Quality Support Groups Research Project

A Report on Dementia Support Groups in New South Wales

Phase II
A literature review, leaders’ perspectives and group composition

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ALZHEIMER’S AUSTRALIA NSW
Supported by The Centre for Research on Social Inclusion, Macquarie University
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We would like to acknowledge and thank

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- Associate Professor Michael Fine from Macquarie University’s Centre for Research on Social Inclusion for his technical consultation, advice and feedback with regard to all aspects of the Project and his contribution to Chapters 1, 2, 3 and 4

- The staff of Alzheimer’s Australia NSW particularly Anne Tunks; Lisa Ralphs, past manager Client Services; and Lewis Kaplan, past Chief Executive, for their support and encouragement

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- Special thanks to the support group run by Janet Godsell, the Daughters and Sons Group run by Anne Tunks and Lyndell Huskins and the support group run by Fay Crampton for allowing us to attend and photograph their support group meetings.

This report presents the second phase of the Quality Support Groups Research Project, which acknowledges the voices of past and present members of dementia carer support groups.

Alzheimer’s Australia NSW recognises the demands of caring for a person with dementia and continues to pursue the development of quality resources and services to assist carers in their everyday life.

To this end, the Quality Support Groups Research Project provides new and worthwhile information that will enable a better understanding of the diversity of experience amongst dementia support group membership, the needs of current and former carers and the ability to pursue excellence in our quest for quality support groups for all carers of people with dementia.

Bill Northcote  
Chief Executive
Phase I of the Quality Support Groups Research Project presented the first part of a comprehensive investigation of dementia support groups for carers of people with dementia across New South Wales. It provided an expansive review of current literature on the subject of dementia support groups for carers of people with dementia and noted the global changes that have taken place with regard to their content, process and appropriateness for this particular clientele. In addition a large survey of over 150 support group leaders was conducted to explore their views and so begin an understanding of what constitutes a quality support group.

This second phase of the Quality Support Groups Research Project continues the investigation by canvassing the views of carers who have at some time attended a dementia support group. Over 200 carers, from both urban and rural areas of New South Wales, participated in this research by way of a questionnaire or as part of a focus group or telephone interview.

The findings establish overwhelmingly that for many carers of people with dementia an ongoing dementia support group is a vital and worthwhile source of assistance in both practical and emotional terms. The research found that the desire to access education and information about dementia and related service options is the main impetus for support group membership. However, members who continue to attend a dementia support group stated that the mutual aid they give to, and receive from, other members is paramount and often becomes the main reason for membership.

The optimum success of a mutual aid model within a support group can only be achieved if the group has a leader skilled in group work. As was established in Phase I of the Project, and replicated in the findings from Phase II, the groupwork skill level of a leader can either enhance or detract from the quality of a support group.

Although the self-selected sample of research participants did not provide a large representation of carers from culturally and linguistically diverse backgrounds there were other presentations of diversity. These included evidence of: different relationships between the carer and the person with dementia; diversity amongst the different stages that are being lived through for the person with dementia and their carer; and the diversity of residential arrangements for the person with dementia and their proximity to the everyday lives of the carer.

Support and advocacy for all carers of people with dementia drives the work of support groups resourced by Alzheimer’s Australia NSW. As a result of findings from this research the following recommendations have been made:

- Continue carer advocacy
- Recognise and accommodate the different needs of all carers
- Increase the use of information technology
- Expand group skills training for leaders
- Acknowledge emotional stress amongst carers
- Increase community awareness
- Expand the availability of respite services and
- Determine quality standards for dementia support groups
I realised I was not alone ...
1. Introduction

As the number of groups operating in different fields of human service grows, it is easy to overlook just how innovative their approach to care and welfare in Australia is and to forget how recent the introduction of support groups has been. It is unknown how many support groups are currently operating in Australia and the number of people who participate in sessions on a regular basis. Yet the very existence of these groups raises important questions about the place of support groups within the broad range of possible interventions, and about current patterns of provision and use.

Alzheimer’s Australia NSW has a particular interest in these issues due to the important role support groups play in providing assistance to carers of people with dementia. The organisation has worked to popularise the operation of such groups since the early 1980s. For many people in this State the local support group is their main connection to Alzheimer’s Australia NSW. There exists anecdotal research into NSW dementia support groups but, until now, there has been no systematic study available of the operation of, or the experience of belonging to, ongoing support groups for dementia carers in New South Wales.

This report presents the results of the second phase of a major study undertaken by Alzheimer’s Australia NSW into the operation of dementia support groups in this state. The first stage of this research released in 2005 helped map current groups and sought the perspective of group leaders about their operation. This second phase aims to hear the voices of carers who have at some time attended a support group in New South Wales. It documents the results of a questionnaire-based survey undertaken in 2006 and completed by over 200 current and former members of support groups in New South Wales. These results are complemented and informed by a series of in-depth interviews and focus groups conducted by the researchers amongst the members of dementia support groups.
... the opportunity to share with others your unique experience of caring for someone with Alzheimer’s. You can’t share with people not involved ...

To talk about what is happening to my father and to learn from and feel supported by the experiences of others in the same boat
This study is the second phase of an ongoing program of research into the operation of dementia support groups, begun by Alzheimer’s Australia NSW in 2003. The first phase of the research (Brown and Tweedie, 2005) identified a total of 159 active support groups in the State. Drawing on the results of a comprehensive literature review of research into dementia support groups, Phase I presented the results of a survey of group leaders responsible for the operation of such groups across the New South Wales.

Support groups may be thought of as one of the products of the introduction of the self-help or consumer empowerment movement in human services. Due to their low cost and their capacity to actively engage carers, or others requiring support, they are able to provide powerful forms of assistance. Support groups appear to act in a preventative fashion, reducing the need for more invasive and expensive forms of intervention. Since their introduction in the 1970s the number of groups in Australia and overseas has grown enormously, not least of all in the field of support for carers of people with dementia.

Findings from the first phase of the Quality Support Groups Research Project provided strong evidence that, from the perspective of the group leaders, dementia support groups provided considerable social support for participants. There was evidence that group leaders made efforts to provide up-to-date education and information to participants.

The results indicate wide variation in the way support groups operate, as a result of local adaptation, the history of each group, and the skills and perspectives of the group leader. This second phase of the Quality Support Groups Research Project surveys support group participants to develop a more comprehensive picture of the current operation of dementia support groups.

The recommendations from the first phase of the research cover six areas (Brown and Tweedie, 2005, pp.45-46):

i. Extend investigative research with carers

ii. Development standards, based on clear indicators of quality and process

iii. Develop specific programs to include short-term focused models of intervention; develop strategies to disseminate successful models and programs; develop services for culturally and linguistically diverse (CALD) populations, including teleconferencing models; establish new services in areas not serviced; and develop an overall strategic plan for research and program direction

iv. Expand group skills training for leaders, following further investigation

v. Identify the different needs of all carers, including males and females, spouses, daughters, sons, friends, neighbours and people from various CALD backgrounds

vi. Identify service gaps in relation to location and new or expanding service areas, and develop networks and strategies to address these gaps.

This study is a response to the first of these recommendations and intends also to help advance the others. It intends to expand and deepen the research program by identifying issues of relevance to the participants of support groups operated by or linked to Alzheimer’s Australia NSW. In accordance with these recommendations, this study surveys both carers who attend a support group and others who previously belonged but no longer attend such a group. To ensure that the voice of carer participants will be directly heard, a triangulated form of research was implemented which included use of a questionnaire-based survey, telephone interviews with a smaller number of carers and a number of focus groups.

The significance of dementia support groups

Dementia support groups were the first public program developed by Alzheimer’s Australia NSW (then known as ADARDS) in the early 1980s. As Lovi and Tweedie noted, these support groups were intended

- to provide family carers with the opportunity to meet with other family carers, for the purpose of obtaining information about dementia and caring strategies for a person who was affected by dementia (2001, p.1)

The widespread take-up of the program, which helped it expand to cover most localities in the State, showed that the groups were meeting a deep-seated need. Research on the outcomes of carer support programs,
Mutual aid is a process whereby different people come together with a shared problematic situation that is solved or at least lessened by the giving and receiving of information about the shared situation.

Including the landmark studies of dementia support groups by Brodaty and Gresham (1989) and Toseland and Rossiter (1989), confirmed the value of these groups. These studies stressed the significance of an educational component to attain measurable outcomes, such as the reduction of the rate of institutionalisation of the person with dementia.

Currently in New South Wales there are approximately 220 support groups affiliated with Alzheimer’s Australia NSW, making it a widely recognised and popular program of assistance.

The literature review in the first phase of the Quality Support Groups Research Project showed two types of groups: ongoing groups, essentially based on the principles of mutual aid, and groups that are typically more short-term and more closely focused on the provision of psychoeducational interventions (Brown and Tweedie, 2005). The mutual aid approach is based on the development of informal social support mechanisms through members sharing their experiences. This approach fosters the development of social networks that provide participants with ongoing ties to other group members, relieving the isolation that is so often experienced by those who need, or provide, ongoing care in the home. Psychoeducational interventions, in contrast, are focused on skills development through the provision of specific information and the development of new competencies, by members attending structured and planned sessions. Many groups try to combine elements of both approaches.

Internationally, a move towards increased professional involvement in the operation of support groups is evident over the past 10 years (Adamsen and Rasmussen, 2001). This suggests that the early emphasis on self-help as an alternative to reliance on professional interventions may be giving way to a more integrated approach. Now support groups are recognised as a legitimate form of intervention at the meeting point of informal, familial help, and the more traditional and established professional system of formal support.

The results of the first phase of the Quality Support Groups Research Project suggested that existing group leaders in New South Wales believe the main purpose of dementia support groups is to provide an opportunity for carers to experience support through sharing education and information about services within a social group setting. Providing education and knowledge about services and resources are clearly important inputs for those commencing a ‘caring career’, but these are not sufficient, over time, to sustain the interest of carers who have been caring for some time.

Another recent development gaining recognition in the research literature concerns new directions and challenges for carer self-help groups. All over the world, increasing use is being made of new information technologies, such as the internet (Bass et al, 1998). Developments in innovative group work involving virtual and telephone support programs often occur on the edge of existing practices, as newly emerging client groups, such as employed caregivers, have been recognised but have remained outside the existing service system. The flexibility of the internet, which can enable the formation of support groups for individuals who live in widely separated areas, is clearly a significant factor in this. Chat rooms provide one such possibility, but other approaches, such as email chains and the use of bulletin boards, are also increasingly common. Driving this trend is the need to find ways of adapting to an increasingly individualised pattern of modern life, as well as the demographic and generational effects associated with technology. Carers are both increasingly familiar with IT mediated communication and, in some cases at least, less disposed to seek time during the day when they can attend lengthy locally based meetings.

