD COMMUNITIES IN MORE DETAIL

| HARDEST THING FOR CARERS | CALD COMMUNITY |
|---|---|
| **Overloaded** | |
| Everything is difficult, too hard to choose | Cambodian, Chinese, Italian, Regional: Mt Gambier, Whyalla |
| Too much responsibility | Dutch, Greek, Hungarian, Italian, Ukrainian, Regional: Whyalla |
| Sole carer | Croatian, Greek, Hungarian, Italian, Jewish, Latvian, Ukrainian, Regional: Whyalla |
| 24/7 care | Cambodian, Chinese, Croatian, Dutch, Greek, Italian, Hungarian, Latvian, Jewish, Polish, Ukrainian, Regional: Mt. Gambier |
| Caring for two or more people (including children and grandchildren) | Cambodian, Dutch, Greek, Italian, Jewish, Latvian, Ukrainian |
| Running two homes | Dutch, Italian, Ukrainian |
| Juggling work, caring and family | Cambodian, Croatian, Dutch, German, Greek, Jewish, Polish, Regional: Whyalla |
| Older carers caring for elderly | Greek, Hungarian, Italian, Latvian, Ukrainian, Vietnamese |
| Being husband and wife, having to think for two people, doing work of two people | Greek, Italian |
| Not enough time | Cambodian, Dutch, Greek, Italian, Jewish |
| | |
| **Not enough opportunities to regenerate and rest** | |
| No breaks | Cambodian, Croatian, Dutch, Greek, Hungarian, Italian, Ukrainian, Vietnamese |
| No respite | Cambodian, Chinese, Croatian, Dutch, Hungarian, Latvian, Polish, Vietnamese |
| Insufficient respite | Cambodian, Dutch, Hungarian, Italian, Polish, Ukrainian, Vietnamese, Regional: Whyalla |
| No time alone for self and own needs | Cambodian, Chinese, Dutch, German, Greek, Italian, Vietnamese |
| No time alone with spouse, own family | Cambodian, Greek |

| TABLE 2.3 HARDEST THING FOR CARERS CONT. | CALD COMMUNITY |
|---|---|
| **Lack of support** | |
| Not enough support | Cambodian, Croatian, Hungarian, Italian, Latvian, Ukrainian, Vietnamese, Regional: Whyalla |
| Being the only child | Croatian, Dutch, Latvian |
| Having a large family but no one helps | Croatian |
| No friends or family to help | Croatian, Greek, Italian |
| Lack of support after discharge from hospital | Regional: Mt. Gambier |
| Feeling unsupported by community | Croatian |
| | |
| **Difficulty getting support for caree** | |
| Caree will not go to respite | Dutch, Hungarian, Italian, Regional: Mt Gambier |
| Being the only person the caree will let help them | Cambodian, Dutch, Italian, Vietnamese, Regional: Whyalla |
| Caree does not want any strangers in the home | Hungarian, Italian, Latvian, Polish, Vietnamese |
| Lack of culturally and linguistically appropriate services | Regional: Mt Gambier, Riverland |
| Finding bilingual respite for at home | Regional: Whyalla |
| Caree will only accept care in own language from someone they know and trust | Italian |
| Finding good carers | Italian, Regional: Whyalla |
| Language barrier( impact on getting help and use of respite) | Chinese, Dutch, German, Hungarian, Latvian, Polish, Vietnamese |
| Caree reverting to language other than English | Dutch, German, Latvian, Polish |
| Trying to get respite whilst carer is unwell | Polish |
| Doctors do not do home visits | Regional: Whyalla |
| Lack of medical support | Cambodian |
| Not enough information | Cambodian, Chinese, Dutch, Vietnamese |
| Navigating the system | Latvian, Vietnamese |
| Problems getting help from organisations | Hungarian |
| Paperwork | German, Latvian, Regional: Whyalla |
| Waiting lists | Croatian, Dutch, German, Hungarian, Latvian |
| Needing to reapply once have services | Regional: Riverland |
| Not enough community resources | Cambodian, Croatian, Hungarian, Vietnamese |

| TABLE 2.3 HARDEST THING FOR CARERS CONT. | CALD COMMUNITY |
|---|---|
| **Difficulty getting support for caree cont.** | |
| Locating secure high care for person with dementia | Latvian |
| Hard to get to respite | Italian |
| Getting caree to medical/healthcare appointments | Cambodian, Croatian, Dutch |
| Getting ACAT assessment | Dutch |
| | |
| **Confinement to home** | |
| Caree not wanting them to leave house or go anywhere | Cambodian, Hungarian, Jewish, Ukrainian, Vietnamese |
| Parent wants you to stay at home and entertain them | Dutch, Italian, Latvian |
| Being confined at home day and night | Croatian, Dutch, Greek, Italian, Polish |
| Night-time and being alone | Dutch, Greek |
| Caree's refusal to leave the house | Cambodian, Croatian, German, Italian, Polish, Vietnamese |
| Can't access ethnic TV because of cost (reduces isolation) | Greek, Regional: Riverland |
| Unable to get to support group | Italian |
| | |
| **Transport** | |
| Transport | Cambodian, Chinese, Croatian, Hungarian, Greek, Italian, Latvian, Polish, Ukrainian, Vietnamese, Regional: Mt Gambier, Riverland, Whyalla |
| | |
| **Issues related to specific conditions of carees** | |
| Dealing with dementia and memory loss | Cambodian, Croatian, Dutch, Italian, Latvian, Ukrainian, Vietnamese, Regional: Whyalla |
| Family in denial about dementia | Croatian |
| Caree needs very stable, quiet environment | Polish |
| Caree's pain | Cambodian, Dutch, Polish |

| TABLE 2.3 HARDEST THING FOR CARERS CONT. | CALD COMMUNITY |
|---|---|
| **Issues related to specific conditions of carees cont.** | |
| Communication issues with caree because of deafness or dementia | Dutch, Ukrainian, Vietnamese |
| Dealing with challenging behaviour (general) | Cambodian, Croatian, Dutch, Greek, Hungarian, Italian, Polish, Vietnamese, Regional: Whyalla |
| Dealing with violent and/or aggressive behavior | Cambodian, Croatian, Dutch, Polish, Vietnamese |
| Caree anxiety | Cambodian |
| Dealing with incontinence | Cambodian, Croatian, Dutch, Greek, Vietnamese |
| Always having to say 'yes' to caree because of mental health issues | Italian |
| Post-Traumatic Stress Disorder | Polish, Ukrainian |
| Dealing with paranoia | Hungarian, Ukrainian, Vietnamese |
| | |
| **Impacting on carer's emotional wellbeing** | |
| Isolation | Croatian, Dutch, Greek, Jewish, Polish, Ukrainian, Vietnamese, Regional: Whyalla |
| Lost touch with family and friends because of caring | Dutch, Greek, Jewish, Latvian |
| Loneliness | Dutch, Greek, Vietnamese |
| Unable to catch up with friends, no social life | Greek, Italian |
| Cannot get to church | Greek, Italian |
| Depression | Ukrainian |
| Emotional stress and strain | Cambodian, Chinese, Croatian, Dutch, Greek, Italian, Hungarian, Vietnamese |
| Stress | Cambodian, Chinese, Croatian, Dutch, Greek, Italian, Latvian, Vietnamese |
| Tiredness | Cambodian, Croatian, Dutch, Greek, Hungarian, Vietnamese |
| Carer not in good health | Cambodian, Croatian, Dutch, Latvian, Ukrainian, Vietnamese, Regional: Mt Gambier, Whyalla |
| Older and also need support but don't get it | Greek, Hungarian, Italian, Ukrainian, Vietnamese |
| Feeling helpless | Italian |

| TABLE 2.3 HARDEST THING FOR CARERS CONT. | CALD COMMUNITY |
|---|---|
| **Impacting on carer's emotional wellbeing cont.** | |
| Grief | Hungarian, Ukrainian, Regional: Whyalla |
| Feeling guilty | Croatian, Dutch, Greek, Hungarian |
| Anger and frustration | Dutch, Hungarian, Latvian, Ukrainian, Regional: Whyalla |
| Anxiety/worry about leaving caree alone at home | Cambodian, Dutch, Hungarian, Italian |
| Anxiety about providing the 'right' care | Italian, Regional: Whyalla |
| Fear of finding parent dead | Dutch |
| Fear of the future | Cambodian |
| Worried if (caring role) is 10 to 20 years | Italian |
| Letting family down by not caring for grandchildren | Greek |
| Pressure from caree | Cambodian, Dutch, Italian, Jewish, Vietnamese |
| Dealing with caree's moods | Cambodian, Croatian, Italian, Polish, Hungarian, Ukrainian, Vietnamese |
| Difficulty assisting caree without upsetting them | Dutch, Latvian, Polish, Ukrainian |
| Caree will not listen to carer or does not understand them | Chinese, Italian, Polish |
| Resentment at having to provide care (not able to choose) | Regional: Mt. Gambier |
| Trying to be positive and supportive all the time | Italian, Ukrainian |
| Always having to plan in advance | Greek |
| Their work as a carer not acknowledged | Italian |
| Accepting any services | Regional: Riverland |
| Letting people into my home | Regional: Riverland, Whyalla |
| Heavy reliance on children | Regional: Riverland |
| Not enough support post death | Italian, Ukrainian, Regional: Whyalla |
| | |
| **Financial** | |
| Finance | Cambodian, Dutch, German, Jewish, Latvian, Ukrainian, Vietnamese, Regional: Riverland |
| Centrelink related issues | Cambodian, Hungarian, Greek, Jewish, Latvian, Ukrainian, Vietnamese, Regional: Mt. Gambier |
| Giving up work to care | Jewish |

| TABLE 2.3 HARDEST THING FOR CARERS CONT. | CALD COMMUNITY |
|---|---|
| **Domestic and caring role** | |
| Home maintenance | Cambodian, Greek, Italian, Ukrainian, Regional: Riverland |
| Meal preparation | Cambodian, Chinese, Italian, Latvian |
| Showering, bathing caree | Chinese, Croatian, Italian, Ukrainian, Regional: Mt. Gambier |
| Assisting with toileting | Italian |
| Cleaning and home maintenance | Dutch, Italian, Polish, Regional: Riverland |
| Heavy lifting | Greek, Regional: Riverland |
| Dealing with weekends | Dutch |
| Gardening | Greek |
| Mornings whilst trying to get ready for work | Greek |
| Shopping | Regional: Riverland |
| Medication | Regional: Mt. Gambier |
| **Dealing with the system** | |
| Legal issues | Dutch |
| Cost of residential care | Dutch, Latvian |
| Lack of communication between organisation and carer | Italian |
| System is all wrong | Italian |
| Being the go-between caree and professionals because interpreters are not used | Regional: Whyalla |
| **Other** | |
| Problems with being labeled a 'carer' (either from carer or caree) | Croatian, Hungarian, Latvian, Vietnamese |
| Professionals not culturally sensitive | Regional: Whyalla |
| Counsellors too young, don't understand culture | Regional: Whyalla |
| Volunteers' needs not recognised, costs not reimbursed | Hungarian, Ukrainian |
| Nursing homes are '*dumping grounds*' | Italian |
| Nursing homes do not do enough activities | Italian |
| Some nurses good brains but lack compassion | Regional: Whyalla |
| No place to go for multicultural assistance | Regional: Whyalla |

Many older carers indicated that they struggle to meet both their own needs and those of the person they are caring for. Many of them said this caused physical and/or emotional stress. As one woman said "*It is hard caring for two people. Sometimes I am a bit hard on myself and I cry because it is too much. The stress just spills over to myself."* Older carers and carers who were not in good health found it hard to take care of their own needs, and in many instances would have liked someone to care for them, but had no one. Many indicated that they felt unsupported, particularly if they were the sole carer. Some felt they were unable to take care of their own needs either on a physical, social or emotional level, and, as one carer said "*I do not exist anymore it is just (name deleted)."*

*Ten communities said that the emotional impact of caring was one of the hardest things to deal with*

Carers who also cared for grandchildren sometimes felt resentful, whereas one woman who was unable to care for her grandchildren felt guilty.

Many carers faced conflicting priorities when trying to balance their commitments to one or more people they were caring for: parents, spouses, children, grandchildren, and sometimes work. Caring takes its toll, and some carers admitted to feeling frustrated, angry, guilty, resentful, anxious, worried, emotionally stressed, unable or barely able to cope, and always feeling rushed and pulled different ways.

Many carers admitted to worrying a lot. Some were anxious about leaving the caree alone. One carer said "(*they are constantly on your mind when not home. Every couple of hours I phone home to make sure she is OK ... I am afraid when not there even for an hour, something will happen because she has already had one fall*". Others worry about what will happen if they get sick or are unable to cope, and, for many, financial issues added another layer of concern. Some carers felt that their own families suffered as they care for parents, and they worried about not having enough time for their spouse and children.

