



Alzheimer's
Australia NSW
Living with dementia

Quality Support Groups Research Project



A Report on Dementia Support Groups in New South Wales

Phase I







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Phase I

A literature review, leaders' perspectives and group composition

Jo-Ann Brown

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ALZHEIMER'S AUSTRALIA NSW

Supported by The Centre for Research on Social Inclusion, Macquarie University
NSW Health Non-Government Organisation Program



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Foreword

I am delighted that Alzheimer’s Australia NSW has been able to conduct the *Quality Support Groups Research Project*. Alzheimer’s Australia NSW has worked to establish and resource dementia support groups across New South Wales since our organisation began in 1982. This survey of dementia support group leaders will provide knowledge and innovative ideas that will allow us to address the service quality of dementia support groups in a measurable way, and widen service options so that we can move forward in this field.

The role of the family carer is demanding. Carers must constantly change and adapt to meet the needs of the person with dementia and, as support groups are part of the continuum of care, there is an ongoing need for us to provide appropriate assistance to dementia support group leaders so that they can work effectively in this highly relevant service.



Lewis Kaplan
Chief Executive

Executive Summary

It has been estimated that the number of Australians with dementia will pass the 200,000 mark during 2005 and that one in three Australians living with dementia will reside in New South Wales (Access Economics, 2005).

2005 will also see substantial numbers of the first of the baby boomers¹ preparing to turn 60 years old. This will mark the start of an increase in the incidence of people with dementia and of the numbers of carers of people with dementia. Service providers will need to be prepared to appropriately accommodate this growing population.

These core considerations regarding Australian society, along with recent research findings, will mould the way we deal with the crucial life-changing aspects of dementia, for people with dementia, their carers and their families.

Open, ongoing support groups for carers of people with dementia have been a core service of Alzheimer's Australia NSW² for over two decades. These groups are seen as a popular and cost effective intervention to assist carers and, in many cases, delay the institutionalisation of the person with dementia (Brodaty and Gresham, 1989). Government and public support for the expansion of these groups is imperative.

Alzheimer's Australia NSW does not 'own' these support groups but has developed a leadership role in training and resourcing group leaders. Alzheimer's Australia NSW is recognised for this work by NSW Health, through its funding of the support group program.

Funding for dementia support group leaders in New South Wales is provided by three major stakeholders: NSW Health; the Department of Ageing Disability and Home Care (DADHC); and the Australian Government. These organisations and other funding bodies promote support groups as a component of their service for carers.

There is little knowledge, however, of the way support groups in New South Wales are currently functioning or how effectively they are providing support to their participants. For this reason, in 2003 Alzheimer's Australia NSW initiated the *Quality Support Groups Research Project*. The project constitutes three phases:

- **Phase I** (2003-2004) presented in this Report, is a literature review of research conducted into dementia support groups and a survey of existing support groups

in New South Wales to investigate the views of support group leaders.

- **Phase II** (2005-2006) will be a survey of the perceptions of carers across New South Wales regarding the role and value of dementia support groups in their lives.
- **Phase III** (2006-2007) will analyse findings from Phases I and II of the Project to determine quality standards against which the effectiveness of a dementia support group may be measured.

The purpose of the *Quality Support Groups Research Project* is to: understand the operation and structure of dementia support groups in New South Wales; ascertain what constitutes a quality support group; and determine how a quality support group can be achieved.

As of February 2004, research for this Project identified 159 active support groups in New South Wales. The leaders of all of these support groups were asked to complete a questionnaire (Appendix 1) providing information about group membership and how they, as leaders, perceived their role and carers' needs, and how they rated their knowledge, communication and group skills.

Responses were received from 140 support group leaders, which was a high rate of return (88%) providing strong validity of results.

The findings provided substantial evidence that many of the social needs of carers appear to be met through their participation in the support groups surveyed. The data indicated a wide variation amongst groups and suggested that there is a need to: strengthen and enhance the structure of dementia support groups across New South Wales; provide quality assistance to support group leaders; and expand existing options to adequately meet carers' needs. These findings have led to the following **recommendations**:

- investigative research with carers
- development of standards
- specific program development
- expand group skills training for leaders
- identify the different needs of all carer groups
- identify service gaps.

