

Family carers' health and well-being and community capacity building in rural areas

Rosemary Warmington, Carers Association of SA

OVERVIEW

This paper will explore the impact of caregiving on the health and well-being of family carers and their lifestyle choices. The experience of carers in rural parts of South Australia is in resonance with the experience of family carers across Australia including rural regions.

This paper reflects upon the work done by the Carers Association in South Australia's rural and remote areas. It will describe approaches taken by carers in rural areas to redress the impact of caring through local networks of support.

This paper will also consider current trends in Australian policy with particular focus on Rural Australia and what changes need to be addressed so that family caregivers are able to maintain their health and well-being whilst still continuing in their caring role. A final comment is on the long-term consequences of our current policy approaches.

Carers associations

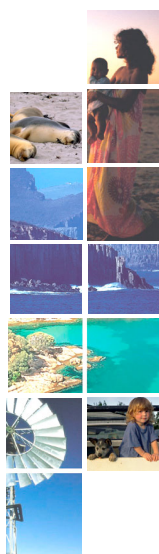
The Carers Association of SA is the peak organisation representing all carers in South Australia. We are a non-profit incorporated community-based organisation, established in 1989 by a grass roots movement of carers. Working directly with carers is important to us. Through feedback we initiate research, develop policy and advocate at all levels of government on behalf of all carers.

There is a Carers Association in each state and territory. The national body, Carers Australia, works at a national level to address matters of national importance.

Carers: who are they?

Family carers are those people who provide care and support for their parent, partner, child or friend who has a disability, is frail aged, or who has a chronic mental or physical illness. Carers come from all cultural and social backgrounds and range greatly in age, from children to the elderly. Often they take on caring for the simple reason that the situation arises; for example a parent requires care; a partner has a mental illness; or a parent needs to care for their child with a disability. They give up their time, income and resources to care.

There are an estimated 2.3 million carers in Australia¹, representing one in five households. Their contribution to the Australian community is estimated at \$18 billion per year². The majority of primary carers are of workforce age, yet paid work is usually not possible.



CARERS LIFESTYLE: HEALTH AND WELL-BEING

Lifestyle choices rely on people's abilities to choose and participate in life's options. A person's lifestyle is affected by their access to finances, social networks, supports and opportunities. A positive lifestyle is related to the degree of choice people feel they have in their life and ultimately what they can choose to do with their time. A positive lifestyle goes hand in hand with positive health and well-being. Impediments to maintaining a healthy lifestyle include:

- lack of resources
- social and geographic isolation
- lack of time
- lack of knowledge/information
- detrimental lifestyle.

Research shows that carer well-being is negatively affected not only by the demands of the caring role, but more importantly by the extent that caring impinges on other roles, particularly paid employment and the opportunity to participate in other activities³. This research concluded, "those who have strong personal and social networks and greater economic resources are better equipped to undertake care giving roles and these resources provide a considerable buffer against the demands of care giving, so that well-being remains at reasonably high levels relative to other carers and the population as a whole."⁴

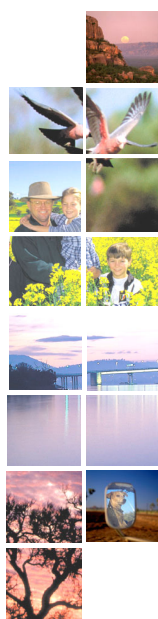
Research on carers' health and well-being

The National Survey of Carer Health and Well-being, *Warning – Caring is a Health Hazard*⁵ conducted by Carers Australia, surveyed 1449 carers from across the nation. 10.7% of those who responded cared for two or more people. 19% were living in rural or remote areas.

Overall carer health

Carers reported the following about their sense of well-being:

- only 16% of respondents rated their health and well-being as excellent to good
- 46% rated their health as fair to poor, with 50% for long-term carers
- a staggering 95% of respondents who had a poor health rating attributed this to their caring work including the constant pressure of caring, disturbed sleep, physical lifting and supporting the person as part of their caring role
- numerous health changes, particularly tiredness or exhaustion, upper body problems, arthritis, high blood pressure and other heart problems were cited.



Injuries attributed to the caring role

Physical injuries were highlighted as a major outcome of caring:

- strains, sprains and injury to muscles and joints represented 70% of direct injury to respondents as a result of their caring role
- back problems relating to manual handling such as lifting and lowering were identified by 30% of those with direct injuries, with men slightly more likely to report back injuries.

Re-occurrence of injury

- 60% of all respondents reported re-occurrence of the injury.
- A surprising 77.3% of all respondents stated that there had been no impact as a result of the injury on their caring role (female 75%; male 84%). It would appear that carers with substantial back injuries are ignoring their own health and well-being to continue their caring role.
- Men in particular were delaying their own hospital treatment because of their caring role, stoically carrying on with their caring role and refusing to let injuries or their own health needs stop them from caring.
- This is resulting in the long-term health failure of the carer.

Financial compensation

- 98% of respondents had never received financial compensation for injury.