*In twelve of the communities carers were suffering from high blood pressure and diabetes*

Carers who were in unfamiliar territory as a carer, indicated that they face anxiety as they try to deal with pain and the needs of someone facing a terminal illness or an illness such as dementia. Some carers also found it hard if community or family members were in denial about dementia. In some cases, this meant they felt unsupported, ashamed, or as though they needed to hide the illness. Carers said they felt guilty about using respite, not doing enough, or not being able to stop pain. Some worried about whether they had found the right medical help for the person they care for. Guilt lasts, even after carers have relinquished care. One former carer, who had to put her mother in a hostel because her husband was sick as well, still feels guilty and says " … *think (I) should have done more...I tried (my) best but couldn't do it. No-one to help me, only myself. Son coming sometimes, but expected to always help with grandchildren".*

Carers who were caring 24/7 and not getting breaks appeared physically and emotionally exhausted at some of our meetings. This was particularly the case if they were dealing with physically or verbally abusive behaviour and other types of challenging behaviour.

Being the sole form of entertainment for housebound carees was tiring for some carers. Some adult children who needed to work or had other commitments indicated that their parents wanted them to stay home all day and entertain them.

Waiting for help of all kinds adds to carers' distress. One said "*all I ever have is phone calls and promises*". Some former carers spoke of parents dying before they progressed high enough up the list for help.

## "... SHOUTS, HITS, AND IS ANGRY ALL THE TIME"

Dealing with aggressive behaviour and verbal abuse was a theme at a number of meetings where one or two people would name it as the hardest thing.

People spoke of:

- being yelled at constantly
- being hit, pushed, harassed
- the strain of dealing with someone who was always angry
- needing two people to change continence pads because the caree would hit them while they were doing it
- having no safe place they could retreat to and having the bedroom door broken open with a hammer when they retreated to it
- having furniture, ornaments and televisions being smashed, broken and thrown around
- the difficulty and cost of having to replace things which were broken
- the aggressive behaviour starting the minute the caree opened their eyes in the morning
- being questioned and challenged whenever they wanted to leave the house.

*Thirteen out of the sixteen metropolitan and regional communities said that they need assistance dealing with challenges with difficult behaviour*

It appeared that, in some instances, this behaviour was related to one of the following:

- dementia
- post-traumatic stress disorder
- a mental illness
- brain damage
- extreme frustration because of limitations due to their condition.

A number of these issues emerged in communities where people came from countries where they had experienced wars, concentration camps or extreme adversity.

*Thirty five carers said they were the sole carer caring 24/7 for someone with dementia.*

The majority of complaints were related to the behaviour of males, however, two instances were related to the behaviour of females.

Our observation was that some of these carers looked extremely exhausted and under great strain. In some instances they were unable to speak because they did not want to break down, and other community members or the community worker who was aware of the situation spoke for them.

One person caring for someone with dementia had found the carer education course useful, as it increased their understanding of what was happening and gave them some skills and the strength to cope. Another had had some sessions with a psychologist to deal with their own depression. In one instance, to get respite, the caree had been admitted to Glenside for a period.

However, some carers appeared to be receiving little or no help to deal with these challenging situations and a number indicated they felt they had no choice but to endure it.

## "… I CAN'T GO ANYWHERE"

A significant number of people spoke of feeling isolated and being unable to go anywhere. Several carers said they felt as if they were in jail or on home detention, unable to go anywhere. The reasons for this included:

- spouses who exhibited jealousy, paranoia and/or anger when the carer tried to go out of the house
- carers being locked out of the house if they attended an evening function
- spouses who refused to have anyone come into the house to provide respite care or to go anywhere for respite
- spouses and family members who were suspicious of strangers and would only allow help from a family member, their own community, someone who spoke their own language, or someone who was their own age or gender
- carees who would only accept care and medication from one person. In one instance, it was the daughter in-law, and the husband virtually never saw his wife alone because of his father's demands
- a lack of help from family or friends
- being on a waiting list for assessment or assistance
- being deemed ineligible for assistance
- insufficient respite to do more than attend to the basics such as doctors visits, shopping or bills
- a lack of transport because they either could no longer drive, had never driven or could not afford taxis (even subsidised)
- a lack of knowledge and language or cultural barriers to applying for assistance
- a view that it was their 'duty' to provide care, which made carers more vulnerable to the carees' demands that no one else to do the caring

*Eleven communities spoke of finding confinement in the home one of the hardest things to deal with.*

*Seventy one percent of carers said that they were the sole carer.*

- an unwillingness to leave the caree alone or with someone else because of concern about their wellbeing, or because their condition worsened or their distress levels rose when other people were caring for them.

Carers of people with advanced dementia exhibited higher levels of distress than some other carers.

One carer, whose spouse with dementia can no longer shower, dress, recognise her children or communicate, said he "*get(s) that frustrated, start(s) to raise voice – need to walk away. I have to lock doors to stop her wandering. The frustration starts first thing every day; starts at 5.30 every day - won't come back to bed – 6 am takes off all clothes – walking around ice cold ... I have had my name down for care for more than 6 months. I keep asking, pestering. Hopefully, in a month's time there will be a place – just praying ... gets to you that badly, sometimes say I don't care if I wake up the next day ... Kids organised a trip away ... they can see it's getting to me … Should be excited but can't feel anything ... Can't be honest and tell my wife I am going overseas. Married 48 years and now lying – pressure all the time ... get lonely at night – day is easier. At night, wife won't go to bed without me. She may want to go to bed at 8pm. I want to watch TV – but she thinks people are coming out of the TV – constant pacing. Night time the worst. Now nowhere to go, can't go to kids, they have their own stuff".*

*Twenty eight percent of carees had dementia and thirty six percent of carees had memory problems.*

Another felt that her community isolated some members once they knew a person was ill. She felt she was "*in a prison for 4 years with him*". At the thought of having to resume caring because the low care institution he was in wanted him placed elsewhere, this carer said she felt suicidal, and, if forced to resume care would "*drive under a train*". (NB this carer is getting professional support to find alternative care.) This particular carer had become involved with Alzheimer's Australia and said without them she "(*didn't) know what would have happened. Hardest part was (I) didn't have anybody, if didn't get their help* (*I*) *don't think would still be here today".*

A number of carers indicated that they found wandering behaviour, loss of communication, memory issues and the difficulty of making carees with dementia understand what they were saying very exhausting. One carer found that "*caring for someone who (I) can't communicate with (is) very lonely*."

Some felt they had abandoned their own needs because dementia meant the caree's needs came first all the time. Carers were often grieving the loss of companionship and support from their parent or spouse, as well as dealing with the caring role and struggling to do both caring and other domestic and household tasks which formerly the caree would have done.

*Sixty four percent of carers said that they do not use respite. Only sixteen percent nominated residential respite as one of their most preferred options.*

Dementia made some carees more dependent. One carer said she found it very hard "*always having a shadow and having no relaxation time ... time always taken up*".

The issue of dementia leading to challenging behaviour (including physical and verbal aggression in some cases) was raised a number of times. Support from Alzheimer's Australia, and joining an ethno specific carer education program or an ethno specific support group appeared to have greatly assisted carers. One carer said they "*Smile more often after our group. Gives me strength for another day".* Others indicated that the courses gave them skills to help cope with the progress of the disease. A number of carers of people with dementia indicated they needed residential respite or a break of one week or more to recuperate.

## "... TIRED ALL THE TIME"

Tiredness was raised frequently in many communities, both as a health issue and as the thing which people found the hardest to deal with. Some people spoke of being constantly tired or chronically tired. One carer said "*I am overly stressed and tired to the point of being unstable*".

The most common reasons given for tiredness included:

- 24 hour care (for people with disabilities, strokes and dementia)
- caring for more than one person (one family was caring for three members with serious problems and needed to cook four separate meals each day as well as undertake multiple caring tasks including dealing with incontinence and behaviour issues). In another, a woman spoke of caring for her mother, husband, children and grandchildren
- caring for someone with challenging and/or aggressive behaviour
- caring for someone who refused to be left alone or have anyone else do the caring
- sequential caring without any kind of support either from family, organisations, their community or friends
- carers who were elderly themselves and found the extra burden of doing all the domestic jobs, shopping, outside maintenance, extra finances and legal issues plus caring to be onerous
- carers who had health issues of their own
- carers who received little sleep because of night wandering, needing to help with toileting and pain management
- carers whose distress was leading to insomnia
- carers who were running two households, their own and that of the person they were caring for

*Sixty percent of carers said that they care 24/7.*

*Fourteen communities said they needed some relief from tiredness and stress. In some communities such as Whyalla, most of the carers present indicated that they were suffering from stress.*

- carers who were trying to work, fulfil other family commitments and still care for an elderly parent
- older carers who were helping to care for their grandchildren as well as care for their spouse
- carers who lived some distance from the person they were caring for and spent considerable time driving back and forth
- carers (particularly older carers) caring for someone with incontinence or other issues which necessitated bed linen being changed daily and substantially more cleaning.

## CARER RETREATS

### REST AND RELAXATION TO RECOUP ENERGIES

Carers SA (Carers Association of SA) administers the Home and Community Care funded Carer Retreats Program for South Australia. The Retreats Program enables groups of carers to take a break together thereby helping carers to cope better, feel less stressed, build networks, offer support to other carers, acquire knowledge and develop new skills. The reported outcome of Retreats is to give carers more energy and better health, and the benefits of a retreat can last for months.

The Retreats Program started some ten years ago and has been positively received by a wide range of community groups including those with a CALD background. The program is driven by the needs of the community carers and not those of Carers SA. The program builds the resilience of carers. Critical features of the Retreats Program include flexibility, value for money, and its value to carers – in providing a break from the caring role, opportunities for self-empowerment, to choose for themselves, and to share experiences with other carers.

The success of the program has been due to the simplicity of the application process and an absence of cultural barriers to accessing the funding. A range of ethnic communities have accessed carer retreat monies over the years, including the Italian, African, Chinese, Croatian, Cambodian, Polish, Vietnamese, Hungarian, Filipino and Greek, Lebanese communities, to name a few.

Carers SA has not directly advertised the Retreats Program to ethnic communities, yet communities have been made aware of it through informal networks and through general promotion in the media. The Retreats Program is extremely flexible and valuable for ethnic communities, particularly the smaller groups who have limited resources available to them.

## CARERS VOICES # 6

"... FED UP WITH CLEANING 24 HOURS A DAY"

Housework and domestic chores were generally an issue, both for older carers and for children struggling to find the time to assist their parents and run their own households. Some children mentioned that their parents benefited as well from the social aspect of having other people come into the home to help.

A carer commented that, when you are the carer "*you do everything: cook, clean, garden, home maintenance, as well as caring*". This theme was echoed at a number of meetings where carers indicated home maintenance would be a big help and that home help would relieve stress at home.

*Eleven communities said that they found dealing with home duties on e of the hardest things. Twelve communities said they needed some or more support, including maintenance and outdoor work.*

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The amount of assistance received varied from none to once a week. Many of those receiving some help still felt it was insufficient. This was particularly the case with older carers who also had health issues of their own. One older carer who was caring for someone with continence issues was "*fed up with cleaning 24 hours. (I find*) *that part the hardest*".

One older carer who was suffering from low back and shoulder pain and caring for a spouse with anger issues said that once a week was not enough domestic assistance. She said "*I can't cope with domestic chores ... (I) need some assistance twice a week*".

Many carers appear to be receiving less help than this. One couple had been receiving one hour of cleaning per month for seven years. Their daughter said that *"... this is not enough. You cannot keep things like the toilet clean on this. If Mum does the cleaning she is in bed for two weeks.*" Another male carer receiving help once a fortnight faced the same problem. He said "*anything else can get by but, home cleaning if (I) do it myself condition get worse*".

Assistance across councils varied and was a source of discontent in some metropolitan community meetings where

*Eighty eight percent of carers are on either a carer payment or an Australian pension.*

it was clear that people living in some council areas received more assistance than others.

Those who were receiving cleaning assistance said the cleaners had been told only to clean inside units, but not attempt gardening or windows. At one community meeting the question was asked: "*If nursing homes hire cleaners to clean home units why can't they help in (the) community as well?*"

Carers who had to pay for help said gardening and cleaning services were cost prohibitive.

A number of carers, particularly female, were unable to cope with outside chores such as gardening and lawn mowing. Home maintenance and irregular spring cleaning such as washing curtains and windows or changing light bulbs were problems in a number of communities, particularly where the carer was also elderly.

