



Quality Support Groups Research Project Phase III, 2009, Alzheimer's Australia NSW, Sydney

Executive summary

A constant and key service deliverable of Alzheimer's Australia NSW, since its inception in the early 1980s, has been the assistance the organisation provides to dementia support groups for carers.

As the 'dementia tsunami' headed toward us some five years ago, service providers began to make plans to accommodate the projected increase in the number of people living with dementia (Access Economics, 2003). At the time there was little documented evidence about dementia support groups in New South Wales: their content and processes; their quality or effectiveness. Due to the scarcity of research undertaken in Australia or elsewhere, Alzheimer's Australia NSW instigated the *Quality Support Groups Research Project*. The aim was to investigate and document what constitutes *quality* in a dementia support group for carers in New South Wales.

The results of this research provide the first comprehensive state-wide Australian study of ongoing support groups for carers of people with dementia. The term *ongoing* support group refers to groups that run continuously, as opposed to short-term support groups, and are generally open to new members on an ongoing basis.

The Project consists of three phases. Phase I of the Project comprised a literature review of dementia support group research and an investigation of the views of support group leaders.

At that time (2005) over 150 active groups were identified across New South Wales with a significant percent (68%) in regional and rural communities.

Support group leaders who responded to the survey were mostly health professionals (86%) with the remainder volunteers. The findings indicated the social and informational needs of carers were 'met well' in the group setting; however, many leaders requested an increase in group skills training to assist them in meeting the emotional needs of carers. Also, leaders requested an opportunity to increase their capacity to network with each other.

Phase II of the Project comprised of an investigation of the views of carers across New South Wales who had, at some time, been members of an ongoing dementia support group. The majority of respondents were female (75%) and spouses (72%) although there was some diversity among the group members such as their relationship to the person with dementia, and cultural background. Analysis of the research from Phase II indicated that the carers' capacity to manage and cope with their day-to-day concerns is strongly influenced by their support-group experience and that the most positive socio-emotional outcomes are experienced by members who attend group sessions on a regular basis.

This third and final phase integrates and synthesises the findings of Phase I and II to provide for a holistic understanding and the formulation of best practice guidelines.

The findings highlight significant discoveries: the most notable of these is the uncelebrated capacity of group members to provide mutual aid in support of each other in the safe and trusting environment of the carer groups. The data also revealed the experience of grief and loss as a profound commonality shared by group members.

Carers of people with dementia can experience five different dimensions of grief and loss: at the time of diagnosis of dementia; as the known personality of the person with dementia changes; on the transition to a residential care facility; during palliative care and post death and; as the carer's self-identity changes. It was found that the way these dimensions are managed by the individual and the group is influenced strongly by the skills and experience of the group leader.

The adoption of best practice guidelines by the many quality dementia support groups in New South Wales has the potential to assist all groups. Best practice guidelines support and encourage groups that require extra assistance and affirm those that currently reflect quality in their practice.

In the quest to continually improve modes of support and service delivery for carers of people with dementia, findings from the *Quality Support Groups Research Project* highlight the following areas for ongoing consideration and research:

- The recognition of best practice guidelines for quality support groups
- The expansion of group skills training for leaders
- The acknowledgement of carer diversity

- The acknowledgement of emotional stress experienced by carers
- The development of specific program sessions
- The reduction of stigma associated with dementia
- The investigation of a model of voluntary endorsement for quality support groups.