1 Those born post World War II from 1946-1961

2 Originally called Alzheimer's Association (New South Wales)



The purpose of the group is to provide support, information and education to carers. Group members can share experiences and openly discuss any issues or concerns relating to them in their caring role.

1. Background

It is estimated that the number of Australians with dementia will pass the 200,000 mark in 2005 and that one in three of those living with dementia will reside in New South Wales (Access Economics 2005). These figures mark the beginning of an increase in numbers of people with dementia and of the carers of people with dementia.

2005 will also see substantial numbers of the first of the baby boomers preparing to turn 60 years old. As the baby boomer population tends to be well educated and has higher expectations for service delivery than the previous generation of carers, service providers will need to be prepared to accommodate them appropriately.

Meanwhile, the female labour force is increasing with a subsequent decrease in the traditional availability of women to actively participate in the role of carer. The structure of families is also changing. Less children and a higher divorce rate mean that society can no longer automatically depend on the spouse or children to be caregivers to a person with dementia. In addition, developments in government policy are keen to encourage care at home for people with dementia.

These core considerations regarding Australian social life, along with recent research findings, will mould the way we deal with the crucial, life-changing aspects of dementia, both for people with dementia and for their carers.

Dementia support groups in New South Wales

For nearly two decades, support groups for carers of people with dementia have been a core service supported by Alzheimer's Australia NSW. Support groups were established "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" (Lovi, 2001, p.1).

These groups are seen as a popular and cost-effective intervention to support carers and, in many cases, delay the institutionalisation of the person with dementia (Brodaty and Gresham, 1989). Government and public support for the expansion of these groups has therefore been vital.

Alzheimer's Australia NSW does not 'own' these dementia support groups but has developed a leadership role in supporting and resourcing them. This is recognised by NSW Health through its funding of the support group program.

The need for increased clarity

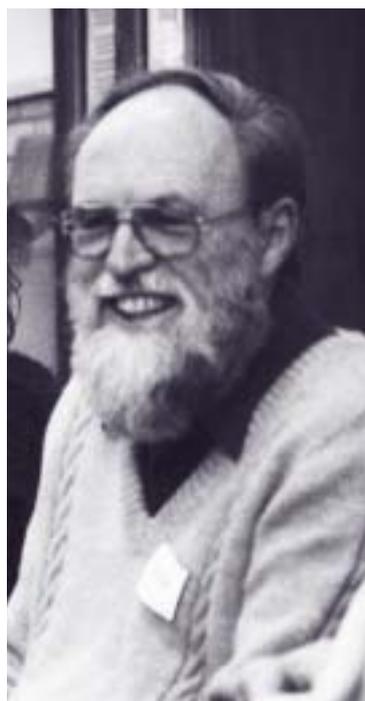
Despite their popularity and importance, very little is known about dementia support groups in New South Wales, including who funds them, how they run, what processes are in place and what program content is being delivered.

No tools are in place to measure standards and efficacy within support groups, except through the self-reported satisfaction rates of participants. Logically, this may be a good sign that carers are happy with their particular support group. There is, however, no measured standard in place to compare one support group with another. It is therefore not possible to objectively assess whether one group may be more suitable for a particular carer than another. Standards against which the efficacy of support groups could be measured would set benchmarks for providing quality support services for people affected by dementia.

Recognising this, in 2003 Alzheimer's Australia NSW initiated the *Quality Support Groups Research Project*. The Project is conducted by the Alzheimer's Australia NSW Group Development Unit and has ethics approval from Northern Sydney Health Human Research Ethics Committee. A formal agreement has also been arranged with the Centre for Research on Social Inclusion, Macquarie University to provide a review of the research design and assist in coding and data analysis.

Organisation of the Report

Chapter 2 of this Report summarises the purpose of the Project. Chapter 3 provides a review of research literature from the dementia support group field. Chapter 4 describes the study methodology employed by the Project. Chapter 5 summarises key findings, Chapter 6 addresses issues for the future, and Chapter 7 presents recommendations.



I watch carers change, grow in self-esteem, become more assertive, use resources and learn to take care of themselves.

2. Purpose

The purpose of the *Quality Support Groups Research Project* is to:

- Provide basic information about the operation and structure of dementia support groups in New South Wales
- Ascertain what constitutes a quality support group and determine how this can be achieved
- Document the number of support groups in New South Wales and obtain a basic profile of their membership and leadership.