## TABLE 3 HEALTH ISSUES OF CALD CARERS

| HEALTH ISSUES | CALD COMMUNITIES WHO LISTED THIS ISSUE |
|---|---|
| High blood pressure<br>Diabetes | ********** |
| Back and neck pain related to lifting<br>Stress | ********** |
| Tiredness | ******** |
| General aches and pains from old age<br>Heart problems | ******* |
| Arthritis<br>Depression | ****** |
| Anxiety, nervous disorders | ***** |
| Cancer<br>Emotional distress | **** |
| Asthma<br>Cholesterol<br>Immune disorders<br>Insomnia<br>Mobility<br>Osteoporosis<br>Vision | *** |
| Hearing<br>Hip replacements<br>Knee problems<br>Lungs<br>Thyroid | ** |
| Asbestosis<br>Bending problems<br>Blood clots<br>Blood disorders<br>Dementia (early stage)<br>Dental<br>Disability<br>Grief<br>Kidney problems<br>Memory issues<br>Rheumatism<br>Sleep apnoea<br>Stomach problems | * |

## "TRANSPORT IS A HUGE ISSUE"

Transport was repeatedly mentioned as one of the hardest things carers faced. For some people it was "*a huge issue*".

Every single community wanted extra transport assistance.

Carers wanted more transport and more flexible transport, on weekdays and weekends, both between towns in the rural areas and across metropolitan Adelaide.

Carers faced problems getting to:

- doctors
- hospital appointments
- shopping
- respite
- carers' functions
- community functions
- church
- social functions.

*Transport and feeling tired and stressed were the two hardest things for carers, with fourteen communities listing each of them. Some carers spoke of needing to catch three buses to get to appointments. .*

The difficulty of moving across council areas was mentioned several times, as was the problem of moving between towns in the rural areas.

The issue of transport was raised in all three regional areas and seemed to be particularly difficult when people lived out of town. One person in the Riverland said that they had to walk several kilometres to get medication.

Lack of transport was mentioned many times as a contributing factor to isolation.

A number of the carers voicing concern were female carers who had never driven, and some of those whose husbands had early stage dementia or effects from a stroke were very concerned about what would happen when their husbands

could no longer drive. Several of these also exhibited anxiety about their spouse's current driving ability.

Those who lived further away from their community centre or who had to catch multiple buses to medical appointments found it difficult.

The financial cost of transport was mentioned a number of times and many people seemed unwilling or unable to catch taxis because of the expense. Not all people had heard of Access Cabs and the SATSS voucher scheme. Those who had were still reluctant to use it because it only met part of the cost. Transport to and from respite was mentioned as a "*huge drain on families*".

*In every single community carers said they needed help with transport.*

Rural carers were also concerned about the cost of travel both locally and to medical appointments in Adelaide. The need to pay for transport once they reached Adelaide was mentioned.

Transport was also an issue for relinquished carers. One woman, whose husband has been in a nursing home for 5 years, visits him daily with a meal and still looks after him. She "*still need(s) the support*" of her community for transport and emotional support.

A number of children caring for parents had to take time off work to take their parent to the doctor.

The MCC community buses were mentioned several times. Communities thought that more buses were needed and one community mentioned the difficulty of paying to use it because of increasing insurance costs when their own funding had not increased.

## " ... EASIER TO GET INTO JAIL THAN TO GET MONEY OUT OF CENTRELINK"

In the community forums, issues regarding Centrelink were often raised as one of the hardest things people faced. A number of people mentioned the emotional stress in applying for benefits and how upset they felt dealing with Centrelink. The complaints included:

- being treated disrespectfully
- no flexibility
- being given the run around
- time consuming
- endless forms which were hard to fill out
- difficult to access by phone
- system is often difficult to navigate
- information hard to understand even with an interpreter
- Carer Allowance can take years to get
- Centrelink does not tell you all your rights or advertise allowances people are entitled to
- Carer Allowance does not cover extra costs of caring such as respite
- the system disadvantages workers who are providing care
- volunteers are ineligible for Carer Allowance and are not compensated or recognised
- Carer Allowance form is more geared to physical disability than to mental illness
- delays in bridging visas increase stress for the whole family
- being unaware of Carer Allowance until community meeting.

*Fifteen communities said they needed help with financial issues.*

One carer said "*Centrelink is a disaster ... they are worse than the Gestapo in Germany*". Another said you would "*think we were robbing the Bank of England*". In another community, a woman said it was "*easier to get into jail than get money out of Centrelink*".

One woman felt she had been "*pushed from pillar to post*" and that the experience was "*very, very hard, degrading and humiliating*". She said "*(I) hope to God I never have to go through it again*".

People found dealing with Centrelink time consuming. One carer said *"All I do is go to Centrelink ... endless hassle, so don't need and don't want".* Several people said it took a long time to '*fight*' for the Carer Allowance and that to get information you "*have to dig and dig*".

One woman said "(I) *do not want to put my husband in residential care ... know what nursing homes cost. Why don't they just pay me some more money, even $100 a week so I can manage better at home*?"

Many carers indicated that if they are refused once, they choose not to reapply. Several communities said that the term 'carer' is not understood. Some people said their husbands refused to have them labelled as a 'carer' as it was their "*duty to look after them*", so they could not apply for assistance.

*Eleven communities said financial issues were one of the hardest things they faced. Six communities nominated the Centrelink newsletter as one of their sources of information but they all wanted it translated and available to carers who were not receiving payments.*

There were several instances of carers caring for people with Alzheimer's disease being turned down for benefits. One woman's view was that the form is designed in such a way that you can't qualify if the person has Alzheimer's disease.

One couple, who could not afford to stop work, had been providing 24 hour care for a family member for many years, with one working days and the other nights. They had been told they were not eligible for any financial support.

Carers were more comfortable accessing a Centrelink office if someone from their community worked there. There was some positive feedback and one carer felt that the "*government is doing a wonderful job ... in (my) opinion, best country ... appreciate it, don't have to beg for anything". Thank God I am here ... because of the care I get and interest I get*".

Both carers and carees had relatively low levels of functional English. This problem was exacerbated by carees who had reverted to their birth language (Dutch, German, Latvian and Polish communities).

Numerous carers indicated that language is a barrier to finding and accessing services. It was clear at the meetings that many of those who found it easiest to access services had good English skills and/or had prior knowledge of this sector or contacts in the service sector who could assist them.

As one carer said "*When I have a problem, (I) don't know how to find someone to help*". This carer was unable to communicate in English when seeing their doctor and did not know how to ask for an interpreter. Carers complained about the lack of interpreters and some said they found it hard when doctors asked them to interpret for the caree. One was very unhappy about being asked to convey information about a terminal illness to the caree.

*Both carers and carees had relatively low levels of functional English. This has relevance for all aspects of program and service delivery to this group of carers.*

One carer likened trying to get help to the problems they faced when they first came to Australia. "*It is almost like a new era for immigrants, as have to learn how this system works."*

Many carers indicated they needed the support of their community workers because of language problems. Some said that their communities did not have enough funding or staff to help. For instance one person said "*I need more support, more information and more resources in my own language*".

## HUNGARIAN CARITAS SOCIETY IN SA

### COMMUNICATION CHANNELS

The Hungarian Caritas Society in SA provides culturally appropriate assistance, help, information and care to the frail, aged, and younger disabled Hungarian population. It has regular Wednesday lunches at a reasonably low cost, which are well attended by the community. It also provides day-trips and excursions which relieve the isolation and boredom of so many elderly people within the community.

This community particularly stands out for some the exceptional programs it provides for its community members. An outstanding example is its monthly Sunday program on radio 5EBI, which covers a range of issues such as: safety in the home, Centrelink issues, depression, dementia, grief, mental health issues, carers' issues and what to do when someone dies. These programs are researched, developed and placed on air by a team of well known and trusted members/volunteers of the community. (It is important to note that the majority of the volunteers who support Caritas are all in their late sixties and early seventies; they do not have paid workers.)

The radio programs are run once a month and Caritas advertise the program in the Hungarian monthly newsletter, providing an outline of the program and the time and date to listen to it. In some instances, volunteers of Caritas visit people's homes and tune in their radios prior to the program, or ring people to alert them to the program and get them to listen. All radio programs are favourably received and feedback is extremely positive. Following radio programs, people are encouraged to contact Caritas for additional information or support regarding issues. Caritas are quite often inundated with calls.

The ethnic radio program is the foundation of Caritas' communication process that enables rapid dissemination of current information to the community, particularly for those who are housebound and isolated, as many carers are. There are many other ethnic communities that use the radio as a tool for educating and informing community members; it is extremely valuable for getting information to a wider group.

## TABLE 4: INFORMATION SOURCES USED BY CALD COMMUNITIES

| INFORMATION SOURCE | CALD COMMUNITY WHERE CARERS STATED THAT THEY USED THIS INFORMATION SOURCE |
|---|---|
| ACAT assessors | Regional: Mt Gambier |
| ACH | Regional: Whyalla |
| Alzheimer's Australia SA (AASA) | Chinese, Croatian, Greek, Hungarian, Latvian |
| Ask questions | Croatian, Greek, Hungarian, Italian, Ukrainian, Regional: Whyalla |
| Community group Meetings | Croatian (sg), Italian (sg), Hungarian, Polish, Vietnamese (sg) |
| Carer Education course (funded by AASA) | Croatian, Dutch, Hungarian, Italian |
| Carers SA | Croatian, Chinese, Greek, Hungarian, Italian Polish, Ukrainian |
| Centrelink newsletter | Chinese, German, Italian, Polish, Ukrainian, Vietnamese |
| Church | Croatian, Greek, Ukrainian, Regional: Whyalla |
| Commonwealth Carelink | Jewish |
| Community Organisations | Cambodian, Chinese, Croatian, Dutch, German, Greek, Hungarian, Italian, Jewish, Latvian, Polish, Ukrainian, Vietnamese |
| Council on the Ageing (COTA) | Latvian |
| Council | Croatian, Hungarian, Italian, Jewish, Latvian |
| Day care, respite | Regional: Riverland |
| Domiciliary Care | Croatian, Italian, Ukrainian, Vietnamese, Regional: Whyalla |
| Ethnic Link | Ukrainian, Regional: Whyalla, Riverland |

| TABLE 4 INFORMATION SOURCE CONT. | CALD COMMUNITY WHERE CARERS STATED THAT THEY USED THIS INFORMATION SOURCE |
|---|---|
| Ethno-specific services | Chinese (Overseas Chinese Association, Chinese Welfare service)<br>Croatian (Croatian Welfare Service<br>Dutch (NASSA )<br>German (German Club)<br>Greek (Greek Welfare Centre)<br>Hungarian (Caritas)<br>Italian (ANFE, IBF, CIC)<br>Jewish (Jewish Family Services)<br>Polish (Polish Welfare Services)<br>Vietnamese (Vietnamese Aged Care Service) |
| Family | German, Greek, Jewish, Italian |
| Flyer | Chinese |
| Friends | Greek, Hungarian, Italian, Latvian, Polish, Regional: Riverland |
| GP | Croatian, Dutch, German, Hungarian, Latvian, Polish, Ukrainian, Regional: Mt Gambier, Whyalla |
| Hospital | Croatian, Italian, Ukrainian, Regional: Whyalla |
| IDSC | Jewish, Vietnamese |
| Internet | Hungarian, Greek, Regional: Whyalla |
| Library | Regional: Whyalla |
| Mainstream services | Croatian, German |
| MALSSA | Vietnamese |
| Multicultural SA | Hungarian |
| Newsletter | Cambodian, Chinese , Latvian, Ukrainian, Regional: Mt Gambier |
| Newspaper (language) | Chinese, Greek, Polish |
| Newspaper (local) | Hungarian, Italian, Polish, Vietnamese |
| Nursing home | Greek(c) |

| TABLE 4 INFORMATION SOURCE CONT. | CALD COMMUNITY WHERE CARERS STATED THAT THEY USED THIS INFORMATION SOURCE |
|---|---|
| Phone | Chinese (c), Croatian (pb), Dutch (c, pb), Greek (c), Italian (c), Ukrainian (c, pb) |
| Radio | Cambodian<br>Chinese (SBS Chinese radio and 5EBI only listen to weather)<br>Croatian (ethnic or mainstream)<br>German (5EBI)<br>Greek (ENA and 5EBI)<br>Italian (Radio Italiana)<br>Latvian (ABC 891,5EBI)<br>Polish<br>Vietnamese (Radio SBS)<br>Ethnic radio Italian, German/Austrian) |
| RDNS | Croatian |
| Reading books | Jewish |
| Referral by mainstream to ethno specific service | Ukrainian |
| Royal Society for the Blind | Polish |
| SA Services | Regional: Whyalla |
| Seniors Information Service | German, Greek, Latvian |
| Social workers | Latvian, Regional: Whyalla |
| Television (satellite) | Greek, Regional: Riverland |
| Work links (current or previous) | Croatian (pw), German (pw), Hungarian (pw, vw), Italian (pw, vw),<br>Jewish, Ukrainian (pw) |
| Word of mouth | Greek, Italian, Ukrainian, Regional: Mt Gambier, Whyalla |
| Wyatt Holidays | Italian |

