



Executive Summary

**Ageing Carers of a  
Son or Daughter with a Disability  
(Including Mental Illness)  
– Planning for the Future**

***DECEMBER 2006***

## Carers SA

Carers SA is the peak organisation representing all family Carers in South Australia. It was established in 1989 by a grass roots movement of Carers. Carers SA is a not-for-profit incorporated community-based organisation with a membership in the thousands, most of whom are individual Carers. Carers SA runs a variety of programs aimed at supporting Carers.

## The Project

The National Centre for Social and Economic Modelling (NATSEM) Study *Who's Going to Care? Informal Care and an Ageing Population Report* was prepared for Carers Australia in 2004. The report forecast that the largest growth in the number of family Carers will occur amongst older people. Between 2001 and 2031, the number of Carers aged over 65 years of age in Australia will grow by an estimated 110 percent, and by 2031 Carers aged over 65 years are predicted to comprise 56% of all Carers.

The report *The Ageing Population - can we rely on informal, unpaid care to provide? - a Discussion Paper* (Carers Australia February 2005) comments that:

*"As ageing Carers they will be vulnerable to normal risks of age related illness and disability which may be compounded by their caring responsibilities."*

*"Ageing lifelong Carers of sons and daughters with disabilities raises another set of issues around transition of care from the parents to alternative permanent care arrangements and the interface between disability services and aged care service for the person needing care."*

*"In addition to health and welfare considerations, in line with general demographic trends and population profiles, an increasing proportion of Carers are likely to be from culturally and linguistically diverse backgrounds." (page 15)*

The Ageing Carers project addresses the first and second of these issues, focusing mainly on the transition from lifelong care by parents to alternative arrangements.

Ageing lifelong Carers need information and education about:

1. navigating the service system
2. the legal and financial requirements of permanent care arrangements and,
3. their options for permanent care arrangements.

This knowledge will assist them to effect the transition of care successfully.

In addition, Carers' own needs need to be addressed. This includes respite, caring for their own health and wellbeing, and future life planning.

## **Project Outcomes**

The following resources have been developed as a result of this project:

- A Background Paper "Ageing Carers of People with a Disability" February 2006: This paper looks at the needs of ageing Carers and the issues that they face when making plans for the future for both themselves and the person they care for.
- Checklist: The Checklist was developed to assist ageing Carers in planning for the future, it acknowledges that planning is difficult and assists in breaking down the process of planning into smaller more manageable parts.
- Checklist presentation: The presentation is used at the forums to show Carers how to use the checklist for their own future planning and for the future planning of the person they care for.
- Forum program and material: The program and material for a five hour forum has been developed. This program has an emphasis on Carer participation
- Feedback and information: Feedback forms have been developed as a result of this project to gather information from Carers about the forum itself as well as about the information provided at the forums such as the Checklist and Information Pack. Feedback surveys have also been developed for service providers.
- Contact List: A contact list to assist Carers planning for the future has been developed as a resource for Carers.
- Information Pack: A comprehensive Information Pack has been designed to provide information to Carers as they plan about services that are available to assist and fact sheets and other information which may assist them to make decisions about the future.
- Project Report: A report has been written about the project which provides an overview of the project, its outcomes and the feedback received from Carers and service providers who participated in the Ageing Carers Project.

## **Forums**

The project was delivered through a series of ten forums held in both metropolitan and country regions across South Australia. The forums provided an Information Pack and planning Checklist to participating Carers.

The principal purpose of the forums was to focus on the planning needs of ageing Carers caring for a son or daughter with a disability including mental illness.

This can be broken down into two areas of planning: a) the Carer's own future and b) the future of the person they care for.

In particular, the forums provided :

- Information to ageing Carers to assist them in planning for the future
- Opportunities for Carers to meet and network
- A setting for Carers to connect with Carers SA and local Carer Support
- Recognition of Carers for their contribution to the community, including Aboriginal and Culturally & Linguistically Diverse (CALD) Carers
- Acknowledgment of Carers' participation in Carer and consumer committees
- Information about services available to assist them
- The chance for Carers to meet local service providers
- Avenues for service providers to present information about their services to Carers
- Possibilities for Carers to hear about new initiatives
- Feedback from Carers about service delivery and the impact of this on Carers' needs from Carers
- Opportunities for service providers to provide feedback to Carers SA about the forums
- An opportunity for service providers and community leaders to be informed of the feedback.