What is missing in the literature, surprisingly, is evidence from the participants themselves – especially the long-term and recent participants of such groups for whom fellow members have often become their only meaningful social contact. This study aims to address this by drawing on a mixed-methods research approach in seeking participant’s views, combining the breadth and representative capacity of a postal survey with the in-depth investigative capabilities offered by individual interviews and focus groups. It will inform the ongoing operation of groups linked to Alzheimer’s Australia NSW as well as provide insights into the general phenomena of support groups.

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1 Mutual aid is a process whereby different people come together with a shared problematic situation that is solved or at least lessened by the giving and receiving of information about the shared situation.
We have an excellent leader who has helped each and every one of us along the line. We have much respect and love for her and really appreciate what she has done to help us all. She is always caring and has a lot of insight into our feelings and situation.
... I would like more guest speakers on Alzheimer’s. Would like the yearly seminars to continue: there is so much information from the people who have given them.
The second phase of the Quality Support Groups Research Project is based on data collected from carers of people with dementia who, at some point, have belonged to a dementia support group. This research, which surveyed carers, aimed to extend and complement the views of the support group leaders documented in the first phase. To ensure that the results were comparable, a written, questionnaire-based survey of respondents is common to both phases. It was clear, however, that such a survey would not allow some of the most important questions to be addressed in any depth, so an additional, qualitative component of the research was added by way of telephone interviews and focus groups, for this second phase.

Recruiting Participants
To ensure the survey was as representative as possible, invitations to participate were circulated to all support groups via the group leaders and the Alzheimer’s Australia NSW newsletter Intouch. Participating carers were required to either be, or to have been, a member of a dementia support group at some time, even if the person they cared for had died. Completion of the Living with Memory Loss program, an educational course offered by Alzheimer’s Australia NSW that includes the option of participation in a short-term support group, did not constitute dementia support group membership. Only those carers who responded to the invitation and who fit the criteria were included in the survey. As data collection proceeded, participants who accepted the invitation to complete a self-administered questionnaire were asked whether they would also like to participate in a focus group.

In total 213 support group members responded. From this group 12 respondents were eliminated who did not fit the selection criteria, leaving a total of 201 valid respondents. This represents approximately 10 per cent of the total membership of dementia support groups in NSW and has ensured the sample is a good representation of the total membership. The number of respondents represents a return rate of 87 per cent. An overview of respondents is presented in Table 1.

The typical respondent is female (75% of respondents), aged between 50 and 75, and is a long-term member of a support group, having attended for at least a year, and in almost half of the cases for more than four years. Almost all are close family members of the person with dementia. By far the largest group were spouses, mostly women. Over 98 per cent of those who completed the questionnaire spoke English at home.

Amongst the 166 who provided information about the person with dementia, 58 per cent reported that they lived together. Indicative of the severity of the condition, over one third had already been admitted to residential care or another form of supported accommodation. Once again, almost all of the people with dementia spoke, or had spoken, English at home.

The Questionnaire
A questionnaire was developed from the results of Phase I of the research project, and from the review of current literature and other evidence from carers. The questionnaire was divided into three sections:
1. Questions about the carer
2. Questions about the person being cared for
3. Questions about the carer’s support group membership

The questionnaire was reviewed by research colleagues then piloted with a selection of carers. It was distributed within a package that included a cover letter, the questionnaire, and two consent forms – one for the carer to retain and one to be returned to Alzheimer’s Australia NSW with a reply-paid envelope. To encourage the respondent to sit down and think through their responses, a tea or coffee bag was also included. Personal details were not recorded, except the carer’s postcode, which helped to identify the geographical areas canvassed. Ethical approval procedures allowed follow-up contact with carers who did not return their questionnaires. If a carer expressed interest in participating in the Project but was unable or reluctant to complete the written questionnaire, a telephone interview was offered at a time convenient to them.

Telephone Interviews
Telephone interviews were conducted with 12 carers who at some time had been members of a dementia support group. These carers included those who had...

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Most of these respondents confused the Living With Memory Loss short term support groups with the ongoing support groups under investigation.
### Table 1. Overview of respondents

<table>
<thead>
<tr>
<th>Characteristics of Carers</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td>male</td>
<td>49</td>
<td></td>
<td>female</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>under 40</td>
<td>0</td>
<td></td>
<td>41-50</td>
</tr>
<tr>
<td><strong>Carer status</strong></td>
<td>current</td>
<td>166</td>
<td></td>
<td>past</td>
</tr>
<tr>
<td><strong>Time spent caring for a person with dementia</strong></td>
<td>less than 1 year</td>
<td>2</td>
<td></td>
<td>1-3 years</td>
</tr>
<tr>
<td><strong>Relationship to the person with dementia</strong></td>
<td>Husband</td>
<td>38</td>
<td></td>
<td>wife</td>
</tr>
<tr>
<td><strong>English spoken at home</strong></td>
<td>yes</td>
<td>160</td>
<td></td>
<td>no</td>
</tr>
<tr>
<td><strong>Group membership status</strong></td>
<td>current</td>
<td>158</td>
<td></td>
<td>past</td>
</tr>
<tr>
<td><strong>Attendance at meetings</strong></td>
<td>every time</td>
<td>77</td>
<td></td>
<td>most times</td>
</tr>
<tr>
<td><strong>Length of membership of a support group</strong></td>
<td>less than 1 year</td>
<td>20</td>
<td></td>
<td>1-3 years</td>
</tr>
</tbody>
</table>

### Table 2. Characteristics of the person with dementia

<table>
<thead>
<tr>
<th>Characteristics of the Person with Dementia</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Residential status</strong></td>
<td>lives with carer</td>
<td>97</td>
<td></td>
<td>lives alone</td>
</tr>
<tr>
<td><strong>Officially diagnosed with dementia</strong></td>
<td>yes</td>
<td>166</td>
<td></td>
<td>no</td>
</tr>
<tr>
<td><strong>How long person has had dementia</strong></td>
<td>less than 1 year</td>
<td>2</td>
<td></td>
<td>1-3 years</td>
</tr>
<tr>
<td><strong>English spoken at home</strong></td>
<td>yes</td>
<td>153</td>
<td></td>
<td>no</td>
</tr>
</tbody>
</table>
selected the telephone interview option as well as those who were unable to complete the questionnaire on time. Interviewees were asked the same questions as those in the questionnaire, however due to the ‘one-on-one’ nature of these calls extra anecdotal information was a positive addition to the data.

Focus Groups
A number of carers expressed interest in attending a focus group. Groups were conducted in Sydney, the Central Coast and Dubbo. In addition, a teleconference style focus group was held to link carers from remote areas such as Broken Hill and Gunnedah. These groups not only geographically expanded our investigation but gave the data greater depth and context.

Questions in the focus groups were kept to a minimum and had these themes:
- Loss of self in long-term caregiving
- Expectations prior to membership of a dementia support group
- Positive and negative consequences of membership of a dementia support group
- Suggested improvements for dementia support groups

The groups were facilitated by a member of the research team and a second staff member took notes. A tape recording of the session was also made.

Data Analysis
Closed questions from the questionnaire and telephone interviews were analysed using the SPSS\(^3\) program. Manual content analysis was conducted for the open questions in the questionnaire, telephone interviews and the focus group data.

After the data collection had been finalised, a dialogical research session was conducted with stakeholders within Alzheimer’s Australia NSW and a representative from Macquarie University’s Centre for Research on Social Inclusion, to articulate common concerns and the continued direction of the Project.

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\(^3\) Statistical Package for the Social Sciences
I learnt to understand my situation. I could not learn from books as there was no time for me to read. I learnt to understand unusual behaviours and deal with them with kindness and love.
Support groups help both the carer and the care recipient, according to those participating in this phase of the study. Respondents consistently reported that belonging to a group and participating on a regular basis provided them with a double benefit. On the one hand, membership kept them abreast of current developments in treatment and services and ensured that they had access to the information they needed to best look after the person with dementia. On the other, they acknowledged the significance of belonging for their own wellbeing, as the group was a source of companionship, advice and personal support, and confirmed they were not alone.

Research with family caregivers has consistently shown that caring for a relative with dementia is an isolating and often lonely experience (Schofield et al, 1998; Seltzer and Wailing, 2000). Support groups, in contrast, bring people together and enable them to share their experiences, if not the work and the long hours involved, with others. Some researchers go so far as to argue that membership of a support group helps to normalise the experience of its members. The authors of one recent review, for example, report that despite a feeling of having been stigmatised and possibly also ostracised from other social relations, participants … sense that, with the group, they belong to some kind of community (Adamsen and Rasmussen, 2001, p.913).

This raises a number of important questions: What draws members to the support groups? What do they find valuable once they are there? And why do so many carers appear to choose not to belong?

This chapter considers the benefits of belonging to a carer support group from the perspective of those who have chosen to belong. Drawing on the data from both the questionnaire and the follow-up focus groups, it looks at the pathways dementia carers follow by joining support groups; reasons for attendance; their expectations of the group experience; and their experiences as members. Possible reasons for other carers’ non-attendance are also considered.

To enable an understanding of the different characteristics each carer brings to a support group this report examines the health and wellbeing of carers, with a focus on mental health; their responsibilities other than caring for a person with dementia; how they cope with the changes in their lives; and how their membership in a dementia support group provides assistance.

Lastly, this chapter acknowledges other sources of support, including member friendships, which carers utilise outside the group time.

From diagnosis to support group membership
When a person is diagnosed with dementia the immediate effect on the carer can be devastating. Some carers reported a lack of direction during this time, not knowing where to turn. Furthermore, it was reported in both the questionnaire and the focus groups that some GPs did not always offer referrals or information about dementia support groups. Therefore, to avoid undue carer distress and anxiety, it is imperative to reduce the length of time between diagnosis and contact with quality support services for carers of people with dementia.

Our research found the average time span between a diagnosis of dementia and joining a dementia support group was three years.

**How do carers find out about dementia support groups?**

When asked to specify the source of referral to the dementia support group attended, carers’ most common response was medical services (see Table 3). These services included Aged Care Assessment Teams (ACAT), GPs, medical specialists and hospitals. Alzheimer’s Australia, including the National Dementia Helpline, was the next most common source of referral. Other referral sources were community services such as day care centres; the community nurse; the local council; friends and family; the media; and residential care facilities.
Why do people join dementia support groups?

Findings from the research indicate that the initial driving force for support group membership is a need for education and information about dementia. Strong indications of a need for ‘support’ were expressed as a desire to meet other carers in a similar situation and share experiences.

As shown in Table 3, recommendations by other parties were a major factor in the decision to join a support group. A small percentage of respondents, however, indicated a lack of information and support from other sources had been a motivation for them to seek out a group.