c=community, pb =phone book, pw=paid work, sg=support group, vw=voluntary work

## TABLE 5: NUMBER OF CALD COMMUNITIES WHICH USE DIFFERENT INFORMATION SOURCES

| INFORMATION SOURCE<br><br>**Each * refers to one community.** | NUMBER OF CALD COMMUNITIES WHERE CARERS STATED THAT THEY USED THIS INFORMATION SOURCE |
|---|---|
| Community organisations | ********** |
| Radio (mainly ethnic) | ********** |
| Ethno specific services | ********** |
| GP | ********* |
| Carers SA | ******* |
| Ask questions<br>Centrelink newsletter<br>Friends<br>Phone<br>Work links (current or previous) | ****** |
| Alzheimer's Australia SA (AASA)<br>Community group meetings<br>Council<br>Domiciliary Care<br>Newsletter<br>Word of mouth | ***** |
| Carer Education course (AASA funded)<br>Church<br>Family<br>Hospital<br>Newspaper (local) | **** |
| Ethnic Link<br>Internet<br>Newspaper (language) | *** |

| INFORMATION SOURCE CONT. | NUMBER OF CALD COMMUNITIES WHERE CARERS STATED THAT THEY USED THIS INFORMATION SOURCE |
|---|---|
| IDSC<br>Seniors Information Service<br>Social workers<br>Television (satellite) | ** |
| ACAT assessors<br>ACH<br>Commonwealth Carelink<br>Council on the Ageing (COTA)<br>Day care<br>Flyer<br>Library<br>Mainstream services<br>MALSSA<br>Multicultural SA<br>Nursing home<br>RDNS<br>Reading books<br>Referral (mainstream to ethno specific service)<br>Royal Society for the Blind<br>SA Services<br>Wyatt Holidays | * |

TABLE 6:1 OVERVIEW OF HELP WHICH CALD COMMUNITIES SAID THEY NEEDED.

| HELP NEEDED<br><br>**Each * represents one community** | CALD COMMUNITIES IN WHICH CARERS STATED THAT THEY NEEDED THIS HELP |
|---|---|
| Transport | ********** |
| Flexible and extended respite (non residential) | ********** |
| More respite | ********** |
| Help in accessing services/information/financial assistance | ********** |
| Bilingual workers | ********** |
| Carer activities | ********** |
| Home support | ********** |
| Financial assistance | ********** |
| Increased funding for community sector | ********** |
| Improved health care | ********** |
| Support in meeting personal needs | ********** |

| TABLE 6.1 HELP NEEDED CONT. | CALD COMMUNITIES IN WHICH CARERS STATED THAT THEY NEEDED THIS HELP |
|---|---|
| Carer support groups | ******** |
| Additional support | ******* |
| Emotional support | ***** |
| Ethno specific meals | ***** |
| Language assistance/interpreting | **** |
| Residential respite/full-time care | **** |
| Sector-wide improvements | **** |
| Carer education | *** |
| More volunteer assistance | *** |
| More workers with the right skills | *** |
| Help with challenging behaviours | ** |

TABLE 6:2 OVERVIEW OF HELP WHICH CALD COMMUNITIES SAID THEY NEEDED BY COMMUNITY AND LEVEL OF SUB-ISSUES

| HELP NEEDED<br><br>**Each * refers to number of sub issues raised**<br>*******more than 10**<br>******7-10**<br>***** 4-6**<br>**** 2-3**<br>*** 1** | | CALD COMMUNITIES IN WHICH CARERS STATED THAT THEY NEEDED THIS KIND OF HELP |
|---|---|---|
| **Support** | | |
| Additional support | ** | Chinese, Latvian, Vietnamese |
| | * | Cambodian, Hungarian, Polish, Regional: Whyalla |
| Carer activities | *** | Chinese, Hungarian |
| | ** | Croatian, Greek, Italian, Jewish, Polish, Ukrainian, Vietnamese |
| | * | Regional: Mt Gambier; Riverland |
| Carer support groups | ** | Dutch, Greek, Hungarian |
| | * | Chinese, Polish, Ukrainian, Vietnamese, Regional: Whyalla |
| Emotional support | * | Cambodian, Dutch, Hungarian, Vietnamese, Regional: Whyalla |
| Financial assistance | * | Polish |
| | ** | Chinese, Croatian, German, Hungarian, Regional: Riverland |
| | *** | Cambodian, Greek, Italian, Vietnamese |

| TABLE 6.2 HELP NEEDED CONT. | | CALD COMMUNITIES IN WHICH CARERS STATED THAT THEY NEEDED THIS KIND OF HELP |
|---|---|---|
| **Support cont.** | | |
| Help with challenging behaviours | ** | Cambodian |
| | * | Polish |
| Home support | *** | Dutch, Greek, Italian, Latvian, Regional: Riverland |
| | ** | Croatian, Ukrainian, Vietnamese |
| | * | Cambodian, Polish, Regional: Mt Gambier |
| Improved health care | *** | Cambodian, Polish |
| | ** | Dutch, Regional: Riverland |
| | * | Croatian, Chinese, Italian, Latvian, Regional: Mt Gambier |
| Language assistance/interpreting | ** | Ukrainian |
| | * | Chinese, Vietnamese, Regional: Whyalla |
| Support in meeting personal needs | *** | Italian |
| | ** | Cambodian, Chinese, Croatian, Dutch |
| | * | Hungarian, Greek, Vietnamese, Polish |
| Transport | *** | Greek |
| | ** | Cambodian, Hungarian, Italian |
| | * | Chinese, Croatian, Dutch, German, Jewish; Latvian, Polish, Ukrainian, Vietnamese, Regional: Mt Gambier, Riverland, Whyalla |

| TABLE 6.2 HELP NEEDED CONT. | | CALD COMMUNITIES IN WHICH CARERS STATED THAT THEY NEEDED THIS KIND OF HELP |
|---|---|---|
| **Skills & Information** | | |
| Carer education | ** | Italian, Polish |
| | * | Dutch, Regional: Mt Gambier |
| Help in accessing services/information/financial assistance | *** | Regional: Whyalla |
| | ** | Chinese, Dutch, German, Latvian, Regional: Riverland |
| | * | Cambodian, Hungarian, Italian, Ukrainian, Vietnamese, Regional: Mt Gambier |
| **Respite** | | |
| More respite | ***** | Italian |
| | **** | Chinese, Croatian, Greek, Vietnamese |
| | *** | Hungarian |
| | ** | Cambodian, Jewish, German, Polish |
| | * | Dutch, Latvian, Ukrainian |
| Flexible and extended respite (non residential) | **** | Italian |
| | *** | Dutch, Vietnamese, Chinese, Hungarian |
| | ** | Cambodian, Croatian, Greek, Jewish, Polish |
| | * | German, Latvian, Regional: Mt Gambier, Riverland |

| TABLE 6.2 HELP NEEDED CONT. | | CALD COMMUNITIES IN WHICH CARERS STATED THAT THEY NEEDED THIS KIND OF HELP |
|---|---|---|
| **Respite cont.** | | |
| Residential respite/full-time care | ** | Dutch |
| | * | Hungarian, Italian, Vietnamese |
| **Service needs** | | |
| Bilingual workers | ** | Chinese, Croatian, German, Greek, Hungarian, Italian, Vietnamese |
| | * | Latvian, Polish, Ukrainian, Regional: Mt Gambier |
| Ethno specific meals | ** | Regional: Mt Gambier, Riverland |
| | * | Chinese, Dutch, Latvian |
| Increased funding for community sector | *** | Hungarian |
| | ** | Cambodian, Chinese, German, Italian, Latvian, Vietnamese |
| | * | Croatian, Regional: Riverland, Whyalla |
| More volunteer assistance | * | Croatian, Vietnamese, Regional: Whyalla |
| More workers with the right skills | *** | Italian |
| | ** | Croatian, Regional: Riverland |
| Sector-wide improvements | ** | Italian |
| | * | Hungarian; and two carers (community not listed) |

## TABLE 6:3 HELP NEEDED BY CALD COMMUNITIES IN MORE DETAIL

| HELP NEEDED | CALD COMMUNITIES IN WHICH CARERS STATED THAT THEY NEEDED THIS KIND OF HELP |
|---|---|
| **Service features** | |
| Services and paid carers that take language and culture into account | Croatian, German, Hungarian, Italian, Latvian, Vietnamese, Regional: Mt Gambier |
| The care they want (not what organisation wants to offer) | Italian |
| Bilingual care workers | Chinese, Croatian, German, Greek, Hungarian, Italian, Polish, Vietnamese |
| Trained workers who speak the language | Chinese, Italian, Ukrainian, Vietnamese, Regional: Mt. Gambier |
| Emphasis on family needs | Italian |
| Flexibility | Italian |
| Sympathetic, empathetic workers | Italian |
| Trustworthy workers | Italian |
| Workers who know what we need | Regional: Riverland |
| Paid workers rather than volunteers | Croatian |
| More trained community staff | Vietnamese |
| More trained volunteers | Vietnamese |
| More volunteers | Croatian, Regional: Whyalla |
| More staff in day care centres | Italian |
| Fewer hoops to jump through for help | Italian |
| Culturally appropriate food in mainstream organisations | Regional: Mt Gambier |
| Culturally appropriate Meals on Wheels | Regional: Mt Gambier, Riverland |
| **Personal needs** | |
| Emotional support | Cambodian, Dutch, Hungarian, Vietnamese, Regional: Whyalla |
| Own social life | Croatian |
| Time for their own family | Cambodian |
| Time with spouse | Dutch |
| Time alone | Chinese, Croatian, Dutch, Hungarian |
| To meet my own needs | Cambodian |
| Exercise for carers | Chinese, Vietnamese |
| Personal care | Italian |
| Relaxation training | Italian |
| Massages (subsidised) | Italian |
| Yoga | Italian |
| Study and self enhancement for carer | Greek |
| Patience | Polish |

| TABLE 6.3 HELP NEEDED CONT. | CALD COMMUNITIES IN WHICH CARERS STATED THAT THEY NEEDED THIS KIND OF HELP |
|---|---|
| **Carer activities** | |
| Social activities to reduce isolation for carers and give them a break | Chinese, Croatian, Hungarian, Greek, Italian, Jewish, Polish, Vietnamese, Regional: Mt Gambier, Riverland |
| More community centre based activities for carers | Chinese, Croatian, Greek, Jewish, Polish, Ukrainian, Vietnamese |
| Carer outings in own language groups | Chinese, Italian, Polish, Vietnamese |
| Half or full day trips for carers | Chinese |
| Carer lunches | Chinese, Hungarian |
| Regular phone contact | Hungarian, Ukrainian |
| Carers' groups | Dutch, Greek, Hungarian, Ukrainian, Vietnamese, Regional: Whyalla |
| Comparing notes with other carers | Dutch, Hungarian |
| More carer support groups in own language | Chinese, Greek |
| Share caring role half week on, half week off | Greek |
| Help to maintain motivation | Polish |
| Role models of people coping well | Hungarian |
| A holiday | Dutch, Hungarian, Polish |
| | |
| **Transport (see also finance)** | |
| Transport assistance | Cambodian, Chinese, Croatian, Dutch, German, Greek, Hungarian, Italian, Jewish, Latvian, Polish, Ukrainian, Vietnamese, Regional: Mt Gambier, Riverland, Whyalla |
| Transport across Local Government boundaries | Greek, Hungarian, Ukrainian |
| Transport for health appointments and hospital | Cambodian, Greek, Vietnamese |
| Transport to nursing home | Vietnamese |
| Transport to respite | Italian, Hungarian |
| Transport on weekends | Greek |