The Project proposes to address the following research questions:

- What skills, knowledge, resources and assistance do group leaders need to effectively facilitate a support group?
- What are the needs of carers and what needs are/are not being met by participating in a support group?
- What systems, structures, content and processes might assist a carer support group to effectively address these needs?
- How can a support group be flexible enough to meet the varying needs of carers?

The Project is divided into three phases:

- Phase I** Literature review and survey of existing groups to investigate the views of support group leaders.
- Phase II** Survey the perceptions of carers across New South Wales regarding the role and value of dementia support groups in their lives.
- Phase III** Analyse findings from Phases I and II to determine quality standards against which the effectiveness of a dementia support group may be measured.

This Report summarises Phase I of the Project and includes recommendations for future strategic directions to Northern Sydney Area Health Service, NSW Department of Health, Alzheimer's Australia NSW and other 'carer' organisations.



The group provides a forum for carers to meet and share with other carers in an emotionally safe environment where they can receive professional support, information and education.



It is satisfying to see the warm greetings the carers give each other. Carers attentiveness, enthusiasm to return, determination to improve their situation, their openness and their support of each other.

3. Literature Review

To provide an understanding of the history and effectiveness of the support group as a form of caregiver assistance, a review was conducted of the literature available from English-speaking countries for the period from January 1985 to December 2004. Searches were conducted using OVID, PUB-MED and ASK-ERIC databases, using the search words: support, support group, carer(s), stress, depression, Alzheimer's, dementia, coping and carer support groups. Relevant research was primarily located in gerontological, nursing and social work journals and specific journals relating to Alzheimer's disease. Subject matter was confined to dementia specific information regarding support groups. Approximately 120 articles and texts were initially identified, with a final subset of approximately 40 articles selected for inclusion in this Literature Review.

History of support groups – the mutual aid model

Support groups began in the 1970s, stimulated by the rise of the self-help movement. Groups that developed at that time were based on a mutual aid model of shared experiences and provided social and educational support to carers who brought their different experiences to the group.

In 1976 Katz and Bender described support groups as: *... small voluntary group structures that through mutual support aim to complete specific tasks. For the most part, they consist of participants that gather in order mutually to satisfy a common need, help with a handicap or a life problem and to create a desired social or personal change.* (Katz and Bender, 1976, p.141, cited in Adamsen and Rasmussen, 2000, p.5)

Zarit (1983) asserts that the development of support groups at this time reflected the merging of two theoretical perspectives: social support; and small group theory. In combination, these theories normalised the caregiver experience through interpersonal learning and cohesion. The emphasis was very much on a social type of support. Indeed, research studies by Toseland and Rossiter (1989) and Hardy and Riffle (1993) reported that evidence of outside networking that resulted from connections made at these groups was a reliable sign of their success.

During the 1980s this model was utilised by Alzheimer's associations across Australia as an important support resource for carers (Farran and Kean-Hagerty, 1994). The focus of these support groups was one of mutual aid, service information and education about dementia. (Alzheimer's Association Australia, 1991; Lovi and Tweedie, 2001).

In 1989 Judith Gonyea conducted a study of dementia support groups in Massachusetts, USA, that were based on the mutual aid model. This model was similar to that being used in New South Wales. Gonyea's study of 47 support group leaders and 301 members was designed to identify current, unmet needs of families confronted with dementia and to suggest future directions that support groups might pursue to address these needs. Gonyea found that support groups focused primarily on education and peer support and gave less attention to carers' other emotional needs. Gonyea reported the goal of the ongoing support group was not psychotherapy. Rather there was a need for greater acknowledgement of the carers' emotional needs.

In 1991 a modest student survey of 30 carer support groups was undertaken for Alzheimer's Association Australia in consultation with Alzheimer's Association NSW. This survey confirmed the prevalence of the mutual aid model in New South Wales and provided valuable statistical information about the composition and extent of groups in the sample. The survey provided little insight into the content or process of the groups' frameworks and, except for the self-reported rate of satisfaction by members, did not elicit any objectively measured values of efficacy. It must be noted, however, that the survey did collect data on why caregivers ceased to attend support groups. This information will provide beneficial comparisons with results of Phase II of this Project.