Carers come to groups with a variety of expectations. In both the quantitative and qualitative data this survey found the expectation of the level of education and information that would be gained from membership of a dementia support group was met effectively for a high number of carers.

On first joining the group carers did not place a high priority on meeting their social or relational needs. However, when questionnaire respondents were asked what benefits they had received since they had been part of a support group, the overwhelming response was what can be described as the social process of mutual aid.

It would appear that the mutual aid model, which has been adopted by many dementia support groups in New South Wales, is the main reason that regular members continue to attend. The benefits of support group membership are strongly felt from this social model of care. Both social and educative connections are made with others in similar situations, reducing the sense of isolation.

In the groups, information about services and tips for managing a person with dementia are imparted on an informal and practical level and, once social connections are made and the carer feels safe within the group setting, emotional support becomes another important consequence of group membership. Sharing experiences and feelings with others in similar situations is an important psychological benefit of the group.

---

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**Table 3. Joining a Dementia Support Group**

<table>
<thead>
<tr>
<th>Participants’ Responses</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Referral source to the support group</strong></td>
<td></td>
</tr>
<tr>
<td>Medical Services</td>
<td>38.3</td>
</tr>
<tr>
<td>Alzheimer’s Australia</td>
<td>25.4</td>
</tr>
<tr>
<td>Community Services</td>
<td>14.4</td>
</tr>
<tr>
<td>Friend/family</td>
<td>12.1</td>
</tr>
<tr>
<td>Media</td>
<td>7.0</td>
</tr>
<tr>
<td>Residential Care Facility</td>
<td>2.8</td>
</tr>
<tr>
<td>All responses</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Reasons for joining a support group</strong></td>
<td></td>
</tr>
<tr>
<td>Education and information about dementia</td>
<td>47.7</td>
</tr>
<tr>
<td>For ‘support’</td>
<td>40.8</td>
</tr>
<tr>
<td>Recommendation from others</td>
<td>8.4</td>
</tr>
<tr>
<td>Followed on from Living with Memory Loss Program</td>
<td>2.5</td>
</tr>
<tr>
<td>Lack of help from GP</td>
<td>0.6</td>
</tr>
<tr>
<td>All responses</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Notes: 1. n=166; 2. Respondents were able to give multiple responses to this item n=321

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I have discussed intimate details amongst the group members that I would not even talk to my family about
(female spousal carer)

I have met people in the same situation and can express my feelings as we all understand each other. The support group gives me aids to help me understand
(daughter)

Helps me to know I’m not alone. Can express my most personal and intimate experiences with the group with no ‘censorship’
(female spousal carer)

(It helps) that others are in the same situation, and the ability to share and help each other, and also to
be able to laugh at some aspects of the situation (former female spousal carer)

Carers who proffered less enthusiastic responses about the benefits of support group membership often referred to a lack of this type of shared understanding and emotional support within their particular group. While many respondents (47.7%) said a need for information and education was a major reason for their initial attendance at a support group, it was those who received social and emotional support who continued to attend.

**Attendance**

Attendance at support groups was fairly regular, with 88.2 per cent of current members reporting that they attend meetings ‘most times’ or ‘every time’. This consistent attendance pattern enables social and emotional connections amongst members and, in turn, the development of trust and reciprocity. The length of current group memberships reported ranged from less than one year to 15 years. The average length of time for membership was in the one – three years category.

**Reasons for non-attendance**

Why, then, do so few carers attend support groups? Most commonly, a lack of community awareness of dementia support groups was articulated as a reason for non-attendance. Many carers indicated they would have joined their group earlier if they had been aware of its existence. One carer from rural NSW asked “Why wasn’t I told about this sooner?”

Negative community attitudes have stigmatised dementia. This stigma creates adverse implications for carer support as carers are often reluctant to assert their need for assistance. Some focus group participants assumed that others, as they themselves had once been, were too embarrassed to join a group of strangers, due to the intimate and emotional issues they were facing, particularly immediately after the person for whom they care had been diagnosed with dementia.

Practical issues such as the meeting time, location of the venue, and transport or respite constraints also played a part in preventing some carers attending a support group. Unavailability of respite services was reported frequently by respondents as a reason for non-attendance, with many stating they would attend more regularly if they could bring the person they care for along with them.

Research conducted by Brodaty et al (2005) into the major impediments to service use by caregivers of people with dementia reflect these findings and claim “better public promotion of services, destigmatising dementia and encouraging referrals from health professionals” (2005, p.542) would help increase service use.

Of carers who had once been members of a support group but were no longer, the reasons for non-attendance were varied. Some stated they had joined only to gain information about dementia and dementia-related services to help them in a practical way, and when that need was met they ceased attending.

Some male carers, in particular, did not like the informal social aspect of the group, with one carer exclaiming there was “too much chit chat!” Despite this there was strong evidence that male and female carers joined for, and gained significantly from, the social connections made. If this aspect was not evident in the group, particularly on an emotional level, attendance by the carer often ceased.

**Carer health and wellbeing**

The health and wellbeing of the members of the dementia support groups is a key focus for the Quality Support Groups Research Project. Many researchers, Brodaty and Gresham amongst them, acknowledge the “unremitting” burden of dementia that leads to carers becoming “demoralised, isolated and psychologically distressed” (1989 p.1375). Furthermore, current research (Hooker et al, 2002, cited in Frias et al, 2005) indicates that carers with poor emotional and physical health may not only have difficulty coping with their care activities, but that this adversely affects the wellbeing of the person for whom they care.

Carer health is an important research consideration as it impacts on the issues carers bring to a support group and, in turn, influences their needs as a
caregiver. Responses showed the number of health problems that affect each carer ranges between one and 10, with a mean of three health problems.

It is normal to expect an increase in health problems as a person ages and so, when asked if caring had affected their health, it was not surprising to find (Table 4) that most carers gauged their health to be between ‘normal for my age’ (41.0%) and ‘slightly worse due to my caring role’ (36.6%). While a lesser 22.4 per cent of carers stated their health problems had become ‘significantly worse due to my caring role’ there was a correlation between the length of time someone had been caring for a person with dementia and the increase in their health problems.

### Coping with change

The theme of change came up often throughout the Project, particularly emotional change and how it is accommodated.

The data found much evidence of change in the lives of carers:

- Reports of change in the carers’ social lives, such as friends who didn’t understand the new life of the carer, and the embarrassment and discomfort this caused
- Reports of change in the transition to full-time care. When a loved one is placed in full-time residential care, the wrench can be traumatic for the carer if appropriate support is not available
- Reports of tension amongst family members who don’t understand the diagnosis of dementia, the carer’s new life, or who are inaccessible
- Reports of carers’ responsibility for the person with dementia combined with additional responsibilities previously carried by the person with dementia.

Morris et al states that, unlike caring for a mentally alert but disabled person, the relationship between a family carer and a person with dementia is not mutually supportive:

> Carers of people with dementia become not only the minders but also the substitute minds for their carers (1988 p.147)

### Dealing with grief and loss

Grief and loss can be experienced by the carer:

- as the personality of the person with dementia begins to change
- when they must place the person they care for in a residential care facility
- when the person with dementia dies
- as the carer makes adjustments to their self-identity as a result of the demands of long term caregiving.

Mum is no longer the person we remember (daughter carer)

My husband shows aggression to me. He says I was the one who dumped him in the nursing home. I feel hurt and depressed when I visit him and the one-hour drive home is too much (carer in rural NSW)

Carers identified with the themes of grief and loss but gave a variety of responses about their experience within a support group setting. Many carers said grief and loss was acknowledged in the group setting, particularly by other members. Findings indicated

### Table 4. Have carers’ health problems become worse since caring for a person with dementia?

<table>
<thead>
<tr>
<th>Response</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No, my health is normal for my age</td>
<td>66</td>
<td>41.0</td>
</tr>
<tr>
<td>Slightly worse due to my caring role</td>
<td>59</td>
<td>36.6</td>
</tr>
<tr>
<td>Significantly worse due to my caring role</td>
<td>36</td>
<td>22.4</td>
</tr>
<tr>
<td>Total</td>
<td>161</td>
<td>100.0</td>
</tr>
</tbody>
</table>
the groups also offered practical advice during times of grief and loss, such as with financial and legal requirements, nursing home placement and access to services as dementia progressed. However, many other carers reported their support group did not offer any emotional support during the inevitable periods of grief and loss.

The group gives me an insight into how to preserve relationships and understand what was happening (wife of a person with younger onset dementia)

(The group has given me) experience in coping personally and coping with each stage of dementia. Emotional support and total honesty from others in the group at each stage crisis including planning and coping with death and after (female spousal carer who has been a group member for seven years)

The group avoids the painful and emotional issues whenever they begin to arise (daughter caring for 14 years)

Grief and loss is commonly experienced when a carer decides to relinquish full-time care of the person with dementia to sharing care with a residential care facility. This can signal a time of intense grief and loss. Not only does the carer endure the ‘loss’ of the person they care for to a formal care institution, but also the loss of day to day ‘social’ connections that exist via community nurses, visits to the doctor and other support services that are set up to aid the carer and the person with dementia living at home.

One female carer reported that her support group had been an invaluable source of support during the period in which she placed her husband in residential care but, once he had been permanently settled, she had not heard from anyone. She described the terrible guilt and loneliness that she felt and wished that she had received at least a phone call to “check up on her, and see how she was going”.

Kellett (1999) tells us that “family caregiving does not always stop at the nursing home door” and that the care recipient’s entry to a residential care facility can often be accompanied by the carer experiencing feelings of losing control; of sadness and relief simultaneously; and of guilt at having to make an at-times reluctant choice. Kellett (1999) states that this time “signals the beginning of a different but still potentially stressful involvement” for the carer. Kellett’s research supports this report’s findings that sound social and emotional support of a dementia support group at this vulnerable time is paramount.

Carer’s self identity

While people have to change many aspects of their everyday lives to accommodate the care of a person with dementia, they also have to alter many of their personal traits to cope with the change that dementia brings to their lives.

   I go on guilt trips after I’ve been impatient (female spousal carer)

The issue of the carer’s changing self identity was broached at focus groups. Often this touched a raw nerve and emotions were brought to the surface.

One tearful woman explained she had been caring for her mother for the whole period of her retirement and had not had the opportunity to undertake any of the plans she had made while she was still working.

Interestingly, at the same focus group another woman claimed that she had lived in the shadow of her husband, who now had dementia. Through the knowledge she had attained at the dementia support group she had found a new sense of self. This new found assertiveness and empowerment was a support for her in the care of her husband and also strengthened her own self-esteem.