| TABLE 6.3 HELP NEEDED CONT. | CALD COMMUNITIES IN WHICH CARERS STATED THAT THEY NEEDED THIS KIND OF HELP |
|---|---|
| **Home Support (see also respite and finance)** | |
| Support post hospital | Regional: Mt Gambier |
| Domestic assistance | Croatian, Greek, Italian, Latvian, Ukrainian, Vietnamese, Regional: Riverland |
| Lawn mowing | Dutch, Latvian, Vietnamese, Regional: Riverland |
| Cleaning | Cambodian, Croatian, Dutch, Greek, Italian, Latvian, Regional: Riverland |
| Linen service for Berri | Regional: Riverland |
| Gardening | Croatian, Dutch, Italian, Latvian |
| Window cleaning | Dutch |
| Curtain washing | Dutch |
| Home maintenance | Greek, Italian, Latvian, Ukrainian, Regional: Mt Gambier |
| Cooking | Chinese, Dutch |
| Ethno specific meals delivered or available for purchase for weekends | Latvian |
| Another sibling | Italian |
| Assistance dressing caree | Cambodian |
| Assistance changing nappies | Cambodian |
| Assistance with shopping | Greek, Polish, Regional: Riverland |
| Assistance showering or bathing caree | Croatian, Chinese |
| Home security assistance | Latvian |
| Regular doctor or nurse home visits | Cambodian |
| Doctor speaking their own language who works privately | Cambodian |
| No delays at medical appointments because of incontinence problems | Latvian |
| Doctor to tell carees any hard news and protect the children's relationship with their parents | Dutch |
| Ethnic TV | Greek, Italian |

| TABLE 6.3 HELP NEEDED CONT. | CALD COMMUNITIES IN WHICH CARERS STATED THAT THEY NEEDED THIS KIND OF HELP |
|---|---|
| **General Support Issues** | |
| Additional support | Cambodian, Chinese, Hungarian, Latvian, Vietnamese, Regional: Whyalla |
| Support on everything | Whyalla |
| Help accessing support | Chinese, Dutch, German, Hungarian, Latvian, Regional: Mt Gambier, Riverland, Whyalla |
| Help accessing council help | Ukrainian |
| Additional support from community organisation | Chinese, Latvian, Polish, Vietnamese |
| Access to support package | Cambodian |
| Help filling in forms | Italian, Regional: Whyalla |
| Help locating low care residential | German |
| Help with communication | Ukrainian, Regional: Whyalla |
| Help with language barrier, interpreting | Chinese, Ukrainian, Vietnamese |
| Ethno specific service with information and advocacy | Regional: Whyalla |
| Support accessing residential care | Dutch |
| Additional English classes | Chinese |
| More information | Chinese, Latvian, Vietnamese, Regional: Riverland, Whyalla |
| Centrelink information translated | Ukrainian |
| Help with behavioural problems | Cambodian, Polish |
| Carer education dementia | Italian, Polish |
| Carer education | Italian, Polish |
| Knowledge about difficult/challenging behaviour | Polish |
| Help to reduce carees' pain | Cambodian |
| Better ways to dispense medication | Regional: Riverland |
| Training on lifting | Italian |
| Faster assessments | Dutch |
| Regular caree assessments | Dutch |
| Yearly visits from a case manager | Italian |
| Better dental services | Regional: Riverland |
| Plan for emergencies or if they pass away | Cambodian |
| Palliative care program | Polish |
| Help after caree dies | Hungarian, Italian |

| TABLE 6.3 HELP NEEDED CONT. | CALD COMMUNITIES IN WHICH CARERS STATED THAT THEY NEEDED THIS KIND OF HELP |
|---|---|
| **Respite** | |
| Respite (some or additional) | Cambodian, Chinese, Croatian, Dutch, Greek, Hungarian, Italian, Jewish, Latvian, Vietnamese, Regional: Mt Gambier |
| More flexible respite | Italian |
| Respite service in my own language | Chinese, German, Greek, Hungarian, Italian, Polish, Vietnamese |
| Culturally and linguistically appropriate respite | Chinese, Croatian, German, Greek, Hungarian, Italian, Polish, Vietnamese |
| Respite workers able to help carers with information | Chinese |
| Respite with the same worker each time | Vietnamese |
| Affordable respite | Italian |
| Flexible respite | Italian |
| Someone happy to be a companion to caree | Croatian |
| Additional time for paid worker to connect with caree and build trust | Italian |
| Respite so can visit doctor | Vietnamese |
| Respite carer same gender | Croatian, Italian |
| Community respite | Chinese, Croatian, Polish, Hungarian, Greek, Italian, Vietnamese |
| Respite with community lunches | Chinese, Hungarian, Italian |
| Monthly community meeting for carees | Croatian |
| More caree groups in own language | Greek |
| Respite with social activities for caree | Croatian, Greek, Hungarian, Jewish, Polish |
| Respite with ethnic satellite TV | Greek |
| Weekend respite ( including transport to community activities such as church) | Dutch, Greek, Italian |
| Night-time respite | Dutch |
| Day care respite | Chinese, Vietnamese |
| All day respite options | Chinese, Greek, Italian |
| Language specific daycare centre with activities | Chinese, Croatian, Greek, Italian, Vietnamese |
| Small family-like day care | Italian, Vietnamese |
| Home Visits | Chinese, Hungarian, Italian, Ukrainian, Regional: Mt Gambier (speak same language), Riverland |
| Longer respite provided at home | Italian |
| Respite at home | Cambodian, Chinese, German, Hungarian, Italian, Vietnamese |
| Caree to be taken out of home for respite | Dutch |
| Respite with other carees and or staff speaking the same language as caree | Chinese, Italian |
| Respite for carer and caree together | Chinese, Hungarian, Vietnamese |

| TABLE 6.3 HELP NEEDED CONT. | CALD COMMUNITIES IN WHICH CARERS STATED THAT THEY NEEDED THIS KIND OF HELP |
|---|---|
| **Respite cont.** | |
| Carer support groups with respite attached | Chinese, Croatian, Hungarian, Italian, Jewish, Ukrainian, Vietnamese |
| Retreats which both carer and caree can attend, with assistance looking after caree | Italian |
| Respite from challenging behaviour | Cambodian, Vietnamese |
| Emergency respite help | Chinese, Latvian, Polish |
| Respite (one week or more) | Cambodian, Dutch, Hungarian |
| Residential respite | Dutch, Hungarian, Vietnamese |
| Full time residential care | Dutch |
| Quality nursing homes so can relinquish care | Italian |
| Caree able to return to country of birth for a visit | Cambodian, Vietnamese |
| **Financial** | |
| Financial help | Cambodian, Chinese, Croatian, German, Greek, Vietnamese, Regional: Riverland |
| Financial assistance with transport costs | German, Greek, Hungarian, Italian, Ukrainian |
| Financial assistance for continence products | Cambodian, Croatian, Greek, Vietnamese |
| Financial subsidy for emergency button | Hungarian |
| Financial help to provide personal care for carer | Italian |
| Financial help with respite costs | Greek, Italian, Ukrainian |
| Carer given funds directly and able to buy in help they need | Croatian, German, Greek, Italian |
| Financial help from Centrelink | Cambodian, Chinese, Vietnamese |
| End means test for Carer Payment and Carer Allowance if providing 24 hour care | Cambodian |
| Carer Allowance for 6 months while return to home country | Vietnamese |
| Access to Carer Allowance | Italian |
| Financial increase in Carer Allowance | Greek, Hungarian, Italian, Polish |
| Discounts | Regional: Riverland |
| Doctors to bulk bill | Regional: Riverland |
| **Funding** | |
| Funding for more programs | Italian |
| Financial help for community radio program | Hungarian |
| Financial help for community transport | Hungarian |
| Increased support for their community organisation | Chinese, German, Hungarian, Latvian, Vietnamese |
| More government assistance to ethno specific agencies | Hungarian |
| Reimbursements for volunteers | Hungarian, Regional: Whyalla, |

| TABLE 6.3 HELP NEEDED CONT. | CALD COMMUNITIES IN WHICH CARERS STATED THAT THEY NEEDED THIS KIND OF HELP |
|---|---|
| **Miscellaneous** | |
| Community care and palliative care coordinator | Regional: Mt Gambier |
| Meals on Wheels to deliver further out | Regional: Mt Gambier |
| Ethno specific workers who do broader range of work than Ethnic Link | Regional: Riverland, Whyalla |
| Ageing programs | Regional: Riverland |
| Same service across all Riverland towns | Regional: Riverland |
| Improved accountability by Public Trustee | Community kept confidential |
| To be able to negotiate with Public Trustee about their friend's needs | Community kept confidential |
| Same services no matter where you live | Italian |

## THE SOUTHERN ITALIAN CARERS GROUP

### "CARER SUPPORT EXTENDS OVER MANY YEARS"

The Southern Italian Carers Group (SICG) is a program coordinated by the Passa Tempo Program, an initiative of the Italian Benevolent Foundation (IBF) as part of a suite of programs (day care, social and respite programs, EACH and CACPs packages, Healthy Lifestyle Dementia Respite program, and residential care) that it provides for the Italian-speaking community of South Australia. IBF are committed to developing partnerships with a broad range of services, both mainstream and ethnic, for a more effective program delivery to their client base.

The SICG evolved some fourteen years ago as a result of the first Italian Dementia Carer Education Program which was run in partnership with Alzheimer's Australia SA. This partnership has continued over the years, and the Italian Carer Education Program is offered as part of their core programs.

At least 12 of the current 25 carers are from the original group. Some are relinquished carers and some are widowed, but have continued with the group due to the strong bonds formed over the years. The group is supported by the Carer Support and Respite Centre (South & East), which provides transport and respite, two key elements in carer support programs. They also access Carers SA retreat funding to provide outings such as a trip to Murray Bridge.

The group meets once a month and provides information sessions on subjects such as relaxation, mental health, Centrelink issues, loss and grief, dementia, and Domiciliary Care issues, and outings to Parliament House, the Art Gallery, or the movies. As well as the difficult issues, the group also focuses on lighter aspects of life, and sees getting together for mutual support, sharing laughter, food and strategies for coping as essential ingredients of carer support.

Carer support groups were seen by carers as serving multiple functions. According to some carers they:

- provided information
- helped reduce depression
- gave you a chance to connect with your own culture
- provided a support network
- provided a place to talk to other people who understood what you are going through
- provided outings and social activities for carers (particularly those who were unable to organise them for themselves)
- reduced isolation and loneliness
- provided role models and potential solutions for future or current problems.

*Carers in eleven communities said they wanted carer support groups.*

As one carer said "*it helps when people in your community seem to be having (the) same issues … (I) don't feel so alone*."

In the metropolitan area, most carers indicated that they wanted to attend a carer support group in their own language. A few wanted to attend general groups, particularly if they dealt with a specific illness such as dementia. In the regional areas where specific groups were not available carers' preferences were for multicultural groups, as they saw the issues of being a carer and having a non-English speaking background as common bonds.

Some said that getting transport and respite to attend carer support groups was a "*nightmare".*

## CROATIAN WELFARE SERVICES

### COMMITMENT TO MEETING COMMUNITY NEEDS

Croatian Care for the Aged Association is a small agency providing a range of services for frail aged, people with disabilities and their carers. The services include monthly lunches for the elderly and a carer support group.

In 2004, Croatian Care for the Aged Association undertook their first Dementia Carer Education program in partnership with Alzheimer's Australia SA, and, as a result of that program, formed their first carer support group.

The Association struggles to resource the group but sees it as an essential support mechanism for carers and is refusing to end such a valuable program. The support group meets monthly, and provide information sessions on a range of issues, support as well as outings. The agency would like to offer this on a fortnightly basis subject to resources. Carers very much appreciate the outings and see them as an opportunity to relax away from their caring role.

Like so many other ethnic communities, they struggle to find sufficient volunteer support. Consequently, a core group of volunteers are relied upon to provide a range of services that many mainstream agencies have paid staff undertaking. Many smaller communities have the will, but limited or non-existent resources to meet the real needs of their communities. There is a reliance on community goodwill, but with so many ethnic communities ageing, so is their volunteer base. This desperately needs to be addressed.

## "I NEED A BREAK"

Numerous carers said that they wanted a break or respite.

Some carers have had only limited breaks. One carer said they had only had two weeks off from caring in 26 years.

Other carers of people with dementia or challenging behaviour indicated a high need for regular or extended breaks. One carer who badly needed an extended break said that "*I need to have a break/ holiday… very tired. Psychologically, the caring role gets to you. Frustration every day, starts every morning"*. They had been waiting 6 months for assessment: "*(I) find it really frustrating … deteriorating, … what more information do they need*"?

*Carers in every single community said they wanted some or more respite.*

Whilst many carers wanted a break, how they wanted that to occur varied enormously, depending on both their own and the caree's needs. Some carers said that they love the day centre " … *because (I) can have a break by myself*".

Other carers wanted in-home respite whilst others wanted a "*a home-like environment where (carer and caree) can attend and undertake individual activities, just for (our) community*".