According to Bourgeois et al (1996) studies of these early dementia support groups were "overwhelmingly positive" with consistent reports of carer satisfaction due to improved knowledge and shared experiences. They concur with Toseland and Rossiter (1989), however, while anecdotal and self-reported rates of member satisfaction give us a broad understanding of a group's success, this information does not provide a

measured standard to which we can compare other groups and thus quantify efficacy.

Emergence of the psychoeducational approach

By the end of the 1980s, a clear division was emerging in research literature between two distinct sets of support group models (Table 1). Support groups based on the mutual aid model were no longer the only option for carers of people with dementia. As an adjunct or alternative to support groups in the mutual aid model, psychoeducational interventions were being utilised to assist carers overcome their clinical and psychological needs.

Psychoeducational support groups are defined by Coon et al (1999) as typically short term and employing a structured agenda with expected outcomes.

Coon stated:

Session content derives from cognitive-behavioural therapy and involves acquisition of specific skills (such as challenging negative thoughts and increasing frequency of participation in pleasant events) through various mechanisms such as role-plays, demonstrations, or written materials. Psychoeducational approaches typically make use of homework assignments in order to translate skills learned in class to the caregiver's daily routine.

(Coon et al, 1999 cited in Depp et al, 2003, p.22).

This transition from the mutual aid model to a psychoeducational approach was marked clearly by the work of Toseland and Rossiter (1989) in the United States of America and by Brodaty and Gresham (1989) in Australia.

Toseland and Rossiter's (1989) seminal work surveyed 29 support groups, of which 18 were dementia specific. Almost all groups were based solely on education about dementia and emotional support. All were time-limited, except two which were ongoing with a mutual aid base and no structured design. Most groups spent half of their time presenting information, questions and discussion, and the rest of the time encouraging participants to share issues and concerns with the group. A great majority of the groups reported positive outcomes for participants through the qualitative observations of leaders and the self-reported satisfaction rates of participants who responded to questionnaires.

Brodaty and Gresham's (1989) study acknowledged the "unremitting burden" of dementia that leads to carers becoming "demoralised, isolated and psychologically distressed" (1989, p.1375). The study included 96 carer-patient pairs. Carers received skills training to cope with the dementia specific difficulties of their role. At the same time, those with dementia were given a memory training program. The program design included techniques such as didactic education, group therapy, assertiveness training, skills management and extended family therapy sessions. In contrast to many other studies, Brodaty and Gresham conducted follow-up telephone conference calls at three, six and twelve month intervals and found that an intensive intervention can reduce carer distress and at the same time delay placement of the person with dementia into residential care.

Toseland and Rossiter (1989), and later Bourgeois et al (1996) and Brodaty et al (2003), argued that most of the research up to the late 1980s had been descriptive and exploratory and that more rigor was required for the measurement of the design and evaluation of support groups. While participants' reports of satisfaction with the group had been confirmed, "caregivers' feelings of burden, levels of stress and sense of wellbeing" were not (Toseland and Rossiter, 1989, p.446).

In response to the consistent findings of high levels of stress, social isolation and increased morbidity (Mace and Robins, 1981; Zarit et al, 1985; Haley et al, 1987; Carers Association of Australia, 2000), the 1980s saw a rapid expansion of research on dementia and discovered a range of carer needs that until then had not been acknowledged.

Meeting a diverse range of carer needs

A new focus questioned the initial one-size-fits-all notion of the mutual aid, social support group. The impact of caregiving on the life of the carer was seen in a new light. Increased levels of carer stress and morbidity were reported and the health and wellbeing of the carer became a significant area of research (Brodaty and Gresham, 1989; Mittleman et al, 1993; Carers Association of Australia, 2000). The timeliness of supportive interventions for carers according to the stage or progress of dementia was acknowledged as important. Karlin et al (1999) suggested that perhaps

different interventions could be offered to support group members as they progressed through the different aspects of dementia care. These interventions would be especially beneficial to people providing care for longer periods and also for people who are no longer caring but need support in moving out of the caregiver role.

In addition, the different relationships between carer and care recipient, such as spouses, child/parent or friends, were now seen as important. Similarly, the need to extend support to 'whole family' interventions was acknowledged (Karlin et al, 1999; Brannstrom et al, 2000).

Greater awareness of cultural difference has impacted on the caregiving experience and on outcomes from support groups. In Australia, Bird and Parslow (2001, p.28) suggest that "all groups whose situation places them outside mainstream services" should be considered, with appropriate modifications made to existing services for these carers.