   At last I have the knowledge, I am the authority on dementia and he realises I know what is best for him (female spousal carer)

Another two female spousal carers in the group agreed they felt the same.

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4 younger onset dementia is that which is diagnosed in a person under the age of 65 years.
Storytelling

Storytelling is a valuable feature of the mutual aid model and is intrinsically woven into the process of quality support groups. Support group members unintentionally find a renewed sense of self-worth in having permission to tell their story. Stephanie Dowrick (2006) wrote in the Sydney Morning Herald recently:

There is something about others’ participation through listening that is also vital. When the story is one that really matters to us, it often releases a great deal of tension to tell it – and sometimes tell it again and again. Listening to ourselves as we share with others, we are doing more than ‘getting it out’. We are giving ourselves a chance to receive comfort and validation, and helping ourselves to make sense of things, to find a pattern and perhaps a way forward (2006, p.57).

Value of Respite

Learning the value of having respite time was a pertinent outcome of group membership, with many carers reporting they had no previous knowledge about the value of respite or respite services before joining their group. Leaders and members alike encouraged other carers to take time out for themselves and practical information about respite services was often imparted by the support group leader and other members.

I’ve learnt that respite care for my husband outside the home is invaluable. I’ve shed the sense of guilt and can consider permanent placement rationally
(female spousal carer whose husband has younger onset dementia)

Some carers noted the support group leaders often instilled the necessity of making ‘me time’ and frequently organised for relaxation experts or aromatherapists to visit the group.

Mental health issues for carers

Amongst the quantitative data (see Table 5), mental health issues, including depression, accounted for only a small percentage of responses (7%)5. However, in the qualitative data carers expressed their health conditions with terms such as anxiety, stress-related asthma, chronic fatigue, stress and nervous exhaustion. These disclosures reiterate earlier research findings (Brodaty and Gresham, 1989; Almberg et al, 1997 and Donaldson et al, 1998) that levels of distress are experienced by a significant number of carers. This noteworthy finding often remains undetected and should be recognised by leaders of dementia support groups when planning programs.

Physical and Emotional Stress

Respondents to the questionnaire were asked to rate the frequency of physical and emotional stress in their caring role as: ‘Never’; ‘Sometimes’; ‘Mostly’ and ‘Always’.

The study found 62.8 per cent of respondents experienced physical stress ‘sometimes’. Carers reported (see Fig.1) emotional stress (73%) across the ‘sometimes’ and ‘mostly’ categories. Overall the higher responses for ‘mostly’ and ‘always’ were found for emotional stress while physical stress was commonly in the ‘never’ and ‘sometimes’ category.

Other Responsibilities

Continuing the investigation of emotional and physical stress experienced by carers, when asked whether they had responsibilities other than caring for a person with dementia, 61 per cent responded that they did not. Of the 39 per cent who did have other responsibilities most (67%) responded that they ‘sometimes’ had trouble balancing their responsibilities. These responsibilities included: other dependent family members; paid and unpaid work; the upkeep of the house and garden; and undertaking duties previously performed by the person with dementia such as bill-paying (see Table 6).

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5 Mental health issues (.8%) plus depression (6.2%)
<table>
<thead>
<tr>
<th>Carers’ health problems</th>
<th>Number of responses</th>
<th>Percentage of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arthritis</td>
<td>83</td>
<td>16.7</td>
</tr>
<tr>
<td>Back/neck problems</td>
<td>73</td>
<td>14.7</td>
</tr>
<tr>
<td>No major health problems</td>
<td>60</td>
<td>12.1</td>
</tr>
<tr>
<td>Hypertension</td>
<td>46</td>
<td>9.2</td>
</tr>
<tr>
<td>Hearing loss</td>
<td>37</td>
<td>7.4</td>
</tr>
<tr>
<td>Depression</td>
<td>31</td>
<td>6.2</td>
</tr>
<tr>
<td>Eyesight problems</td>
<td>31</td>
<td>6.2</td>
</tr>
<tr>
<td>Heart condition</td>
<td>26</td>
<td>5.2</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>22</td>
<td>4.4</td>
</tr>
<tr>
<td>Mobility problems</td>
<td>20</td>
<td>4.1</td>
</tr>
<tr>
<td>Chronic pain</td>
<td>18</td>
<td>3.6</td>
</tr>
<tr>
<td>Asthma</td>
<td>17</td>
<td>3.4</td>
</tr>
<tr>
<td>Diabetes</td>
<td>11</td>
<td>2.2</td>
</tr>
<tr>
<td>Stroke</td>
<td>7</td>
<td>1.4</td>
</tr>
<tr>
<td>Cancer</td>
<td>6</td>
<td>1.2</td>
</tr>
<tr>
<td>Emphysema</td>
<td>5</td>
<td>1.0</td>
</tr>
<tr>
<td>Mental illness</td>
<td>4</td>
<td>0.8</td>
</tr>
<tr>
<td>Parkinson’s disease</td>
<td>1</td>
<td>0.2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>498</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

Note: Respondents were able to give multiple responses to this item
Table 6. Responsibilities other than caring for the person with dementia

<table>
<thead>
<tr>
<th>Other responsibilities</th>
<th>% of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dependent children / family members</td>
<td>35.9</td>
</tr>
<tr>
<td>Paid work</td>
<td>28.3</td>
</tr>
<tr>
<td>Voluntary work</td>
<td>16.3</td>
</tr>
<tr>
<td>House / garden upkeep</td>
<td>14.1</td>
</tr>
<tr>
<td>PWD’s former responsibilities</td>
<td>5.4</td>
</tr>
</tbody>
</table>

Table 7. Crosstabulation of carer’s emotional stress and residence of person with dementia

<table>
<thead>
<tr>
<th>Is your caring role emotionally stressful</th>
<th>Where does the person you care for live?</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>lives with carer</td>
<td>lives alone</td>
</tr>
<tr>
<td>never</td>
<td>Number</td>
<td>2</td>
</tr>
<tr>
<td>sometimes</td>
<td>Number</td>
<td>34</td>
</tr>
<tr>
<td>mostly</td>
<td>Number</td>
<td>39</td>
</tr>
<tr>
<td>always</td>
<td>Number</td>
<td>22</td>
</tr>
<tr>
<td>Total</td>
<td>Number</td>
<td>97</td>
</tr>
</tbody>
</table>

Figure 1. Physical and Emotional Stress

(percentages provided to highlight trends)
Issues surrounding employed caregivers are relevant to this study and will continue in importance as more people remain in the workforce for longer periods of time. Balancing the care of other dependent family members with that of the person with dementia will also continue to be relevant.

Goward (2005) recently stated that women, particularly, are increasingly caught within this ‘sandwich generation’. This group carries the responsibility of care for frail aged parents as well as dependent children still living at home. The competing demands of these carers will contribute to an increased need for support services in combination with informal care. Consequently the specific needs of these carers should be recognised when planning for current and future dementia support groups.

**In residence**
The Project hypothesised that distress may be experienced by a carer who resides with the person they care for. The crosstabulation (See Table 7) indicates a correlation between living with the person with dementia and a high level of emotional stress.

As government policy increasingly encourages the deinstitutionalisation of people with dementia, this finding articulates the need for dementia support groups and supporting government agencies to address not only the physical challenges but the emotional implications that arise for carers. In contrast Cuijpers, Hosman and Munnich (1996) cite research (Brodaty and Gresham, 1989 and Montgomery and Borgatta, 1989) to assert that caring for too long at home can be seriously detrimental to the health of a caregiver, especially when the carer is a spouse, and that perhaps early institutionalisation would be an appropriate use of available care services.

**Are support groups addressing the issue of emotional stress appropriately?**
The quantitative data would indicate support groups are addressing the issue of emotional stress; however a deeper examination of the qualitative data tells another story. Responses to describe the way carers’ emotional stress is accommodated within the group process were varied which gave the investigation added dimension. Some anecdotal and qualitative evidence indicated that leaders often avoid emotional issues such as loneliness and isolation.

... leader did not wish to discuss end-stage dementia because there were people in the group who were ‘beginners’. I went home very unhappy that night – so did another lady (female spousal carer)

Others could not praise their leader highly enough in her consideration of their circumstances

She is always caring and has a lot of insight into our feelings and situation (female carer)

The survey showed participants derived significant support from the mutual aid given and the social connections made in the group. Group members often spoke of their reliance on other members to help them through a stressful time and a strong element of reciprocity was evident. Respondents reported a diminished sense of isolation and the joy of ‘discovering’ other people who understood their situation. Northen and Kurland state that the ‘powerful interdependency’ that can develop within support groups is a ‘potent force for development and change’ (2001p.63).

One focus group participant remarked that although she had found her leader emotionally distant, she had made a wonderful friend in the group with whom she has shared much.

I no longer felt I was alone, battling this terrible thing (past support group member, daughter)

Strong evidence amongst the qualitative data indicates that humour was a powerful support tool. Both at the support group, and away from the group, humour played a significant role in alleviating stress. Within the mutual aid model of care, humour is used extensively to relate with other carers who understood the personal challenges of day-to-day care of a person with dementia. Humour is a key factor in creating cohesion within a group and can alleviate negative emotions amongst members. (Perraud, 2004)
On an individual level a significant degree of stoicism was expressed by carers. The phrase ‘there’s always someone worse off than myself’ was reported on more than one occasion. These remarks reflect the participants’ acknowledgement of other carers’ situations and also the use of cognitive behaviour to keep a positive outlook.

We were often told there was ‘life after dementia’. I think it’s important to learn to have a life with dementia. Dementia journeys can be long and to wait over 11 years is a long time not to have a life. To have a life with dementia has helped me through our long journey
(former female spousal carer)

Positive cognitive behaviour is a psychological tool that has been explored extensively as an aid to carers of people with dementia (Schulz et al 2003). The REACH7 program in the United States has had success in this area as a potential short-term intervention model to provide alternative support to carers.

Other sources of support outside the group
Support groups for carers of people with dementia are one of many types of services and support available. A well coordinated network of support, tailored with the carer to suit their needs, is beneficial (Fine, 2005). This study looked at the other sources of support members utilise, so that strategic planning can allow for better integration of quality, effective and appropriate services to assist carers.

Findings amongst the data indicated that formal support services such as GPs, chemists, nursing homes and respite services provided most support (40%) other than the group. Family support provided 37.5 per cent while friends and neighbours provided 13 per cent

Sadly, nearly 10 per cent (8.75%) of respondents claimed to have no one else providing support to them as carers. Perhaps this is a reflection of a non-supportive society, but more importantly it illuminates the need for support groups, as the sole provider of care and support in some cases, to apply quality care and best-practice standards in their structure and delivery.

A small 0.75 per cent nominated spiritual support as their main additional source of assistance.