Carers in several communities wanted outings, day care activities and tours. Some carers spoke at length about why they wanted more social outings and food-based carer programs. One said *"( I) very much like outings but (we) are only able to access very small funds from Carers Association".*

*The three most preferred respite choices were, in the following order: at home respite care with a carer who speaks the same language; respite care at a community centre with a carer who speaks the same language; and respite for the carer and caree together.*

Another said *"I would really enjoy half a day a week or whole day program. I would like it twice a week, once in centre and one day a week go out".* When asked about their preference for a multicultural or ethno specific group this carer said "*my own language, if (I) can't communicate then it's no fun*".

Another carer said "*(I) really need a week away where (we) both can reflect on what we are doing to each other. A couple of hours a week (is) not enough. (You would) have to be a 100% saint not to be upset. (I) know it's harder for him than it is for me. I know he used to be a very different person – it's upsetting*".

## CASE STUDY#5

### CARER SUPPORT AND RESPITE CENTRE (SOUTH/EAST REGION)

#### MUTUAL SUPPORT, SHARING AND ACCEPTANCE

Carer Support and Respite Centre Inc (CS&RC) has an extensive history of working with and supporting carers from a range of CALD communities. The communities which have worked with CS&RC in recent years include: Italian, Cambodian, Greek, Chinese, Lebanese, Ukrainian, Latvian and Dutch.

In providing this support, CS&RC has worked with key community people to establish relationships built on trust, understanding and commitment. CS&RC is a carer driven organisation which aims to empower carers and their communities. By forming these partnerships, CS&RC has assisted many CALD communities to strengthen their capacity to develop, manage and deliver services for carers.

CS&RC's goal is to encourage and support these communities by exploring different models of service provision and undertaking a mentoring and supportive role. Working with and linking these CALD communities has resulted in a shared vision and joint participation in planning, developing and delivering culturally appropriate services.

**The work CS&RC has been doing with these communities in supporting carers and their families has laid the foundations to further strengthen relationships and develop a sense of confidence in the manner in which CS&RC can complement and value-add to the service delivery model.**

CS&RC supports the work of CALD communities by increasing access to the various support services offered via a range of targeted and flexible approaches to how and where the support can be provided. It is important to note that at no time has CS&RC attempted to control or direct the approaches undertaken by individual communities, but, rather, walks alongside to support and assist as required and requested by the various communities and their carers. In building capacity within CALD communities, CS&RC believe the ingredients are connectedness, belonging and identity. They are bound by mutual support, sharing and acceptance. All of this is built on a foundation of respect, sharing, collaboration, social justice and transparency.

# SECTION 4 ADVICE FROM ORGANISATIONAL STAKEHOLDERS

# SECTION 4 ADVICE FROM ORGANISATIONAL STAKEHOLDERS

## NOTES ON FINDINGS

An extensive consultation process was undertaken with organisational stakeholders. This included:

- indepth interviews with core stakeholders
- five advisory group meetings
- a forum with ethno specific organisational stakeholders
- stakeholder discussions at regional meetings
- discussions with community workers at ethno specific meetings in metropolitan Adelaide
- an organisational stakeholder questionnaire which was sent to 50 organisations
- regular meetings with Office on the Ageing (OFTA).

In total 46 organisational stakeholders were spoken to directly either in individual interviews or at group meetings. The stakeholder questionnaire was sent to a broad mix of fifty regional and metropolitan organisations. Of the 50 stakeholder questionnaires which were sent out 24 were returned.

**It should be noted that the two interviewers had organisational links with Alzheimer's Australia SA (AASA) at the time of the stakeholder interviews this may have biased the results.**

## GOOD PRACTICE EXAMPLES

The two tables below are based on information derived from stakeholder interviews and responses to the stakeholder questionnaire. Of the 24 respondents who completed the stakeholder questionnaire only 12 chose to respond to the question "*Are there any especially good examples of service delivery models to carers which need highlighting? And if so, can you provide details?"*

Organisations were able to nominate their own services as a best practice example. Questions were not specifically asked about good practice partnerships, but given that several respondents nominated partnerships, these have been nominated separately.

### TABLE 7:1GOOD PRACTICE PARTNERSHIPS NOMINATED BY STAKEHOLDERS

| ORGANISATION/SERVICE | NUMBER OF TIMES NOMINATED |
|---|---|
| ethno specific carer education for dementia through specific communities (Alzheimer's Australia SA ) | **** |
| carer support in the south working in partnership with CSRC South/East<br><br>carer weekend retreat and City of Tea Tree Gully (includes person for whom they care)<br><br>CSRC working with CCIH / Dutch Aged Care /Cambodian<br><br>Italian Carers Dementia Education working with the City of Tea Tree Gully and AASA<br><br>SIS working with Greek Orthodox Church to develop joint information | * |

## TABLE 7:2 GOOD PRACTICE NOMINATED BY STAKEHOLDERS

| ORGANISATION/SERVICE | NUMBER OF TIMES NOMINATED |
|---|---|
| Alzheimer's Australia SA Inc.(AASA)<br>(carer education program: 4 mentions)<br>ANFE (Da Noi: 3 mentions) | ***** |
| Italian Benevolent Foundation SA Inc (IBF) | **** |
| Carer Support and Respite Centre<br>Carers SA (Carers retreats: 2 mentions)<br>Ethnic Link<br>Seniors Information Service<br>South Eastern Carer Support & Respite Centre | *** |
| Community workers (Italian: CIC, ANFE, Polish, Hungarian, Vietnamese, Cambodian, Jewish)<br>Ethno-specific services<br>MALSSA<br>Northern Carers Network<br>Resthaven (Regency Cottage, Life Care) | ** |
| ACAT – Whyalla<br>Cancer Council<br>Carer Education and Carer Support<br>Carers SA support groups<br>Carer Support and Respite Centre Carers Link Barossa<br>Carer Weekend Retreat and City of TTG<br>Dutch Aged Care<br>Greek Orthodox<br>Greek Welfare<br>Helping Hand<br>Italian Community<br>MAC<br>Mental Health Respite program<br>Metropolitan Domiciliary Care | * |

| TABLE 7.2 ORGANISATION/SERVICE CONT. | NUMBER OF TIMES NOMINATED |
|---|---|
| Northern ACH programs<br>PISA Italian Meals Service<br>Relationships Australia<br>SE Regional Carer Respite Program<br>Southern Collaboration<br>St Hilarion<br>Tea Tree Gully Carer Support Group<br>Volunteers in some communities<br>Western Carers<br>Whyalla Multicultural Communities Centre Inc (closed August 2007) | * |

TABLE 8 KEY PEOPLE AND ORGANISATIONS

| KEY SERVICE PROVIDERS AND KEY COMMUNITY<br><br>**Each * represents one mention. people nominated by stakeholders or Advisory Committee as committed to the implementation of CALD carer support services** | TIMES MENTIONED AND KEY POINTS MENTIONED |
|---|---|
| AASA<br><br>Helena Kyriazopoulos | *****<br><br>carer education<br><br>level of commitment<br><br>services being provided very well<br><br>dissemination of information<br><br>assist in developing appropriate services<br><br>strong links with ethnic communities |
| Resthaven<br><br>Christa Michaelis | *****<br><br>CPC multicultural programs, aged care program |
| Dutch Aged Care | **** |
| Ethnic Link<br>Marika, Angelika Tyrone, Franca Antonello | ****<br><br>regional forums<br>direct contact with them, especially regional managers and staff |
| Helping Hand–Asian Partners Aged Care<br>Fiona Dunt | **** |

| TABLE 8 KEY SERVICE PROVIDERS AND KEY COMMUNITY PEOPLE CONT. | TIMES MENTIONED AND KEY POINTS MENTIONED |
|---|---|
| MAC | **** <br><br> linking carers with systems <br><br> policy and advocacy <br><br> group of carers might need training in (CALD) manual handling (home carers) <br><br> Carers' Recognition Act, may hold information session <br><br> MAC bigger picture, training and development |
| Overseas Chinese Association <br><br> Rebecca Chung | **** <br><br> range of programs run for the Chinese community |
| Vietnamese Association of SA | **** |
| ACH | *** <br><br> community care program, eastern Greek and Italian programs |
| ANFE | *** <br><br> respite program for Italian community, open to all ethnic communities |

| TABLE 8 KEY SERVICE PROVIDERS AND KEY COMMUNITY PEOPLE CONT. | TIMES MENTIONED AND KEY POINTS MENTIONED |
|---|---|
| Cambodian<br><br>Chamnarn Chan | ***<br><br>have community welfare worker as the first point of contact |
| Coordinating Italian Committee (CIC)<br><br>Anna Sheridan | ***<br><br>community care, eastern region has strong links with community |
| Greek Orthodox Community<br>Olympia Vozvotecas | ***<br><br>very focused in supporting community |
| Hungarian CARITAS | *** |
| Italian Benevolent Foundation<br><br>Patricia Kadis | ***<br><br>range of programs run for Italian community |
| Latvian Association<br><br>Helena Reid | *** |
| Seniors Information Service (SIS)<br><br>Miriam Cocking | ***<br><br>information provision to CALD communities |

| TABLE 8 KEY SERVICE PROVIDERS AND KEY COMMUNITY PEOPLE CONT. | TIMES MENTIONED AND KEY POINTS MENTIONED |
|---|---|
| Carers SA | **<br><br>services in last 18 months |
| Carer support and respite centre | ** |
| Chinese Welfare Centre | ** |
| Domiciliary Care<br><br>Gosia Skalban | ** |
| Hungarian Aged and Invalid Persons | ** |
| Jewish Community Services | ** |
| Polish Welfare Services | ** |
| Ukrainian Community<br><br>Tanya Avramenko, Maria Dnistrjanski | **<br><br>provision of support for the community |
| Western Carers | ** |
| All mainstream services which offer respite | * |

| TABLE 8 KEY SERVICE PROVIDERS AND KEY COMMUNITY CONT. | TIMES MENTIONED AND KEY POINTS MENTIONED |
|---|---|
| BASMA<br><br>Arabic speaking community | * |
| Eastern Regional Collaboration Project | *<br><br>participants on committee have CALD links with different organizations |
| Life Care | * |
| Local Councils:<br>- Port Adelaide Enfield (A)<br>- Prospect<br>- Walkerville<br>- Norwood Payneham St Peters | *<br><br>give respite dollars directly to SE Carer Support Respite to administer, matched by HACC |
| Nicky Dimitropoulos | *<br><br>HACC standards training |
| Northern Regional Collaboration Project | *<br><br>collaboration project has CALD focus |
| RDNS | * |
| River Murray Mallee Council | *<br><br>programs for Italian speaking community |

| TABLE 8 KEY SERVICE PROVIDERS AND KEY COMMUNITY PEOPLE CONT. | TIMES MENTIONED AND KEY POINTS MENTIONED |
|---|---|
| Southern Services Reform Group | * <br><br> CALD working party and regional forum for whole range of CALD providers <br><br> attempt to get CALD representation on consumer reference group |
| Western Region Collaboration Project | * |

## COMMUNITY WORKERS MULTITASK

Bi-lingual, bi-cultural community workers who deliver culturally and linguistically appropriate services are in high demand by their communities, often work extensive hours outside their paid employment and undertake a diverse and complex range of tasks. To undertake their duties effectively they need a wide range of skills, to stay up-to-date and to maintain an extensive network of contacts.

At the community meetings it was clear that these workers were the preferred first point of contact for many carers, because they were known, trusted, accessible, spoke their language and understood their cultural needs. These workers offer assistance to carers to help them in overcoming language barriers; access information, services and financial assistance and deal with a complex social system. The wide variety of tasks which they undertake includes the following:

- information provision
- awareness raising about what a 'carer' is
- translation
- language assistance
- identifying service gaps
- developing new programs such as carer support groups
- advocating on behalf of carers
- talk to politicians
- assisting with client assessment for carees and determining if there is a carer involved and assessing their needs
- linking  together a service for clients from a variety of organizations, dealing with different assessment criteria, waiting lists and organising interim help
- assisting carers to access services including council cleaning and Metro Home Link
- assisting carers to access financial assistance
- getting referrals for carer respite, locate respite and then link carer with it.
- employing people to run carer education sessions
- organising and running carer lunches and carer support groups
- providing monthly relaxation techniques training for carers
- providing emotional support and counseling
- ensuring carer is safe
- liaising with relevant mainstream organisations including Alzheimer's SA, Carer Support and Respite Centre, Metro Home Link and ACAT assessors
- liaising with interstate or overseas carers and find people to take the place of family for caree.