Hupcey (1998), Toseland and Rossiter (1989) and Cohen et al (2000) argued that leaders were a dominant variable in the organisation of support groups, as their perceptions of carer need strongly influence the group. Hence, appropriate leadership training was considered by many researchers to be a core element in effective outcomes for support groups (Gonyea, 1991; Monahan, 1994; Brodaty et al, 1994; Mitchell, 1996; and Kitwood, 1997).

These social changes, along with new findings in dementia research, meant that the delivery of

services for the carers of people with dementia had to be adjusted to accommodate a range of carers who have different needs at different times in the progression of dementia (Toseland and Rossiter, 1989; Gallagher-Thompson et al, 2000; Pusey and Richards, 2001; Charlesworth, 2001; Sorenson et al, 2002; Bourgeois et al, 2002; Depp et al, 2003).

Moving toward a new culture of care

Kitwood (1997) described a new culture of care that is focused on the uniqueness of each person, is respectful of what they have accomplished, and compassionate about what they have endured. He states that carers should have the opportunity to be in touch with their "concerns, feelings, vulnerabilities and transform these into positive resources" (1997, p.136).

According to Kitwood, changes toward the new paradigm of care will not happen overnight but will occur through a gradual transformation of the structures that are already in place. He states that *the process consists of a persistent, subtle, ingenious substitution of one way of being by another... [will perhaps be] in the shape of a day care centre, residential facility or support group* (1997, p.142).

Furthermore, in the light of social change and the projected increase in demands for the delivery of service to caregivers that will come from Australia's ageing population (Access Economics, 2005), the notion that one unilateral solution exists for carers can no longer be applied to support groups for those affected by dementia.

Table 1. Characteristics of support groups

	Mutual aid support groups	Psychoeducational support groups
Duration	Long term	Short term (6-10 weeks)
Leader	Leader– health professional / volunteer	Leader – Professional
Focus	Social / educational	Psychoeducational skill training
Program	Informal framework	Structured framework
Model	Mutual aid	Psychoeducational approach

Consequently, there is now significant interest in the development of psychoeducational intervention models for carers as a tool for successfully reducing carer stress, increasing carer wellbeing, increasing coping mechanisms available to the carer over time and, where possible, reducing institutionalisation (Donaldson et al, 1998; Marriott et al, 2000; Pusey and Richards, 2001; Depp et al, 2002; Schulz et al, 2003; Brodaty et al, 2003).

One such program is the REACH (Resources for Enhancing Alzheimer's Caregivers Health) project established at Stanford University in 1995. The aim of REACH is to teach caregivers how to manage their time better, become more assertive in asking for help, channel their thoughts more positively and to prepare for the future. REACH was one of the first programs to make a comparison between psychoeducational interventions and traditional mutual aid support groups – where the key focus was skill building, rather than empathy.

In Australia, Brodaty, Green and Koschera (2003) reviewed the outcomes of 30 studies (34 interventions) over a 17-year period and reported that psychosocial interventions can reduce carers' psychological morbidity and help keep the person with dementia at home longer. As there is little ongoing research in Australia, they recommend ongoing analyses to assess the continued efficacy of these interventions.

Bourgeois, Schulz and Burgio (1996) and Brodaty (2003) claim this new research focus signifies the emergence of an increased understanding of the complex needs of caregivers, as well as advancements in research design to better evaluate the effectiveness of different types of support group programs. This recent attention has allowed the identified purpose of a group to be better articulated. This, in turn, can lead to more effective research as expected outcomes are more objectively measured and evaluated.

A comparison of research findings

These support interventions have a theoretical base which is consistent with many health stress models. Lazarus and Folkman's (1985) theory of stress, coping

and adaptation is widely used, as is the support theory of Berrera (1986) that proposes a relationship between perceived social support and stress. Beck's (1979) theory for managing negative thoughts through cognitive behaviour and D'Zurilla's (1986) model for problem solving have also been given recognition in developing interventions (all cited in Bourgeois et al, 1996).