Member friendships
Many carers reported that old friendship ties had weakened, due in part to friends’ lack of knowledge about dementia. Once the behaviour of the person with dementia deteriorated, socialising became particularly uncomfortable. An equal number of respondents indicated new friendships made amongst the support group had had a positive impact on their social and emotional wellbeing. While the number of friendships made through support groups ranged from one to 25, the average number of lasting friendships made amongst respondents was five. A large number of carers (56%) reported these friendships were continued at times other than during the support group meeting. This replicated the findings in the first phase of the Project that identified friendships as an indication of a successful dementia support group. This is further evidence of the mutual aid model commonly adopted by dementia support groups in New South Wales.

7 Resources for Enhancing Alzheimer’s Caregivers’ Health
It (the support group) has been very important to me personally and in many ways replaces an extended family.

I don’t think I would have coped as well as I have without my group. We can speak or not but whatever we say seems to help someone else.
I can honestly say that the care I’ve received from our leader has been ‘over and above’. I feel we as carers can be supportive to other carers too.

I have met some lovely people – all hurting badly.

We are a diverse group of men and women managing partners or parents – everyone is different.
This chapter considers the operation and structure of the dementia support groups surveyed in New South Wales. While most groups are dementia-specific, an element of diversity exists. This chapter explores this diversity and outlines mutual support as a linking tool for effective cohesion amongst group members. The data from the questionnaire and focus groups provides an explanation of the structure of support groups. This includes social interaction, information and education about dementia, guest speakers and, although not yet widely implemented, a call for the application of information technologies to support carers, especially those in rural areas. Finally, through the eyes of the carers, this chapter looks at group leaders’ skill level and approach.

**Dementia-specific groups**

Ninety per cent of the carers who took part in the Project stated their support groups were dementia-specific. This aids the success and implementation of the mutual aid model, where carers experiencing similar challenges and changes in their lives to come together in the knowledge that other members ‘understand’ their situation.

**Cultural diversity**

Cultural diversity amongst support group members was reported in Phase I of the Project as significant. Half (50.4%) of the support groups surveyed in Phase I were reported to have some members from CALD backgrounds.

In contrast to Phase I, the cohort of respondents for the collection of data for this, the second phase of the Project, was self-selected. While this self-selected sample means the Project has a representation of support groups surveyed in Phase I were reported to have some members from CALD backgrounds.

Amongst the data for carers who attended support groups and for care recipients, only a very small percentage did not speak English at home. This was just 1.5 per cent of carers and 2.5 per cent of the people with dementia.

**Table 8. Carer’s country of origin**

<table>
<thead>
<tr>
<th>Country of Origin</th>
<th>Numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>137</td>
</tr>
<tr>
<td>Netherlands</td>
<td>7</td>
</tr>
<tr>
<td>England</td>
<td>6</td>
</tr>
<tr>
<td>New Zealand</td>
<td>2</td>
</tr>
<tr>
<td>Germany</td>
<td>2</td>
</tr>
<tr>
<td>Czech republic</td>
<td>1</td>
</tr>
<tr>
<td>Hong Kong</td>
<td>1</td>
</tr>
<tr>
<td>USA</td>
<td>1</td>
</tr>
<tr>
<td>Malta</td>
<td>1</td>
</tr>
<tr>
<td>Rhodesia</td>
<td>1</td>
</tr>
<tr>
<td>Italy</td>
<td>1</td>
</tr>
<tr>
<td>Scotland</td>
<td>1</td>
</tr>
<tr>
<td>Japan</td>
<td>1</td>
</tr>
<tr>
<td><strong>Number of responses</strong></td>
<td><strong>162</strong></td>
</tr>
</tbody>
</table>

The use of the term ‘stage’ in relation to dementia is not a clinically accurate term but is used as a broad description for the purposes of this research.

**Diversity of stages**

There are great variations between the different stages of dementia and group members noted difficulties managing the needs of all group members. At any one time a group member can be dealing with anything from a loved one’s recent diagnosis of dementia to the person’s death from the condition.

Carers report a consideration of this diversity through such practices as individual meetings between new members and leaders, and positive support received from both the group leader and members during the palliative care and death of their loved one.
Conversely, some carers reported they were “bored by (discussion of) early-stage now that my needs have changed” and “for new people it is overwhelming and confronting, but in a way it prepared them”.

**Diversity amongst relationships**

Diversity amongst support group members can also be seen in the different relationships between the carer and the person with dementia. Data provided earlier in this report (see Table 2) depicted a range of relationships: spouse, adult child, daughter-in-law and friend of the person with dementia. There were no sons-in-law participants in the study. This diversity creates challenges for group cohesion. As mentioned previously in this report, spousal carers, or at least those who reside with the person they care for, have their own unique stressors. Adult children are more predisposed to placing their parent in institutional care than spousal carers (Seltzer and Wailing, 2000); yet adult child carers are more often carrying extra responsibilities such as dependent children and work commitments.

Our evidence found that the needs of particular carers such as spousal carers are different to, say, adult child carers. A suggestion was made at one focus group that specific groups for these members could perhaps be beneficial. Indeed, a support group for sons and daughters of people with dementia has been re-established in Sydney, following the recommendation from Phase I, and its ongoing popularity has been built on the foundation of a specific group program for this group of carers and their particular needs.

**Former carers**

Former carers are those who once cared for a person with dementia, who has since died. As mentioned already in this report 12 per cent of respondents are former carers who still attend dementia support groups.

Phase I of the Project reported that former carers have unique needs surrounding their grief and loss. They need to be appropriately assisted by support group leaders during and after the death of the person for whom they care, and the cessation of their role as a carer. Concerns were raised that the emotional needs of these people may not be met in dementia support groups.

While these concerns are justified, the responses from the former carers in Phase II of the Project indicate a strong sense of reciprocity between members in the support groups. The qualitative data includes responses by former carers who continue to support others, not to claim a position of authority in the group, but to avoid abandoning other members in their time of need. Some stated that ‘the group’ had been there for them, so they want to be there to help other members. One former carer reported that her group of 12 (10 women and two men) had only one member who was still caring for a person with dementia, again confirming the strong social emotional connections between members that sustain the group.

**Mutual support**

Mutual support amongst members is a key factor in the success of dementia support groups in New South Wales, and a valuable tool for binding the group despite individuals’ diverse situations. As previously reported, many carers claim this as the main reason for their ongoing attendance. While mutual support denotes empathy and connectedness, the supplementary emotional benefit is a quality outcome of the model that, to date, has not been given enough kudos. Findings in this second phase of the research consistently indicate that levels of distress, anxiety, loneliness and isolation are reduced as a result of making connections with other carers in similar situations. Some comments expressed by carers reiterate this:

- “That others are in the same situation, and the ability to share and help each other, and also to be able to laugh at some aspects of the situation” (male carer)
- “I have just been through a very big depression of my own. I have received valuable help from the group for referral to people to help me. I am coping better now” (female spousal carer)
- “I’m glad I joined when I did. It saved me from having more breakdowns” (female spousal carer)

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9 A number of carers identified themselves as ‘former carers’ if the person they care for now resides in a residential aged care facility; however this research identifies these carers as current carers who now share the care.
The participants in the four focus groups conducted across the State were asked whether they considered the group leader or the members to be more supportive. The responses were evenly balanced. Most agreed that both the leader and the other members had at different times been a source of support. Indeed, a leader with good group leadership skills can be the catalyst for quality mutual support between members.

**Group content**

Northen and Kurland tell us “it is through the group’s content that purpose and goals are achieved” (2001 p.144). Ideally the content of a support group should be decided jointly by members and the leader, with consideration given to the needs of all members and the availability of time, funds and supplies.

**Information and Education**

As reported, most carers sought out membership of a group to gain information about dementia and how they could cope as carers. This feature is a prime component of the group content, with sessions comprised largely of information about available services and education about dementia. Information and education relating to the care of a person with dementia ranged from personal tips from members to a more formal delivery, via a guest speaker or the support group leader, who is often a health professional.

**Guest speakers**

Guest speakers were welcomed by most carers, with many attending sessions specifically to hear a guest speaker. Usually a visit from a guest speaker was pre-arranged and carers would choose to attend depending on the topic.

**Social interaction**

Social activities were organised by many groups. Nearly all gave evidence of social interaction amongst members and connections were often sustained beyond the group time. One carer described a group in far western New South Wales that holds a structured educative meeting each month as well as a social get-together each week. This allows carers to ‘pick and choose’ support as their needs and free time dictate

Conversely, and due to the different needs of carers, a small number of respondents indicated they would like less social time lest “the carers meeting become a general conversation time and afternoon tea get-together” (male spousal carer).

**Information Technologies**

The qualitative data indicates the need to consider the use of the internet as a support tool amongst carers. Currently, there is little evidence about the use of information technologies as a means of exchange between support group participants in this state. The topic came up during a telefocus group with carers from rural and regional areas of New South Wales. All were computer literate, due mostly to their geographical isolation from Sydney and family members. Furthermore, age is not an obstacle for internet usage as half the group were over 80 years of age!

These carers expressed a wish for more information, education and support to be given via the internet, especially via chat lines where they could ‘converse’ with others in similar circumstances, thus enabling a virtual mutual aid support group.

**Skill Development**

In the data related to the content of group sessions there are few significant references to formal skill development for carers. Informal skill-building appears to inadvertently occur through the process of mutual aid, yet there is little evidence of formal psychoeducational skill building to help the carer cope. This could be the result of leaders trying to meet the needs of all members at the one time or that successful psychoeducational interventions usually take place as an adjunct to ongoing support groups. However, teaching simple coping skills such as “walking away from frustration” and “observing when things are getting better” (Perraud et al, 2004) would give carers concrete skills to take with them when the group session ends.

**The Support Group Leader**

He deserves a gold medal for putting up with us all – our questions, our tears. He is so very caring, compassionate and understanding of all our needs and answers our questions, making
sure we understand any particular situation we find ourselves in. He never tires of going over and over the same issues until everyone in the group is satisfied.  
(female respondent caring for her mother)

Phase I of the Project surveyed dementia support group leaders across New South Wales to ascertain their current group status, their needs and their skill level as a group leader.

It is acknowledged that support group leaders strongly influence the process, content and outcomes of a group. Furthermore, the findings of Phase I indicate that leaders are aware of the importance of their role in meeting the ongoing practical and emotional needs of a person who cares for someone with dementia.

A large percentage (86%) of support group leaders in New South Wales are health professionals, which reflects a growing trend around the world (Adamsen and Rasmussen, 2001). In New South Wales a few informal, carer-led groups have grown to over 200 structured groups, led mostly by health professionals. This development has led to a renewed focus on the operation and efficacy of dementia support groups, which includes the capabilities and expertise of support group leaders.