## CASE STUDY#6

### HELPING HAND: ASIAN PARTNERS IN AGED CARE

EMPOWERMENT-WORKERS, COMMUNITIES AND AGENCY WORKING TOGETHER

Asian Partners in Aged Care (APAC) was formed in December 2005 as a partnership between Helping Hand Aged Care Inc (Metro North Division), MAC and SE Asian communities in the Northern metropolitan region. The program is supported and funded by the Australian Government Department of Health and Ageing (Community Partners Program) and the key program objective is to assist older persons (65+) from local Laotian, Cambodian, Vietnamese and Filipino communities discover, explore and access aged care services. An additional objective is to raise the awareness and capacity of aged care services in the provision of culturally sensitive aged care services.

APAC uses a peer support model. Peer workers, who have already gained a level of trust within their communities, are recruited to assist the Cambodian, Vietnamese, Laotian and Filipino communities. Workers are also required to have Certificate 3 and supported to undertake this if necessary, as well as being provided with in-house training in skills such as manual handling and first aid. A key contact guide listing local and mainstream aged care service providers has been a useful reference tool for workers and is regularly updated. Monthly meetings are held to collect statistics, discuss gaps in services or any complex cases, and hear from guest speakers. Workers are consulted about which guest speakers would be most useful.

The APAC reference group comprising representation from Helping Hand, each SE Asian community and MAC meets bi-monthly to discuss progress, assess resources and to provide input on issues such as cultural awareness training, a vital part of increasing the capacity of Helping Hand staff to deliver culturally sensitive care to its culturally and linguistically diverse clients. Peer support workers are not involved in case management, but source referral options and information, assist with the process if a client has language or literacy issues, and occasionally interpret at meetings unless a professional interpreter is required.

The community's heavy reliance on its peer support workers means they are frequently called upon out-of-hours. Multiple benefits result from this empowerment model, in which the workers, their communities and Helping Hand work together to expand options and improve access to aged care services for SE Asian communities in the northern region of Adelaide.

## TABLE 9 ROLE OF MAINSTREAM ORGANISATIONS

| ROLE OF MAINSTREAM SERVICES | STAKEHOLDER RESPONSE |
|---|---|
| partnerships with ethno specific and multicultural agencies<br><br>provide information, help sheets and training to ethno specific organizations<br><br>provide services to CALD clients<br><br>refer them to their respective communities and appropriate agencies | ****** |
| empower the communities to take over the running of any successful models<br><br>provide culturally appropriate services | ***** |
| dedicated staff member to work with ethnic community build trust<br><br>networking with ethno specific and multicultural organizations<br><br>provide a support structure and administrative support for communities that do not have the infrastructure to run programs<br><br>provide guidance and mentoring to ethno specific organizations<br><br>work collaboratively with ethno specific agencies | **** |

| TABLE 9 ROLE OF MAINSTREAM SERVICES CONT. | STAKEHOLDER RESPONSE |
|---|---|
| be the drivers in providing resources and support<br><br>CALD representation on mainstream boards<br><br>capacity building<br><br>flexible service provision<br><br>provide relevant and accessible information to CALD carers<br><br>provide services to CALD clients where appropriate<br><br>raising awareness of the concept of a 'carer'in CALD communities | *** |
| advocacy<br><br>identifying trends and unmet needs in the community for carers<br><br>provide financial support<br><br>support CALD services providers meet their specific community needs | ** |
| act as a broker<br><br>assist ethno specific organisations to tailor programs to their needs<br><br>be responsive to the clients' needs<br><br>fill the gaps where a cultural specific service is not available<br><br>health care | * |

| TABLE 9 ROLE OF MAINSTREAM SERVICES CONT. | STAKEHOLDER RESPONSE |
|---|---|
| health service providers are important as a point of contact for people who may not leave the house often and may identify other problems<br><br>case management<br><br>inform them of ethno specific services in their community<br><br>provide infrastructure<br><br>support CALD service providers by auspicing retreats<br><br>support CALD service providers by auspicing carer support groups<br><br>use community development model | * |

## AUSPICES

The following organisations were nominated by stakeholders as possible auspice:

- ACH
- Anglicare
- Alzheimer's Australia
- Barossa CSRC
- Cancer Council
- Carers SA
- Country Home Advocacy Program
  CSRC
- Domiciliary Care
- Ethnic Link
- Italian Community
- Larger ethno-specific groups.
- Multicultural Aged Care (MAC)
- SA German Association
- SE Carers
- Uniting Care Wesley

The view was expressed a number of times that any auspicing body should have a proven history of working with communities. Mentoring was seen as a key part of auspicing. In some cases mainstream organizations who had the infrastructure could reduce costs by helping community organizations avoid the need to set up a whole new system.

Some examples of how auspicing worked in specific instances included:

- peer education by the Cancer Council
- mentoring by the Country Home Advocacy Program in the far North
- SE Carers work with the following communities :- Cambodian, Latvian, Chinese Welfare, Vietnamese (a large degree), Hungarian, Overseas Chinese and Ukrainian
- Domiciliary Care as a good example of volume service provision
- Ethnic Link as a good example of strong links to communities
- SA German Association with their welfare centre auspiced by the German community, a welfare officer and volunteer support auspiced by Care Connect

## NORTHERN CARERS NETWORK

### BUILDING RELATIONSHIPS WITH CALD COMMUNITIES

Based at Davoren Park, the Northern Carers Network (NCN) supports carers in the Northern region. Services include counselling, information, advocacy, carer support groups, social outings, retreats, respite, telephone support and home visits. There are thirty outreach programs in the community, many assisted by volunteers. NCN aims to ensure all communities are able to access their service, and has recently recruited staff to work specifically with CALD communities.

Good working relationships have been developed with ethnic communities by linking with a key member, worker or volunteer from each, who then goes on to promote NCN's services. Some CALD carers, having received information by word of mouth, feel confident to approach the service themselves, with most happy to return for further support. CALD carers are followed up together by NCN staff and a key worker from their community if the carer doesn't speak English. By initially taking the time to build relationships with CALD communities, NCN have found that delivery of services to those same communities can then be undertaken without extra cost.

Flexible, individualised respite is available to all clients. Clients are free to use their respite allocation in any way they wish. They can request a particular worker, and have respite provided in-home or from home. Improvements in carers' health and self-esteem have been a major benefit of respite.

Of an initial 40 respite packages for all clients across the Northern region, 26 were taken up by CALD clients. Additional respite packages have been applied for, though with 3000 registered carers, many more packages are needed.

## TABLE 10:1 INFORMATION SOURCES USED BY ORGANISATIONAL STAKEHOLDERS

| ORGANISATIONS AND NON INTERNET SOURCES OF INFORMATION | NUMBER OF TIMES NOMINATED |
|---|---|
| Alzheimer's Australia<br>Seniors Information Service (SIS) | ***** |
| Carer Support and Respite Centre (CSRC)<br>Carers SA<br>Commonwealth Carelink | **** |
| Multicultural Aged Care<br>Networking (with various mainstream and ethno-specific services locally and state-wide) | *** |
| Co-ordinating Italian Committee<br>Ethnic Link<br>Metro Domiciliary Care<br>Multicultural community service providers<br>Multicultural SA | ** |
| ABS<br>Alzheimer's Australia SA (Access and Equity Worker)<br>Anglicare<br>ARCS<br>Australian Federation of Ukrainian Associations<br>Centre for Cultural Diversity in Ageing Aged & Community Services SA & NT Inc<br>Centrelink<br>CISSA<br>CO.AS.IT<br>Department for Families and Communities<br>Department of Ageing, Disability and Home Care<br>Department of Health and Ageing<br>Email (correspondence with community members)<br>5EBI /FM Ukrainian program<br>Guest speakers<br>Home and Community Care (Department of Ageing)<br>Human Services finder | * |

| TABLE 10.1 ORGANISATIONS AND NON INTERNET SOURCES OF INFORMATION CONT. | NUMBER OF TIMES NOMINATED |
|---|---|
| Italian media<br><br>LifeCare<br>Literature<br>Local directories<br>MALSSA<br>Migrant Resource Centre<br>Multicultural Communities Council of SA<br>Multicultural Mental Health Australia<br>National Cross Cultural Dementia Network members (an Alzheimer's Australia initiative)<br>'Nasha Hromada' (Our Community) monthly bulletin (Ukrainian)<br>Nationally: 2 newspapers: "Church and Life"; "Free Thought" (Ukrainian)<br>Northern Carers Network<br><br>Office for Carers<br>Resthaven<br>SA Welfare Agencies<br>SBS radio programs<br>Statewide, Regional (too many to list)<br>Translations (sourced case by case)<br><br>Ukrainian churches and parishes (all)<br>Ukrainian Senior Citizens<br>Ukrainian Social Services | * |

## TABLE 10:2 INTERNET SOURCES USED BY ORGANISATIONAL STAKEHOLDERS

| INTERNET SOURCES | NUMBER OF TIMES NOMINATED |
|---|---|
| Internet | *** |
| www.culturaldiversity.com.au<br>Google | ** |
| www.agedcareaustralia.gov.au<br>Aged Care online<br>www.commCarelink.health.gov.au\<br>Commonwealth website<br>www.familiesandcommunities.sa.gov.au<br>www.hsfinder.sa.gov.au<br>www.mac.org.au<br>www.seniors.asn.au<br>www.ukraine.com.au<br>Websites in The Netherlands | * |

Responses to the following question in organisational stakeholder mailout "Which organisation(s), media, websites do you source for information for your clients?" 84% of respondents answered this question.

## TABLE 11 RECOMMENDED ELEMENTS OF A GOOD CARER SUPPORT MODEL

| RECOMMENDED ELEMENTS OF CARER SUPPORT MODEL | |
|---|---|
| *Each * refers to number of times raised in responses*<br><br>******* *21plus*<br>****** *16-20*<br>***** *11-15*<br>**** *7-10*<br>*** *4-6*<br>** *2-3*<br>* *1* | |
| ethno specific service providers with cultural and linguistic expertise providing ethno specific program delivery | ******* |
| consult and collaborate/partnerships with CALD groups<br><br>ensure clients and communities are involved in service planning<br><br>provision of culturally and linguistically appropriate respite and transport to attend any program<br><br>services provided by bilingual and bicultural workers rather than using interpreters | ****** |

| TABLE 11 RECOMMENDED ELEMENTS OF CARER SUPPORT MODEL CONT. | |
|---|---|
| flexibility in service provision, taking into consideration cultural and linguistic needs<br><br>provision of culturally and linguistically appropriate services<br><br>cultural awareness/competence staff training | ***** |
| having cultural and language sensitivity<br><br>increase funding to CALD service providers to meet the needs of their community<br><br>mainstream agencies having multicultural liaison position to work with CALD communities, develop services and networks<br><br>mainstream agencies to empower/support CALD groups to be able to provide programs/services<br><br>provide information in appropriate language (written/verbal) and through appropriate networks | **** |
| ideal model would allow CACP's and HACC services to be both utilized<br><br>bilingual workers remunerated for language skills<br><br>language specific carer groups/support networks<br><br>safe and culturally appropriate environment<br><br>small short-stay respite centre with carer support and day centre activities attached<br><br>use of interpreters | ** |
| staffing of agencies to reflect diversity<br><br>workers to be easily accessible<br><br>respect | * |

# SECTION 5 RECOMMENDATIONS

# RECOMMENDATIONS

1. CALD carer support programs need to be supported by a flexible approach which includes flexible respite and funding for transport.

2. Increase in basic HACC services such as cleaning, home maintenance, one-off spring cleans to be provided for all CALD carers in a flexible manner with priority being given to carers who are at risk.

3. Support carers through the development and implementation of carer education programs covering the range of carer issues which CALD carers face on a day to day basis with a particular emphasis on manual handling, dealing with continence problems, caring for a person with dementia, caring for people with complex health needs, dealing with challenging behaviour, carers wellbeing and how to access appropriate support.

4. For HACC to support carers by providing specific funding to ethno specific organisations in metropolitan Adelaide and Multicultural organisations servicing regional South Australia to enable them to educate carers about relevant subsidies, allowances and programs and to assist them where necessary in accessing the full range of assistance to which they are entitled.

5. Where carers are unable or unwilling to access support services, (for instance the provision of at home respite by mainstream providers), provide direct funding (in limited cases) to carers to enable them to buy in appropriate support.

6. For HACC to develop and fund an appropriate ongoing, carer awareness program for CALD communities which is delivered through the information channels most preferred by CALD carers.

7. For HACC to increase direct funding to CALD communities/ethno specific agencies to expand current or implement new carer support services and build the capacity of the communities to support their carers in a flexible manner taking into consideration cultural and linguistic needs.

8. Increase remuneration, training and support for bi-lingual, bi-cultural workers who are delivering a complex and diverse range of culturally and linguistically appropriate services.

9. For the OFTA CALD team to initiate and lead opportunities for carer support workers to meet six monthly to share information, develop skills, strengthen networks and plan shared activities.