Carer mental and emotional well-being

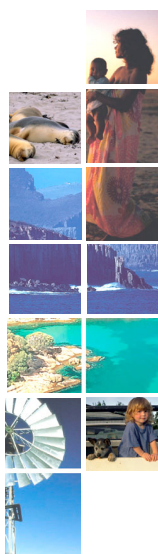
Carers were most likely to report feeling more depressed and anxious as a result of their caring role. The stress of caring, the social isolation and the grief and loss associated with the loss of the “hoped for relationship” were reported as the reasons for worsening emotional and mental well-being. The routine of the caring role, specific practical aspects of the caring role and the relentless responsibilities where there is no end in sight, along with the behaviour of the person cared for, were reported as the major creators of stress.

Impact of caring on energy levels

Of those who reported negative effect on their energy level, 95% said their energy level was worse or much worse. Respondents reported that having “too much to do” and the demands of the caring role had had a negative impact on their energies. The demands meant that carers did not have enough time or the chance to rest and renew their own energies.

Effect of caring on life opportunities

Many respondents reported a major or dramatic effect on their lives as a result of caring including lack of holidays, travel and visits. Men rated these reasons more highly as areas of greatest impact.



SUMMARY OF FINDINGS

The findings of the survey offer a picture of carers:

- whose health and well-being is affected by their caring role
- whose expected life style is negatively impacted by the caring role
- who report feeling depressed, anxious and sad as a result of the grief and loss which they attribute to their caring role
- whose physical health is marked by back injury for which they are probably receiving inadequate treatment because they are unable to find the time, energy or finances to seek and receive treatment, and who throughout it all continue with their caring role, probably despite contra-indications.

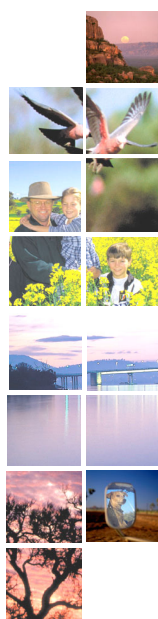
These findings are supported by Schofield et al⁶ who surveyed family caregivers and reported that “high overload, lower levels of perceived social support, diminished life satisfaction and poorer health rating were linked in differentiating carers from non carers.”

What do carers want to assist them?

- **Formal Assistance:** The research showed that the GP is an important person to all carers with 37% of respondents citing the GP as the most highly rated person they would turn to if they had difficulties.
- **Counselling:** and self help groups were valued. Both men and women similarly rated psychologists who offer professional support.
- **Additional Respite:** as well as more flexible respite, carer support activities, home maintenance support and shopping were the most highly rated form of support, in that order.
- **Having some one to talk to:** empathic support, one to one support and general emotional support in various forms are highly sought by carers.
- **Carer support and group meetings and activities:** are by far the most important ways of reducing stress for respondents (28%). Somewhat surprisingly this is more important to reduce stress for male carers (30%). This attests to the popularity and importance of carer support where carers can receive peer support and mutual support from a group who understands their situation. These groups offer enormous support and healing power for many carers.

What the findings mean for rural carers

The findings indicate that carers need to have more options about the balance between their caring role and their other lifestyle choices. This has yet to be seriously addressed within Australia’s model of community care.



and ideas and to give one another strength and courage to continue in the caring responsibilities.

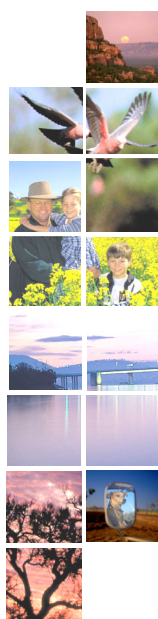
- Provides opportunities for carers to have time out from caring responsibilities.
- Gives carers recognition and values their contribution to the community.
- Works collaboratively with services and community organisations to provide appropriate information through newsletters, forums and information resources.
- Enables carers to assist services by participating in forums, committees and focus groups, as well as consultations.

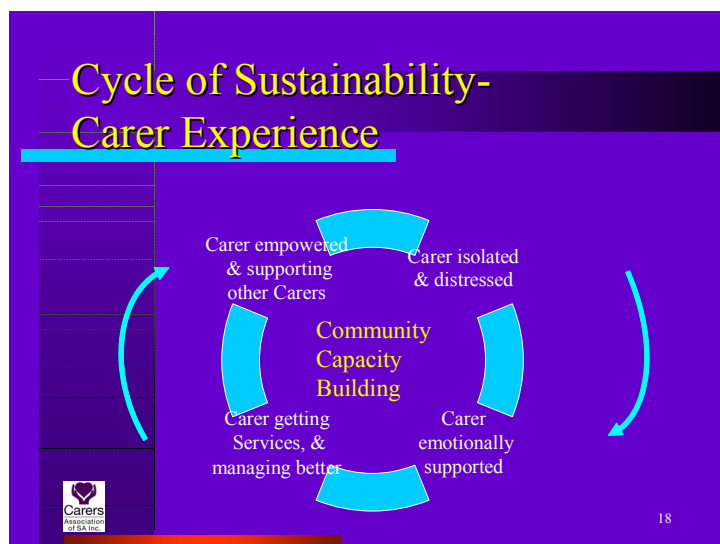
Being able to talk to others in a similar situation is the greatest help of all, because carers best understand other carers feelings, concerns, and needs. Through this support carers are eventually able to offer back support to other people in similar situations and to participate in service providers' structures.