Leader’s skill level
Phase I of the Project asked leaders to critique their abilities and level of skill as a group leader. In Phase II of the Project carers were asked to complete an assessment of their leader using the same categories: ‘unskilled’; ‘some skill’; ‘skilled’ and ‘very skilled’ so that comparisons could be made. The categories for measurement were:

- knowledge skills
- communication skills
- group work skills
- group planning skills

Leaders ranked their knowledge skills most highly and gave their group leadership skills, including group work skills and group planning skills, the lowest score overall. In comparison, respondents in Phase II rated their leaders’ capacities to be higher than the leaders’ own subjective assessment. The quantitative data indicates that the carers’ perceptions of their leaders’ level of skill is quite high with most selecting the ‘very skilled’ category. Amongst these ratings the knowledge skills and communication skills rated highest with the group work skills and group planning skills lowest.

In particular, the following subgroups rated most highly in the ‘very skilled’ category:
- has knowledge and refers to available services
- is friendly and welcoming
- explains things clearly

This was reflected in the following quotes:

I enjoyed the support group very much. The leader was considerate and always looking to encourage. Lovely social occasions organised from time to time which helped friendships form  
(female carer)

I feel our group leader is exceptionally good at her job, is very understanding and helpful. She can be approached at any time about any problem.  
(male spousal carer)

As well as providing us with emotional support and an open forum for discussion, she (the leader) has arranged a lot of educational opportunities for us, provided a safe haven for discussion of taboo subjects and arranged fun activities too. Above all, she has given us encouragement and shown us respect  
(female spousal carer)

Conversely, the following subgroups rated most highly in the ‘unskilled’ category:
- can handle members who dominate group
- encourages member participation in planning
- provides an interesting and varied program

The ability to manage the group dynamics during the session was significantly described amongst the qualitative data.

Leader allows some to ‘ambush’ discussion and dominate issues. Some members are given more freedom to express and state opinions. Others have stories to tell and do not get the opportunity!
The group leader lacks some skill in group dynamics and handling discussion groups (carer)

Had no problem with the leader – the ‘problem’ member was very difficult to control despite leaders’ attempts to manage the situation (carer)

Some carers felt that the inability to manage ‘high needs’ members contributed to the ineffectiveness of the group and ultimately led to non-attendance by some. This finding emphasises the need for effective group leadership skills to enable quality outcomes for both the individual and the group as a whole.

Leader’s approach
To gain an understanding of the group leader’s approach, carers were asked to choose three descriptors from a range of characteristics to illustrate their leader. From the choices provided10, ‘organised’, ‘compassionate’ and ‘approachable’ were the most popular. Although these choices were dependent on the perceptions of the carers and not on any standardised criteria, they nevertheless indicate leaders who work within a structured yet empathic model of support and assistance.

Amongst the qualitative data both positive and negative comments were made, with many carers expressing the desire to be able to tick more than three positive attributes. Yet, a small number claimed that it was their leader’s approach that prevented them from returning to the group.

Suggestions for change
Carers were asked to respond to the question ‘What would you like your leader to do differently?’ While the response rate for this question was not high, those who did respond were overwhelmingly supportive of their leader and the way their group was run. Positive comments accounted for 55 per cent of responses, with many giving the response of ‘nothing!’ (see Fig 2.) Other suggestions include requests for more structure; control of dominant members; more carer input into the planning process; increased ability to deal with emotions; practical considerations such as time and venue; requests for more support for the leader; and provision for more social activities.

![Figure 2. Suggestions for change](image)

10 See Question 31 in the attached questionnaire
I always enjoy our regular meeting and the common friendship that is maintained, considering the high level of stress we all experience.

I’m so thankful I was referred to the group and hope that one day more information and resources will be available to those who care for someone much younger with dementia.
6. Conclusion

The findings from Phase II of the Quality Support Groups Research Project provide further insight into the characteristics and effectiveness of dementia support groups across New South Wales. The study examines how group participants perceive the effectiveness of the group. The data highlights the diversity amongst group members, both past and present, and enables a clear examination of the facts that contribute to group membership. This study investigates the group processes that exist and the importance of quality group leadership skills to encourage these processes. Carers’ voices have been heard and their suggestions for change acknowledged.

This conclusion will expand on the central findings from the research and provide key factors for consideration in the formulation of a quality support group.

Groups are a good source of support

Firstly, and most importantly, it was found that for many of the carers we surveyed, an ongoing dementia support group is a vital and worthwhile source of assistance in both practical and emotional terms. The research found that a desire to access education and information about dementia and related service options is the main impetus for support group membership. However, the evidence overwhelmingly shows that continuing to attend a dementia support group hinges on the mutual aid people receive from other members and the emotional support this provides.

Mutual Aid

Mutual aid is, resoundingly, the reason that many support groups are successful and the main reason that regular members continue to attend. Evidence that this model of care enhances the emotional wellbeing of carers was consistently reported by members of ongoing support groups. The positive impact of the mutual aid model, embedded in many support groups, on emotional support and stress relief for carers is significant. Yet, it is not always given sufficient attention by researchers, educators and policy makers.

Benefits from the connections being made within these groups are clearly articulated in the data collection. Carers reported the benefits of discovering they were not alone; of being able to discuss their concerns with others who understood; and of reciprocating with those who had helped them, sharing the emotional and physical challenges they had confronted. A sense of trust and reciprocity is evident within groups that successfully incorporate a mutual aid model. Group cohesion is a characteristic of a successful group. This creates a feeling of belonging for individual members and makes the group attractive as a whole.

The problem-solving process is a significant characteristic of the mutual aid model. If an individual raises an issue of concern all members give advice based on their own experience. This benefits “both the receiver and the giver of help and is the key to the reciprocity that constitutes mutual aid” (Northen and Kurland, 2001 p.204). While this group process can take place amongst members without leader involvement, this study finds that the groupwork skills of the leader can effectively enhance the process or, conversely, detract from it.

Group leadership skills

Both Phase I and Phase II of this study recognise the influence of the leader upon the effectiveness of group processes. Good group leadership skills are highlighted by members and leaders as an essential element for quality standards in dementia support groups. Many leaders exhibit strong group leadership skills and hence can maintain quality outcomes of care and education for members on an individual and group basis.

Many of the leaders who have difficulty maintaining quality outcomes for their group lack expertise in group leadership skills. These skills include handling dominant or high-needs members; acknowledging the individual needs of members as well as the needs of the group; and also recognising the emotional distress experienced by many carers during such times as the transition of care from a primary caring role to the permanent placement of their loved one in a residential care facility.
Education and information about dementia
A desire for education and information about dementia is the most common reason that carers seek out a support group. Many carers want to understand the nature of dementia and to access services to help them cope with caring for a person with the condition. This need appears to be strongest soon after the diagnosis of dementia, which could be the reason that some members do not continue to attend once that need is met. However, there are other times during the progression of dementia when the need for education and information, particularly on issues surrounding palliative care and death about dementia, is also compelling.

Appropriate psychoeducational interventions that help the carer cope with the changed behaviours of the person with dementia and also their own life’s changes were reported in Phase I of the Project, and a recommendation was made for their incorporation in the group setting or as an adjunct. These interventions suit carers with particular needs who are having trouble coping during a particular time in their ‘carer career’.

Gendered Perspective
The pattern of gender difference is a variable worthy of consideration amongst the findings with regard to group membership. As reported in Chapter 1, approximately 75 per cent of the carers we canvassed were female. Of these, the majority were wives of the person for whom they cared. These data portray a group composition that needs further exploration into whether gender effects the operation of the group.

Much research has investigated the gender differences of carers of people with dementia and examined their coping mechanisms, levels of stress and anxiety and modes of operation in their role as a carer. Reports by Rudd et al (1999); Thompson et al (2004) and Takano and Arai (2005) all indicate that, while men were more pragmatically job-oriented in their approach to caregiving, women were inclined to worry more and therefore become more emotionally stressed. Thompson states that the way men and women perceive and manage their caregiving may be the critical factor in explaining the other gender differences they found surrounding emotional and mental health issues (2004 p.327).

These research findings might explain why fewer men attend support groups. Perhaps the reason that such a large percentage of women continue to attend dementia support groups is that their perceived need for social and emotional connections is being met through mutual aid.

Community Awareness
Community awareness of the availability and accessibility of dementia support groups in New South Wales should be addressed. “If only I’d known about this sooner” and “why didn’t anyone tell me about this group” are typical comments from dementia support group members.

There is an urgent need to consider new ways of promoting dementia support groups. To increase community awareness, Alzheimer’s Australia NSW should utilise its unique position in the field of dementia support groups. Greater follow-up is required following Carer Education sessions, the Living with Memory Loss Program and calls to the National Dementia Helpline. Community awareness drives should be extended to take place regularly through the year, not only during Dementia Awareness Month.

A simple mathematical theory tells us a lot:
Of the estimated 220,000 people with dementia living in Australia in 2007
One in three reside in NSW = approximately 70,000
We can modestly say that at least half of these people would have one carer = 35,000
If we have knowledge of approximately 220 dementia support groups in NSW
With an average of 10 members per group = 2200 members
The current support group network does not include Over 30,000 carers
Community awareness surrounding the notion of dementia itself needs to be considered. Some focus group participants felt that many people initially are too self-conscious to join a group of strangers, due to the intimate and emotional issues they are facing, particularly, immediately after the diagnosis of dementia. Indeed, a small study of the Turkish community in Sydney conducted this year at Alzheimer’s Australia NSW found that cultural factors, such as the perception of dementia, rather than language concerns were the chief barriers to service use. Positive, educated community attitudes would reduce the stigma of dementia. Furthermore, this would enable opportunities for open, honest dialogue between those with dementia, family carers and the service sector earlier in the progression of dementia.

Increasingly, research literature (Gilliard et al 2005) has called for dementia to be included within the social model of disability that has so successfully paved the way for greater community acceptance of people with disabilities and their carers. As the Australian population ages there will be a greater incidence of dementia; therefore, to expand the social model of disability to include dementia would enable greater community awareness and acceptance of all those living with dementia.

A Positive Approach
A positive approach to caring for someone with dementia was encouraged by leaders and members in the groups deemed successful by carers. In many groups the use of humour was part of this approach. Humour is a great equaliser and, when shared, can create a feeling of safety and comfort amongst group members. It is a feature that makes a group attractive to members. Furthermore, a sense of hope appeared to come from the mutual support of members in quality cohesive groups. This sense of hope is a powerful force that can facilitate change for individuals and the group. If members are encouraged to participate in group discussions and social experiences, they feel successful and motivated (Northen and Kurland 2001, P87).