### **Participant Profile**

The following profile of Carers attending the forums has been collated :

- 156 Ageing Carers of a son or daughter with a disability including mental illness registered to attend the forums and 132 attended the forums.
- Of these, 67.5% of ageing Carers live with the person that they care for, with 60.7% performing the caring role for over 40 hours per week.
- Carers who have been caring for their son or daughter with a disability including mental illness for between 36 to 56 yrs, equated to 64.4% of Carers in attendance.
- 53.7% of ageing Carers who attended the forums indicated that they are not in receipt of a Carers Allowance and 71.7% identified that they are not currently in receipt of the Carers Payment.
- Whilst the majority of ageing Carers were born in Australia (74.8%), of the 119 participants who responded to this question 25.2% were from CALD backgrounds.. CALD participants originated from the following countries of birth; England, Poland, Hungary, Italy, Holland, Lebanon, Malaysia, Scotland, Greece and Latvia.

The ageing Carers who attended the forums stated that they care for adult children with the following conditions:

### **Mental Illness:**

- Schizophrenia
- Schizo-affective disorder
- Paranoia
- Obsessive Compulsive Disorder
- Bi-polar disorder
- Depression
- Anxiety

### **Other Disabilities:**

- Intellectual disability
- Diabetes
- Legal Blindness
- Heart condition
- Epilepsy
- Encephalitis
- Macular Degeneration
- Cerebral Palsy
- Emphysema
- Quadriplegia
- Soto's Syndrome
- Attention Deficit Hyperactivity Disorder
- Asperger's Syndrome
- Deafness
- Kidney failure
- Down's Syndrome
- Hydrocephalus
- Chronic Rheumatoid Arthritis
- Autism
- Dyspraxia
- Dementia
- Acquired brain injury
- Dementia
- Tourette's syndrome.

From the one hundred and eighteen responses received from ageing Carers who attended the forums, the following profile was obtained :

- 26.3% care for a son or daughter with a mental illness
- 44.1% care for a son or daughter with a disability
- 23.7% care for a son or daughter with a dual diagnosis
- 5.9% did not identify the condition of their son or daughter

Appendix 1 contains the feedback and data collection forms used to collect information from the Carers who attended the forums.

### **Partnerships with Carers and Organisations**

Twenty four ageing Carers were involved in the delivery of the forums by facilitating forums, and sharing their Carer story, as well as assisting with the registration desk and setting up of forums. Eight organisations partnered with Carers SA in the delivery of the forums.

Working simultaneously with partner organisations and Carers provided a sound basis for the project operation as people felt that they had some ownership of the project. The end result was the building of a team that contributed to the project. Carers seemed to feel comfortable with this team approach and responded by contributing to the team in their own way.

## **Principles**

The mission of Carers SA is to promote, assist, empower and enhance the lives of Carers.

In developing the project, the following principles were developed in keeping with the Carers SA mission statement:

1. Ageing Carers would be consulted about their needs and wishes concerning the project.
2. Carers would be involved in all aspects of the delivery of the forums
3. The needs of Carers would take priority in designing the forum program
4. Carers SA would work in partnership with other organisations to deliver the forums
5. The forums would be aimed at a generic audience, and Culturally and Linguistically Diverse (CALD) and Aboriginal forums should be separately funded.

## **Carers' Stories**

At each Ageing Carers Forum two Carers were asked to share their caring story. Carers shared moving accounts of their personal experiences as Carers of a son or daughter with a disability including mental illness. Carers shared stories about what plans they had put in place and what they were yet to do to plan for their own future care needs as well as the future care needs of their son or daughter.

## **Participant feedback about the forums**

Carers described the section "Planning for future care workshop", presented by Joy Anasta, as excellent and full of helpful information. They appreciated the presentation and professionalism of all of the Carer speakers and service providers as well as the information given and the support gained from sharing with other Carers. Many stated that this would help them to get started on planning for the future.

Many participants found it difficult to suggest any enhancements to the forum content. Some participants commented that they would like more specific information about services while some felt that there was a lot of information to absorb and that the day was quite lengthy.