What have been the outcomes?

Through carer support carers have:

- formed strong supportive friendships
- provided one another with information about services
- been supported to make complaints about services that would never have been heard
- called on the Carers Association as the peak body to follow up issues to avoid retribution
- participated on local service advisory groups
- developed leadership groups
- received experience in committee management
- belonged to groups that have won SA Great Awards
- been heard on radio and been seen in local papers
- participated in important state-wide reviews
- had the confidence to attend Cabinet meetings in the bush
- networked with carers across the region
- volunteered their time to help other carers
- built capacity in the local care organisations
- built capacity in the community of carers





The end result is that, through their involvement in a peer support group, carers have contributed not only to their own health and well-being but to the health and well-being of others and in doing so have built community capacity. All this has happened very quietly through carers meeting together, often in the homes of one another. It is the beginning of the quiet revolution for better recognition and services that support carers.

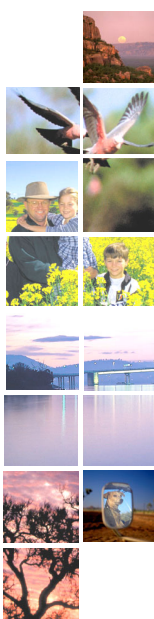
In this model carers are considered true partners in the delivery of community care and in community capacity building. Their strengths as a carer are recognised and built on, they are empowered to fully participate and they contribute more widely to the health and community care debate.

WHAT IS THE REALITY OF CURRENT POLICY?

The research shows that the focus of Australia's current model of community care is indicative of considering the carer as "a resource". In this model the approach is to provide just enough support to enable the carer to continue to care, and is not aimed at providing lifestyle choices, such as respite, to improve "my golf handicap for example". In this model the expected efficiencies and quality of life for the patient are obtained at a cost to the carer's own personal health and well-being and ultimately their lifestyle choices.

If, instead, carers were considered true partners in the delivery of community care, then the health and well-being of the carer and the maintenance of their quality of life and their lifestyle choices would be fundamental.

Informal, unpaid family care is the foundation of community care in Australia. Family carers are conservatively estimated to provide at least 74% of community care assistance.⁷ The formal health and community care system would break down without the support of carers. Public expenditure on care would increase dramatically if only a small percentage of carers stopped providing support. The central role and growing importance of informal family care is strongly supported by demographic trends, most notably related to the ageing of the population. The proportion and numbers of people



- recognition of carers as co providers of services
- training for carers
- measures to assist carers find better ways of managing care in the home
- free treatment for carers for their back and neck injuries; treatment for their associated pain
- inclusion of carers as partners in service planning
- inclusion of carers in the clinical process and decision making process as it relates to their caring role
- recognition of carers' needs in the assessment, care planning and clinical processes
- respite provision including recognition of the carer's need to maintain their own interest and pastimes on a long-term basis. Current research shows that carers rarely use their respite for rest and relaxation.¹¹

CONCLUSION

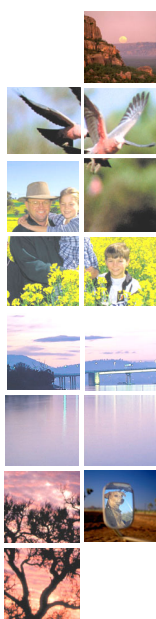
As the population ages we are in grave danger of the whole system failing us all, unless we care for the carer. As we move more and more the care into the home we need to keep the health and well-being of the carers uppermost. If we don't the system will fail us.

Placed within the context of our current and future demographics, it becomes all the more important that family carers are formally recognised as the foundation of all community care and supported as care partners in all our health and community care programs and services.

Currently services and supports for carers are conceptualised narrowly in terms of specific support services which are then provided as a parallel system or an "add-on" to existing service structures. This approach sets carers and their families apart and marginalises them, albeit unintentionally, because it fails to address the wider social context in which caring occurs.

Carers Australia strongly supports the view that support systems for carers should focus on *reintegrating* family caring responsibilities as a normal part of life, with the caring role one of many roles in which individuals are potentially involved. This approach places unpaid family care centrally as the foundation of all care in the community. It also explicitly links carers in the community care system to a range of programs and services that are needed for carers to exercise other important social roles and activities alongside those of caring, including workforce participation.

This is where the quiet revolution of carers can make a difference, in ensuring support for at carers and promoting change across Australia and in rural regional and remote areas.



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PRESENTER

Rosemary Warmington has a BA in Social Work and a Grad Dip in Business Admin. She is the Executive Director of the Carers Association of SA, which is the peak body representing all family carers in South Australia.

Rosemary was born and raised in rural South Australia and has many years of experience in government and community services working across policy, funding and service delivery. She understands the need for policies to recognise in their formulation and implementation the special needs of people living in rural and remote regions. During her time as the executive director, the Carers Association has developed much needed and award winning programs and supports for family carers across rural South Australia.