Diversity amongst members
There is great diversity amongst members of the current support group network in New South Wales. However, due to the nature of the selection process for this project, few members from CALD backgrounds took part; their inclusion will be an important consideration for future research.

There is significant evidence of other diversities amongst the members of dementia support groups. There are a range of relationships between the carer and the person with dementia. There is great diversity amongst the different stages of the condition for the person with dementia and their carer. There is also a diversity of residential arrangements for the person with dementia and the extent of their presence in the everyday life of the carer. All of these differences should be acknowledged in group planning by the leader and members, with program and content structures of the group developed accordingly. Recognition should be given to those group members whose circumstances set them apart from the group and also those whose circumstances prevent them from attending the group.

Use of information technologies
Evidence of the use of information technologies by carers in rural and regional areas of New South Wales supports the need for further investigation in this area. The flexibility of the internet has the capacity to meet the needs of a diverse range of carers, such as employed carers and those not regularly able to attend a support group meeting on a regular basis. Emails and chat rooms are commonly used amongst a large portion of the population as both social and educational tools. Encouraging the use of these, in conjunction with, or as a substitute for, ‘real’ dementia support groups would provide greater accessibility for carers.

Policy and advocacy
By their mere existence they (support groups) help to set the political agenda (Adamsen, 2001 p.915)

As mentioned previously in this research, and in a recent report from Access Economics (21 September 2006), government policy in recent times has encouraged the deinstitutionalisation of people with dementia in order to remain in their own homes longer. To enable this, support groups are amongst a
range of community services that can assist carers in practical and emotional terms. The knowledge about support groups gained in this research gives policy makers the opportunity to “achieve the flexibility necessary to respond to the particular needs of the person with dementia and their care givers through effective coordination of services and well trained workers” (Access Economics 2006, p.8).

As the chief advocate in New South Wales for people whose lives are affected by dementia, Alzheimer’s Australia NSW must recognise that its relationship with the State’s dementia support group network is essential to its position as the peak body in dementia care and understanding.

The support group network in New South Wales collectively provides a core resource for the prevention of emotional distress often experienced by carers of people with dementia, as well as ongoing information and education about dementia and related services. It is important that Alzheimer’s Australia and other human service providers know of the existence of individual support groups, but also understand and recognise the role groups play so that resources can be allocated appropriately. Hatzidimitriadou tells us that support groups can “be essential in helping break down barriers, facilitate dialogue and educate professionals and the wider community about reciprocal help and citizen self-activation” (2002, p.283).

Finally, Nolan, Ingram and Watson remind us that “carers are the final arbiters of what counts as ‘success’” (2002, p.75). Therefore, full continual engagement with carers is imperative for the continued work of Alzheimer’s Australia NSW. This requires that carers are engaged more fully in dialogue about the issues important to them.

The findings from Phase I and Phase II of the *Quality Support Groups Research Project* provide a new interpretation of the characteristics and effectiveness of dementia support groups across New South Wales. They have found that support groups can effectively meet the diverse needs of carers of people with dementia in practical and emotional ways, and that the skills of the group leader have an important impact on the value of the group. This interpretation lays the foundation for the development of evidence-based practices, to produce quality outcomes for all dementia support groups, indeed, all carer support groups.
I valued the educational and emotional support received. My participation in a support group helped me through a very challenging time. I learnt a lot and am very privileged to have shared and hopefully helped others on their dementia journey.

I found the seminars very good when they were held.

Kept me sane. Leader helped me out of my own depression.
As a former carer I keep going mostly because of the social element and to help others. The support group has saved my life!

I found the group to be extremely helpful to me over the years and it has also made me realise that there are a lot of people MUCH worse off than me.
7.1 Continue carer advocacy
Phase II of the Quality Support Groups Research Project sought to hear the voices of carers to contribute to the development of quality outcomes for all dementia support groups.

We recommend the continued development of carer advocacy to hear and act on the concerns of carers whose needs Alzheimer’s Australia NSW and other service providers seek to accommodate.

7.2 Recognise and accommodate the different needs of all carers
This research has identified a great deal of diversity amongst members of dementia support groups. This includes diversity amongst the relationships carers have with the person with dementia; diversity in cultural backgrounds; and diversity between the different stages in the progression of dementia.

We recommend that diversity amongst carers be recognised and group content be planned appropriately in collaboration with group members.

7.3 Increase the use of information technology
Increasingly carers are utilising information technologies for efficient time-saving communication, and where circumstances do not permit face-to-face contact.

We therefore recommend that Alzheimer’s Australia NSW develop support tools for dementia support groups that can be utilised via the internet such as chat rooms and an interactive website.

7.4 Expand group skills training for leaders
Phase II of the Project supports Phase I in finding a need for further development of group skills training for support group leaders. This need has been acknowledged by the instigation of the Effective Group Leadership Training Course for dementia support group leaders in New South Wales and leaders from the Living with Memory Loss Program.

It is recommended that the Effective Group Leadership Training Course be evaluated for its effectiveness for new and existing leaders.

7.5 Acknowledge emotional stress amongst carers
Carers are constantly faced with emotional issues such as grief and loss, which are the source of much stress. This affects the way they care for the person with dementia and themselves.

We therefore recommend that:
– the emotional needs of carers be acknowledged, with particular attention to issues such as the grief that often follows the initial diagnosis of dementia; the transition of care; the loss of identity of the person with dementia and their carer; and the grief and loss surrounding palliative care
– specific program modules be developed to help group leaders when confronted by complex emotional issues in their meetings

7.6 Increase community awareness
The findings from the research indicate a need to increase advocacy for carers of people with dementia through public awareness, promotion of dementia support groups and community education about dementia itself.

We recommend policy changes within Alzheimer’s Australia NSW be implemented to increase community awareness about the location and availability of dementia support groups across the state as well as increased education about the nature of dementia to reduce the stigma in dementia.

7.7 Expand the availability of respite services
Many carer participants in the Project expressed the desire for more respite and articulated this concern as a barrier to regular attendance of groups.

We recommend increased access to respite services to enable carers to attend support groups on a regular basis.

7.8 Determine quality standards for dementia support groups
It is envisioned that Phase III of the Quality Support Groups Research Project will be carried out to analyse findings from Phases I and II to determine quality standards against which the effectiveness of a dementia support group could be measured.

11 This training course has been initiated by the Group Development Unit, Alzheimer’s Australia NSW
Therefore it is recommended that Phase III of the Quality Support Groups Research Project proceed to include the expansion and evaluation of group skills training for leaders; a pilot and evaluation of particular modules to assist group leaders; and a framework of quality standards to determine a benchmark for excellence amongst dementia support groups that can be used in New South Wales and elsewhere.

*Carers are the final arbiters of what counts as 'success'*

(Nolan, Ingram and Watson, 2002, p.75)


Loví, L. and Tweedie, R. (2001), Leaderlink: a resource for leaders of dementia support groups, Funded by the NSW Health Department for Alzheimer’s Association (NSW), Sydney, Alzheimer’s Australia NSW


<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>CALD</td>
<td>Culturally and Linguistically Diverse</td>
</tr>
<tr>
<td>Carer</td>
<td>In the context of this report the term ‘carer’ refers to informal carers only, that is, partners, family members, friends and neighbours of the person with dementia</td>
</tr>
<tr>
<td>Dementia support group</td>
<td>In the context of this report this refers to an ongoing support group for carers of people with dementia.</td>
</tr>
<tr>
<td>Former carer</td>
<td>Former carers are people who have completed their caring role because of the death of the person with dementia.</td>
</tr>
<tr>
<td>Living with Memory Loss Program</td>
<td>Information and short term support groups for people living with early stage dementia and their family members and friends</td>
</tr>
<tr>
<td>Mutual Aid</td>
<td>Mutual aid is a process whereby different people come together on a regular basis, with a shared problematic situation that is solved or at least lessened by the giving and receiving of information about the shared situation.</td>
</tr>
<tr>
<td>REACH</td>
<td>Resources for Enhancing Alzheimer’s Caregivers’ Health</td>
</tr>
<tr>
<td>SPSS</td>
<td>Statistical Program for Social Sciences</td>
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<tr>
<td>Younger onset dementia</td>
<td>Younger people (under 65 years of age) with dementia</td>
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Appendix 1 Questionnaire

The purpose of the Quality Support Groups Research Project is to become better informed about dementia support groups in NSW. Your answers are important to us as they will help us understand the nature of a quality support group and provide us with greater recognition of your needs as a carer.

Your privacy and personal details will be protected and managed in accordance with the Principles of the Alzheimer’s Australia (NSW) Privacy Policy Procedures.

This questionnaire is for current and former carers of people with dementia who have at some time attended a support group. If you have cared for more than one person with dementia please complete the questionnaire in relation to the person you have cared for most recently.

Please remember:
– This is not a test; there are no right or wrong answers
– Where boxes are provided please tick the most appropriate response for you
– Rather than not answering a question you are not sure about please attempt to make a “best guess”, however you may decline to answer any or all of the questions and may withdraw from the study at any time
– Feel free to scribble extra remarks or comments throughout the questionnaire or over the page if the need arises
– Don’t forget to sign both consent forms – the coloured one for you to keep and the white one to send back with the completed questionnaire in the envelope provided

Any questions regarding the study or your part in it can be answered by calling Jo-Ann Brown (Research Officer) on (02) 8875 4636 or emailing groupdevelopment@alznsw.asn.au

Please return the questionnaire with the signed white consent form in the reply paid envelope by Friday 10th February 2006

For research purposes could you please provide us with your postcode? __________________________
The following questions are about you (Please tick ☐ the appropriate response)

1. Are you:
   ☐ Male    ☐ Female

2. What age group are you in?
   ☐ Under 40 years   ☐ 41-50 years   ☐ 51-65 years
   ☐ 66-75 years     ☐ 76-85 years   ☐ Over 85 years

3. My occupation is/was:

4. Are you:
   ☐ A current member of a dementia support group
   ☐ A past member of a dementia support group

5. a. Are you:
   ☐ Caring for a person with dementia (this includes caring for someone in a residential care facility)
   ☐ A former carer of a person with dementia who is now deceased (please go to Q.18)
   b. How long have you been caring for someone with dementia?
      ☐ Less than 1 year   ☐ 7-10 years
      ☐ 1-3 years         ☐ 11-15 years
      ☐ 4-6 years         ☐ More than 15 years

6. Are you their:
   ☐ Husband    ☐ Wife
   ☐ Son        ☐ Daughter
   ☐ Son in law ☐ Daughter in law
   ☐ Friend     ☐ Neighbour
   ☐ Other

7. a. Which country were you born in?
    b. What is your cultural background?
    c. Do you speak English at home?    ☐ Yes    ☐ No

8. a. Do you have any of the following health problems?
   ☐ Arthritis/Rheumatism    ☐ Hearing loss
   ☐ Asthma                   ☐ Heart condition
   ☐ Back or neck problems   ☐ Hypertension
   ☐ Cancer                  ☐ Mental illness (e.g. Schizophrenia)
   ☐ Chronic pain            ☐ Mobility problems (walking)
   ☐ Depression              ☐ Osteoporosis
   ☐ Diabetes                ☐ Parkinson's disease
   ☐ Emphysema               ☐ Stroke
   ☐ Eyesight problems

   Other:
   ☐ I have no major health problems
   b. Do you think your health problems have become worse since you began caring for a person with dementia?
      ☐ No my health is normal for my age
      ☐ Slightly worse due to my caring role
      ☐ Significantly worse due to my caring role

9. Have you given up enjoyable activities because of the time you spend caring for a person with dementia?
   ☐ Yes    ☐ No

10. Do you find your caring role physically stressful?
    ☐ Never    ☐ Sometimes    ☐ Mostly    ☐ Always
11. Do you find your caring role emotionally stressful?
   - [ ] Never
   - [ ] Sometimes
   - [ ] Mostly
   - [ ] Always

If so how?