10. For HACC to provide funding to organisations which have demonstrated a capacity to effectively support and mentor ethno specific organisations to, build capacity and, where appropriate, deliver complementary services including training, general information, carer support, respite and key worker mentoring.

11. For HACC to fund where necessary, specific Access and Equity positions within core mainstream and multicultural agencies and larger ethno specific community organisations that can build and strengthen collaborations and partnerships ; act as a bridge to ethno specific communities; develop networks and culturally and linguistically appropriate services targeting priority communities.

12. For HACC to provide funding for dedicated multicultural workers in key rural centres, and adequately resource them to build capacity at the regional level, and form appropriate links with all relevant metropolitan organisations, so that appropriate carer support services can be provided to regional South Australia,

13. For HACC to review funding arrangements with all agencies that have a responsibility to deliver services to all carers (including CALD carers) to ensure that, at a minimum, a pro rata percentage of their funding is spent on the provision of services for CALD carers. Where this does not occur consideration should be given to redirecting the funding to other organisations.

14. At the end of the second year of the triennial funding undertake a formal evaluation of work undertaken by HACC in relation to CALD carers and CALD carer support services over the intervening period.

15. During this round of triennial funding identify other CALD communities which are ageing and have carer support needs, for instance the Vietnamese Christians and the Filipino community.

# SECTION 6 APPENDIXES

# APPENDIX 1

## ADVISORY GROUP ON SERVICE PROVISION FOR CULTURALLY AND LINGUISTICALLY DIVERSE CARERS COMMITTEE MEMBERS

Franca Antonello, CO.AS.IT
Lan Nguyen, Vietnamese Community in Australia
Maria Dnistrjanski, Ukrainian Social Services
Miriam Cocking, Carers Reference Group
Moss Politis, MALSSA
Olympia Vozvotecas, Greek Orthodox Community of SA
Peter Sparrow, Carer Support and Respite Centre
Rosemary Warmington, Carers SA
Sue McKinnon, OFTA
Tanya Avramenko, Ukrainian Social Services
Vivien Hope, Multicultural Communities Council SA
Kristin Johansson
Helena Kyriazopoulos

## APPENDIX 2

### ADVISORY GROUP ON SERVICE PROVISION FOR CULTURALLY AND LINGUISTICALLY DIVERSE CARERS

### TERMS OF REFERENCE

The Advisory Group will provide their best effort in contributing advice and personal opinions on the following:

- Carer support service delivery models in rural and metropolitan South Australia.
- Needs or constraint which particularly impact on rural communities.
- Service providers and key community people committed to the implementation of CALD appropriate carer support services.
- Possible synergies with mainstream service providers.
- Auspices for the CALD communities which reflect the requirements and autonomy of the communities whilst maintaining minimum service structure.
- Enablers which would maximise the possibility of effective service provision.
- Examples of good practice service delivery models.
- Preferred locations for rural consultations.
- Specific needs for carers of people with varying levels of functionality and specific demographic characteristics.

In addition they will provide feedback on progress reports.

NB It needs to be noted by all members that they have been invited to be on the group as knowledgeable industry and community representatives. They are experts in their own right and not representing their organisational views.

# APPENDIX 3

## COMMUNITIES CONSULTED

Associazione Nazionale Famiglie degli Emigrati ANFE

Cambodian Association

Chinese Welfare

Coordinating Italian Committee

Croatian Welfare Services

Dutch Aged Care – NAASA

Ethnic Link Services Whyalla

German Association

Greek Orthodox Community of South Australia

Greek Welfare Centre (Archdiocese)

Hungarian community CARITAS

Hungarian Aged and Invalid Persons Association

Italian Benevolent Foundation

Jewish Family Services

Mt Gambier Multicultural Forum

Overseas Chinese Association

Polish Welfare Services

RAS Advocacy Program, Riverland

Riverland Ethnic Link Services

Riverland Multicultural Forum Inc

Ukraninan Welfare Services

Vietnamese Association of SA

# APPENDIX 4

## CENTRELINK ISSUES

### CENTRELINK NEWSLETTER IS A VALUABLE SOURCE OF INFORMATION FOR CARERS

Members of the Chinese, German, Greek, Italian, Polish, Vietnamese and Ukrainian communities all cited the Centrelink newsletter as a source of information. Several communities accessed the version in their own language, however the Italian community said in two meetings it was a poor translation and that the translations were inappropriate and too highbrow as the target group was often illiterate in their own language. The Ukrainian community complained that they cannot get the carers update in Ukrainian. There were general complaints that you can only get the information translated if you are on a benefit and some communities were unaware that multilingual translations were available. The Italian group we spoke to in the Riverland had not received an Italian version even though their spoken English was poor in some instances.

### ONE OF THE HARDEST THINGS

In the twenty community forums issues regarding Centrelink were often raised as one of the hardest things which people faced. A number of people mentioned the emotional stress in applying for benefits and how upset they felt dealing with Centrelink.

Some community members felt that older people are not treated with respect by Centrelink and that the people on the counter are very rude at times. Specific complaints included being very upset about being spoken to loudly and being treated in such a way that even after a number of years in Australia they felt they had no entitlement to benefits. Another stated that "*Centrelink is a disaster* – "*they are worse than the Gestapo in Germany*." Another said you would "*think we were robbing the Bank of England*" whilst in another community a woman said it was "*easier to get into jail than get money out of Centrelink*".

One woman felt she had been "*pushed from pillar to post*" and that the experience was "*very very hard, degrading and humiliating*" she "*hoped to God I never have to go through it again*". On one particular day she was sent to Willunga, then Torrensville, then back to Marion when her husband was seriously ill at home. To prove her husband was dying she said she had to take him in there one day after chemotherapy. Her view was that Centerlink was a mechanical process without flexibility.

### Time consuming

Quite a number of people in different communities mentioned the time it took to deal with Centrelink and the repeat visits which are needed. People said that they seem to be forever filling out forms. "*All I do is go to Centrelink ... endless hassle, so don't need and don't want*." Several people said it took a long time to '*fight*' for the Carer Allowance. One woman said she had "*taken time off work specially, phoned, did everything, and still more letters as soon as Dad died".*

### Difficult to access

A number of metropolitan and regional carers said that they had experienced problems accessing Centrelink by phone and that it seems information is not shared between the different Centrelink services.

Some found that the system is often difficult to navigate. Some carers found the Centrelink information hard to understand even with an interpreter. The role of the GP was questioned in filling out forms, with people wanting more help.

### Insufficient information

Several people in different communities complained that Centrelink does not tell you all your rights or advertise allowances that people are entitled to, and that to get information you "*have to dig and dig*". There were complaints that they are not helpful in giving out information about the Carer Allowance or Carer Payment.

### Low numbers on Carer's Allowance

In a number of communities, people who appeared eligible for the Carer Allowance based on what they said, were not receiving it or had not tried to apply for it. In one instance where approximately 25 people were currently providing care, only three were receiving the Carer Allowance. A number of people were unaware that they may be eligible for the Carer Payment or Carer Allowance.

### Insufficient

One woman said no one told her about the Carer Allowance, and once she found out, it took three years to get. She tried and was knocked back, but tried again on her doctor's advice. She was reluctant to try because of what she went through the first time, however, the second time she was successful. This woman said she "(I) *do not want to put my husband in residential care ... know what nursing homes cost. Why don't they just pay me some more money, even $100 a week so I can manage better at home*?"

Another said she spends more than $200 per fortnight on respite but only receive the $98 Carer Allowance.

### Refusals stop further applications

Many carers indicated that if they are refused once, they choose not to reapply. In one instance a carer had the form completed by someone other than her regular doctor. She was upset because her husband couldn't live on his own and the Commonwealth refused her application on the grounds that they didn't think she had to be there permanently to look after him. When she was sent another form to complete she chose not to complete it because she was upset. Her view was that getting recognised as a carer was important. It would give her status which would help her and if her husband needed to go into an institution and she had been a carer for two years they might waive half of the house as her husband's bond. This would mean she would not have to sell her home.

### 'Carer' a difficult term

The word 'carer' stopped people of some nationalities from applying. Members of the Chinese, Italian and Ukrainian communities said that the term 'carer' is not understood. Some people said that their husbands refused to have them labelled as a 'carer' as it was their "*duty to look after them*", so they could not apply for assistance.

### Forms need work

People complained about the application forms. One said it was ridiculous as "*it is difficult to quantify how much personal care you are doing. It varies day to day.".* Another felt that the form for the Carer Allowance is geared more to physical disability than to mental illness. There were several instances of carers caring for people with Alzheimer's disease who had been turned down for benefits. One woman's view was that the form is designed in such a way that you can't qualify if the person has Alzheimer's disease.

### Workers disadvantaged

Some carers said they could not give up work because they could not survive on the Centrelink payments. One said that to stop work she would need the amount she would earn if in employment. One couple, who could not afford to stop work, had been providing 24 hour care for a family member for many years, with one working days and the other nights. They had been told they were not eligible for any financial support. Another had to give up her job because her husband was very depressed and could not stay home by himself, but she was refused the Carer Allowance.

### Refused assistance

Another had benefits refused because Centrelink assessed a condition as not being permanent, but the carer's view was that this doesn't alter the fact that the carer needs help right now. One woman, who suffers back pain was told that she could not apply for the Carer Allowance because she is receiving Disability Allowance."

### Respite Issues

Several carers wished to return to their country of birth and take the caree with them to visit family as a way of getting respite. Their problem was that if they put their partner in care in Australia they are eligible for 63 days respite (which would be a lot more expensive than the Carer Allowance), but when they go overseas they are only eligible for 3 months Carer Allowance, whereas that caree is entitled to 6 months payments. One gentleman was told by Centrelink that a 6 months visit would be okay but when they returned to Australia payments ceased. Others complained that if the caree goes overseas and the carer stays here temporarily, then Centrelink stop payments whereas at least if the carer is here and has funding, they can relax and have a proper break.

### Volunteers

Volunteers in several communities who took on the caring role complained that they were not paid the Carer Allowance and not recognised, but it still cost them money and time and took an emotional toll on them.

### Bridging Visa

One community member whose elderly parent was on a bridging visa said they were told her visa might take 5 years to process because it was a low priority as she was here. This has led to increased stress and increased fear about ill health. She is worried about finances and that if her parent gets sick she will have to pay for all health care. Emotionally and financially it is a huge strain on the whole family.

### Some good news

Carers were more comfortable accessing a Centrelink Office if someone from their community worked there. One person found an Officer at Norwood wonderful. Another found Centrelink very flexible. There was one instance where a Centrelink worker did let someone know about the Carer's allowance.

One person thought Centrelink would be the place to go if you had a problem and needed support. One woman felt that the "*Government is doing a wonderful job ... pension, Carer Allowance ... in her opinion, best country ... appreciate it, don't have to beg for anything. Thank God I am here ... because of the care I get and interest I get*."

# APPENDIX 5

## ATTENDEES ETHNO-SPECIFIC STAKEHOLDER FORUM

Christa Michaelis
Welfare Centre for German-speaking seniors

Dr Ian Harmstorf
SA German Association

Dorit Ninio & Debbie Boock
Jewish Community Services

Franca Antonello
CO.AS.IT

Gosia Skalban
Federation of Polish Organisations

Kim Mai Ly
Vietnamese Community Association

Marius Van Helden
Dutch Aged Care – NAASA

Martin Cheung & Rebecca Cheung
Overseas Chinese Association

Sambath Yun, Chamnarn Chan & Nhey Hean
Cambodian Association

Silvio Iadarola
Co-ordinating Italian Committee

Sophie Dallis
Greek Welfare Centre SA

Tanya Avramenko
Community Care Worker
Ukrainian Social Services

Visnja Perkovic
Croatian Volunteer Coordinator

# APPENDIX 6

## CARER FORUM QUESTIONS

1. What do you find most hard to deal with as a carer?

2. What kind of help would make the biggest difference to you as a carer e.g. respite, transport, financial?

3. How do you get information that you need in your caring role?

4. Do you have any health issues of your own?

# APPENDIX 7

## STAKEHOLDER QUESTIONNAIRE

Name of Organisation:

1 What do you think is the best way to deliver services to culturally and linguistically diverse carers?

2 What are the essential elements of any carer support delivery model to culturally and linguistically diverse carers?

3 What role(s) do mainstream service providers have to play in delivering services to culturally and linguistically diverse carers?

4 Are there any especially good examples of service delivery models to carers which need highlighting? And if so can you provide details.

5 Which organisation(s), media, websites do you source information from for your clients?

**Thank you for completing the questionnaire**

# APPENDIX 8

## CARER QUESTIONNAIRE