Many of the support interventions reviewed for this Project were not described in sufficient detail. This meant that comparisons were sometimes difficult (Burgio et al, 2001; Schulz et al, 2002; Bourgeois et al, 2002). Several research projects had varying outcomes due to the heterogenous nature of the group with regard to age, living arrangements and the severity of dementia of the person being cared for. Subsequently, the high incidence of small sample sizes meant that results could not be generalised or offer any new applicable knowledge (Russell et al, 1989). These methodological problems associated with the incidence of small sample sizes have also been expressed by a number of significant meta-analyses (Burgio et al, 2001; Cooke et al, 2001; Sorenson et al, 2002; Brodaty et al, 2003).

In the studies reviewed, there were few objective measures to indicate why carers continue to attend dementia support groups (Mitchell, 1996). There were no significant findings on the long-term effects of support group interventions for participants such as the resumption of social activities, reduced visits to the GP or better physical health (Brannstrom et al, 2000). Conversely, Brodaty et al (2003, p.663) suggest generic support groups alone are often an "unsuccessful intervention" if the aim of the program is to enhance coping skills and reduce the symptoms of stress in the caregiver. Furthermore, with the exception of the REACH project, there has been very little replication of specific interventions for empirical validation.

Evidence is starting to accumulate about why many carers have *never* attended a dementia support group. Barriers such as the stigma associated with dementia and a lack of awareness about services were identified by carers in a qualitative study by Morgan et al (2003). Research by Karlin et al (1999) suggests that

those who attend support groups were referred by their GPs and were most in need of support, whereas those not attending were often carers perceived as coping in their role.

We know that in New South Wales and across Australia there has been a continuation of the use of ongoing support groups for carers of people with dementia. While professionals instigating psychoeducational models of support groups have objectively measured their effect on participants, little consideration has been given to measuring the value and quality of ongoing support groups based on a mutual aid model.

Results of this Project's literature review suggest the need for a careful examination of the way support groups in NSW operate, and raise a number of specific questions about the nature of support group membership, their goals, their leadership and their programs. Importantly, it raises questions about the nature and value of the 'support' they provide to participants and how groups can be evaluated appropriately to achieve success.

Striking the balance between effective program development and responsible evaluation will be the challenge for educators for many years to come.
(Monahan 1994, p.699)



The carers say that the support, advice and information does help them, and they feel accepted because members of the group understand where they are coming from.

They feel able to discuss their role without being judged.



One of my greatest challenges as a leader is the range of needs of carers, and just how many of them there are.

4. Methodology

Phase I of the *Quality Support Groups Research Project* was based on a survey of dementia support group leaders in New South Wales, as their perception of carer need strongly influences the content and processes of a support group.

A questionnaire (Appendix 1) was selected as the most time-efficient and cost-effective method of making contact with the support group leaders.

Ethics approval for the Project was sought and received from Northern Sydney Health Human Research Ethics Committee.

A structured method of data collection was established by using Alzheimer's Australia NSW's existing database of support group leaders in New South Wales. The database was developed by the Group Development Unit of Alzheimer's Australia NSW and contains details of known carer support groups. Support group leaders had previously provided permission for their names and the name of their group to be in this database and for this information to be used for research purposes.

All of the support group leaders on the database were asked to respond to the questionnaire to achieve a high sample to population ratio and to ensure the validity of the Project.

The questionnaire

A 10-page questionnaire containing 40 questions was formulated by synthesising trends and ideas obtained from the literature review, information gathered in the field from workshops, informal conversations, and feedback from support group leaders across New South Wales.

The coversheet of the questionnaire sought additional current information about the leader's support group, such as its location and sources of funding. The name of the leader was requested for the coversheet only and, on its return, the coversheet was removed from the questionnaire and coded separately to retain the confidentiality of the leaders' responses in the remainder of the questionnaire.

The 40 questions in the body of the questionnaire were divided into the following sections:

- Support group details – location, resources
- The support group leader – professional status, gender, perceived purpose of group, IT access, program planning
- Leadership qualities – self assessed
- Skills audit – self assessed
- Group membership – age, gender, relationship to person with dementia, number of members, culturally and linguistically diverse backgrounds (CALD)
- Session plan – preparation
- Needs analysis of carers – assessing five dimensions of need.

The questionnaire was reviewed by the Centre for Research on Social Inclusion (CRSI) then piloted with six rural, regional and metropolitan group leaders and four professional internal Alzheimer's Australia NSW staff, to gain feedback and to test its validity. Only minimal changes were necessary.

Distribution of the questionnaire

The questionnaire was incorporated into a Research Package (Appendix 2) which was distributed to each of the 219 support groups listed on the Alzheimer's Australia NSW database.