12. a. Do you have any other responsibilities, such as work or dependent children, apart from being a carer?
   - [ ] Yes
   - [ ] No

b. If so, what are those responsibilities?

c. Do you have difficulty balancing your responsibilities?
   - [ ] Never
   - [ ] Sometimes
   - [ ] Mostly
   - [ ] Always

Comments:

The following questions are about the person you care for

13. Does the person you care for
   - [ ] Live with you
   - [ ] Live alone
   - [ ] Live in supported accommodation (nursing home or hostel)
   - [ ] Live with someone else, if so with who?

14. How old is the person you care for?

15. a. Has the person you care for been officially diagnosed with dementia?
   - [ ] Yes
   - [ ] No

b. How old were they when they were diagnosed with dementia?

c. How long has the person you care for had dementia?
   - [ ] Less than 1 year
   - [ ] 7-10 years
   - [ ] 1-3 years
   - [ ] 11-15 years
   - [ ] 4-6 years
   - [ ] More than 15 years
16. Does the person you care for have any of the following medical problems other than dementia? (Tick ☐ as many as apply)
[ ] Arthritis/Rheumatism  [ ] Hearing loss
[ ] Asthma  [ ] Heart condition
[ ] Back or neck problems  [ ] Hypertension
[ ] Cancer  [ ] Mental illness (e.g. Schizophrenia)
[ ] Chronic pain  [ ] Mobility problems (walking)
[ ] Depression  [ ] Osteoporosis
[ ] Diabetes  [ ] Parkinson’s disease
[ ] Emphysema  [ ] Stroke
[ ] Eyesight problems

Other:
[ ] He/she has no major health problems

17. a. Which country was the person you care for born in?

b. What is their cultural background?

c. Does the person you care for speak English at home? ☐ Yes  ☐ No

The following questions are about your support group membership

18. How long have you been a member of your support group?
[ ] Less than 1 year  [ ] 7-10 years
[ ] 1-3 years  [ ] 11-15 years
[ ] 4-6 years  [ ] More than 15 years
[ ] No longer a member

19. How long did the person you care for have dementia before you joined a support group?

20. How often do you attend the support group meetings?
[ ] Every time  [ ] Most Times  [ ] Sometimes  [ ] Only attended once or twice

21. Is your support group specifically for carers of people with dementia?
[ ] Yes  [ ] No  [ ] Don’t Know

22. Why did you join your support group?

____________________________________________________________________________

____________________________________________________________________________

____________________________________________________________________________

____________________________________________________________________________

23. What do/did you see as the purpose of your support group?

____________________________________________________________________________

____________________________________________________________________________

____________________________________________________________________________

____________________________________________________________________________
24. How did you find out about your support group? (Please tick □)
- Aged Care Assessment Team □
- Community Nurse □
- Local Council □
- Day Care Centre □
- Friend/Family □
- GP Referral □
- Dementia Helpline □
- Hospital □
- Media – flyer, radio, TV, newspaper □
- Medical Specialist □
- Pharmacist □
- Residential Aged Care Facility (nursing home or hostel) □
- Service Provider □
- Alzheimer’s Australia NSW □
Other please specify:

25. Have the expectations you had when you joined the support group been met? (Please put a tick □ beside the appropriate response)
Emotional expectation – the group provides you with an environment where you can express your feelings
- Not Met □
- Sometimes Met □
- Met Well □
- Always Met □
Social expectation – the group provides you with an opportunity to develop networks and friendships with others in similar circumstances
- Not Met □
- Sometimes Met □
- Met Well □
- Always Met □
Psychological expectation – the group provides you with opportunities to learn skills and strategies to help you cope
- Not Met □
- Sometimes Met □
- Met Well □
- Always Met □
Educational expectation – the group provides you with access to education about dementia that relates to your situation
- Not Met □
- Sometimes Met □
- Met Well □
- Always Met □
Informational expectation – the group provides you with information about relevant community services and resources
- Not Met □
- Sometimes Met □
- Met Well □
- Always Met □

26. What are the most beneficial aspects you have experienced from belonging to your support group?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

27. How do you think your support group could be improved?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

28. Other than your support group who else gives you help with the person you care for?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
29. a. Have you made any friendships with other group members that extend beyond the group time?
  Yes ☐ No ☐

b. With how many people?

30. Is the information that you receive at the support group meeting adequate for your particular situation?

Please circle the appropriate rating from 1-5 using the following guide:
(1 = not enough; 3 = enough; 5 = Too much)

a. Is there enough education given at your support group meeting about the causes and progression of dementia?

1 2 3 4 5
Not enough Enough Too much

b. Are there enough strategies given at your support group meeting to help you cope with your feelings and your own self care?

1 2 3 4 5
Not enough Enough Too much

c. Has the support group given you enough practical strategies to help you cope with the challenges that arise when caring for someone with dementia?

1 2 3 4 5
Not enough Enough Too much

d. Has your support group given you adequate information to help you plan for the future?

1 2 3 4 5
Not enough Enough Too much

e. If you are a former carer, were you given enough helpful information about residential care?

1 2 3 4 5
Not enough Enough Too much

f. If you are a former carer, were you given adequate help in your grieving process?

1 2 3 4 5
Not enough Enough Too much
The following questions are about your group leader
Please remember that these responses are confidential and will not be identified.

31. Please tick three descriptions (only) that best illustrate your leader’s approach within the group

- Organised
- Empathic
- Flexible
- Insightful
- Approachable
- Educational
- Honest
- Compassionate
- Brings others out
- Dominating
- Creative
- Suffocating
- Overprotective
- Demanding
- Impatient
- Disorganised
- Patronising
- Trustworthy
- Opinionated
- Informed
- Challenging
- Aware
- Patient
- Open minded
- Tolerant
- Consistent
- Casual

Other Comments:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

32. What would you like your leader to do differently?
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
The following is a list of group leadership skills.
Please rate the skill level of your leader by ticking the appropriate rating beside each description below:

### Group Leadership skills

<table>
<thead>
<tr>
<th>Knowledge Skills</th>
<th>Unskilled</th>
<th>Some Skill</th>
<th>Skilled</th>
<th>Very Skilled</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has knowledge of the impact of dementia</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has knowledge about the stress of caring for a person with dementia</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has knowledge and refers to available services</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Communication Skills</th>
<th>Unskilled</th>
<th>Some Skill</th>
<th>Skilled</th>
<th>Very Skilled</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is friendly and welcoming</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explains things clearly and concisely in a way I can understand</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can deal appropriately with people expressing emotion</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Group work Skills</th>
<th>Unskilled</th>
<th>Some Skill</th>
<th>Skilled</th>
<th>Very Skilled</th>
</tr>
</thead>
<tbody>
<tr>
<td>Runs group on time</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helps members learn new ideas and apply them to their own situation</td>
<td></td>
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<tr>
<td>Keeps the group ‘on track’</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Balances the needs of the whole group as well as the needs of each member</td>
<td></td>
<td></td>
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<tr>
<td>Can handle members who dominate the group time</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Allows everyone to have a say</td>
<td></td>
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<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Group planning Skills</th>
<th>Unskilled</th>
<th>Some Skill</th>
<th>Skilled</th>
<th>Very Skilled</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provides an interesting and varied program</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Encourages group members to assist with planning themes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plans and organises groups according to the needs of the group</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Feel free to make any further comments about your time as a support group member.

Thank you for your valued participation in the Quality Support Groups Research Project.
If you would like to speak to someone about any concerns you have in relation to your support group please do not hesitate to contact Anne, Lyndell or Jo-Ann at Alzheimer’s Australia NSW on (02) 8875 4600.
December 19, 2005

Dear Carer,

Thank you for expressing interest in Phase II of the Quality Support Groups Research Project. Phase I of the Project has given us valuable insight into the way dementia support groups operate across the state. Their continued success has been due, in no small part, to the hard work of leaders and their ability to work cooperatively with carers.

Phase II will investigate your perspective of the dementia support groups in New South Wales; how effective they are and their value to you as a carer. As a current or former carer of a person with dementia, who has at some time attended a support group, your voice is important to our research.

To that end, we would be pleased if you would complete the enclosed questionnaire and return it to us in the reply paid envelope by Friday 10th February 2006. If you have any queries about the questionnaire or the Project itself please do not hesitate to call Jo-Ann Brown (Research Officer) on (02)8875 4636 (Monday – Wednesday) or jbrown@alznsw.asn.au

Yours sincerely,

Anne Tunks
Co-ordinator
Group Development Unit

Enclosures:
1. Two consent forms
2. Questionnaire
3. Tea/coffee bags
Consent Form

Please read and sign the following:-

I agree to answer the questionnaire which has been formulated as part of the Quality Support Groups Research Project conducted by Alzheimer’s Australia NSW.

I understand that:
- Approval has been given by the Human Research Ethics Committee (HREC) of Northern Sydney Health.
- My name will only be used to register the completion of the questionnaire.
- Only identified research team members will see this information as it comes in to the organisation and it will not be available to other Alzheimer’s Australia NSW staff.
- Personal details as completed on this form will not be made available to any other parties.
- I may refuse to answer any question and have the right to withdraw from this project at any time.
- If I have any queries or concerns I can contact a member of the Group Development Unit (02) 9805 0100 or email: groupdevelopment@alznsw.asn.au
- If I have any complaints about the conduct of the research project I can contact the Northern Sydney Independent Ethics Committee, Coordinator of Research Administration (02) 99268106

Signed

Date

Please sign both copies of this form.
Return the white copy with the completed questionnaire and keep the coloured copy for your records.