Participants recommended that further sessions be held focusing on the various items in the Checklist in more depth.

## **Feedback about supports for Carers**

Many ageing Carers observed that they gain support from their support groups and their local Carer support organisations, as well as from family, friends, the local community and church, and indicated they were aware of other support options available if required. However, some participants mentioned isolation for themselves and the caree from family, friendship networks and local community.

### **Feedback about services**

Some participants recognised that they had received excellent respite support services in particular regions.

Ageing Carers stated several concerns about services : they are often confused about services, frustrated in accessing services, disappointed by services ceasing or adversely affected by reductions in hours and type of services offered. There was ongoing concern about services dismissing the knowledge and involvement of a family member.

Carers stated that there are too few day program options available for carees. Many participants expressed disenchantment with inflexible eligibility criteria imposed by services, as well as frustration at filling out large quantities of service provider paperwork on an ongoing basis. They expressed concern about who will do this for the caree when they are no longer able to.



*Service Providers (L – R) Wendy Pearce, Francie Boylon (UnitingCare Wesley Adelaide) and Michelle Jenkins (Eyre Carers).*

### **The Value of the Project**

Forum participants were asked to rate the following items on a scale of 1 to 5 where 1 = Low and 5 = High:

#### **Forum Components:**

Overall Forum, Carer Stories, Planning for Future Care Workshop

#### **Materials:**

Succession Planning Checklist for Older Carers & Information about Services

The replies have been summarised in the following table:

Component	No answer	1	2	3	4	5	Total
Overall Forum	1	0	0	3	22	88	<b>114</b>
	.9%	0.0%	0.0%	2.6%	19.3%	77.2%	<b>100.0%</b>
Carer stories	0	0	0	4	17	94	<b>115</b>
	0.0%	0.0%	0.0%	3.5%	14.8%	81.7%	<b>100.0%</b>
Planning for Future Care workshop	6	0	0	5	27	71	<b>109</b>
	5.5%	0.0%	0.0%	4.6%	24.8%	65.1%	<b>100.0%</b>
Succession Planning Checklist for Older Carers	3	0	2	5	21	80	<b>111</b>
	2.7%	0.0%	1.8%	4.5%	18.9%	72.1%	<b>100.0%</b>
Information about services	2	0	1	2	21	74	<b>100</b>
	2.0%	0.0%	1.0%	2.0%	21.0%	74.0%	<b>100.0%</b>

Overall, over three-quarters of the participants gave the forum a rating of 5. The individual component which attracted the highest rating was "Carer Stories", followed by "Information about Services", "Succession Planning Checklist" and then "Planning for Future Care Workshop".

Other comments about the forums by respondents included: "well planned and extremely well organised", "understanding and informative", and "well worth attending".

Feedback was also given by participants about the Information Packs and Checklist provided to ageing Carers with the rating again being 1 = Low and 5 = High:

- 74.6% of Ageing Carers rated Information Packs at level 5
- 68.4% of Ageing Carers rated the Checklist at level 5

### Direction for the future

It was agreed that the Checklist and Information Pack should continue as Carers SA resources; however, they should always be offered in conjunction with each other.

It was also decided that the Checklist should only be given to Carers who have attended a forum on planning for the future, as it may be too overwhelming otherwise; Carers then be given the opportunity to follow through with the more intensive sessional topics.

Carers would like the Ageing Carers forum to continue so that other regions can be targeted along with Carers who have yet to attend. Carers who have already attended, however, require further ongoing support; future funding should be directed towards intensive sessional topics with referral options available.

## **Conclusion**

The success of the project is reflected in both written and verbal feedback collected following the forums. There have been many positive outcomes from this project.

Firstly, Carers SA has supported ageing Carers to commence the succession planning process with great success.

Secondly, the project has generated an excellent tool for Carers that could be formalised into a product available to all Carers in the future.

Thirdly, it has established productive partnerships with other organisations which we hope to continue for the benefit of ageing Carers who are attempting to make plans for their future and the future of the person they care for.

## **Recommendation**

That funding be made available to hold more forums and follow up information sessions for Carers who are planning for the future. This would mean that the Information Pack and Checklist developed as an integral part of this project would continue to assist Carers through the process.