The authors acknowledge that while other support groups may exist in New South Wales, only those groups listed on the Alzheimer's Australia NSW database were approached during research for this Project.

The Research Package consisted of:

- A cover letter that briefly explained the research goal and encouraged a response from the support group leader
- The questionnaire
- Two (2) consent forms – one for the support group leader to retain and one to be returned to Alzheimer's Australia NSW
- An information sheet explaining the Alzheimer's Australia NSW Privacy Policy; data collection methods; systems for expressing complaints; and how to access further information if needed/wanted

- Helpful hints for completing the questionnaire
- A reminder of what to return to Alzheimer’s Australia NSW
- A stamped envelope addressed to Alzheimer’s Australia NSW and marked as confidential to ensure correct internal research procedures were followed
- Coffee/tea bag.

Ethics approval allowed three follow-up contacts with support group leaders who did not initially respond to the questionnaire. In practice, one follow up letter was sent and two phone calls were made to encourage responses from these support group leaders. When talking to these support group leaders by phone, all research team members adhered to the same script.

A letter of thanks was sent to each support group leader who completed the questionnaire.

Analysis of data

The bulk of the data received from respondents was analysed in the sociology laboratory at Macquarie University, in consultation with staff from the Centre for Research on Social Inclusion.

Specific coding and the Statistical Program for Social Sciences (SPSS) data program were used for all closed questions.

A manual content analysis³ of questions was conducted for the 10 open questions and the final comments.



The group encourages a network of social and emotional support in a small and isolated community.

³ Content analysis is the process by which “the various responses to the questions are grouped into a logical and orderly set of discrete categories” (Hall and Hall 1996: pp133-134).



Support groups serve as a useful function in helping people deal with stresses related to common crises, life transitions and chronic conditions. Their proliferation is associated with the increasing need for formal and informal sources of support in the wake of rapid social change, geographic dispersion of families and friends and cutbacks in funding for human services ... they form social networks that have the potential for bridging gaps in service and for providing emotional support, guidance and information.

(Schopler and Galinsky, 1993, p.195)

There needs to be a greater emphasis on targeting interventions according to specific characteristics of the carer and the person with dementia. Interventions are relevant across the entire course of chronic degenerative illnesses, but the aims and content of interventions must necessarily change as needs change.

(Charlesworth, 2001, p.105)



This group gives carers the opportunity to develop networks, process what is happening, receive education and training, and social, emotional, psychological and spiritual support – as well as practical strategies.

5. Findings

5.1 Overview of existing support groups

Of the 219 support groups approached, 60 were found to be no longer in existence. An investigation into the reasons behind the cessation of these groups was conducted by telephone. Reasons provided by respondents included:

- Insufficient staff to lead programs
- Distance and/or time required for travel proved impossible on a regular basis in some rural areas
- Attendance by carers was consistently decreasing
- Insufficient time for leaders to conduct a regular group due to competing work loads
- Local decision that there was no longer a need for a group
- Key staff had ceased their employment.

Consequently, as at February 2004, 159 active support groups were identified in New South Wales (see Table 2). From these, 140 support group leaders responded to our questionnaire. This 88% response rate was very high ensuring validity of results.

Location

The majority of dementia support groups were located outside the metropolitan area of Sydney, with over half of these groups located in rural and regional areas and along mid-coastal areas. (See Table 3, below, and Dementia Support Groups in New South Wales listed in Appendix 3.)⁴ This reflects the current trend for many older Australians, particularly retirees, to move from metropolitan centres to regional and rural areas. Escalating housing prices in the capital cities, particularly Sydney, along with a desire for a better quality of life, have contributed to this shift to smaller urban areas concentrated along the New South Wales and Queensland coast.⁵

We are aware of only a few dementia support groups that service the far western areas of New South Wales. This could reflect time and distance barriers met by service providers. This trend and the findings from our research highlight the need for an increased focus on the particular difficulties experienced in these rural and isolated areas. Reduced access to resources, both physical and professional, lessens the opportunity for carers to attend dementia specific groups.

Table 2. Number of Support Groups

	Number	Percent	Valid percent
Questionnaires distributed	219	100	–
Support groups found to no longer exist	60	27	–
Number of known active support groups at February 2004	159	73	100
Number of responses received	140	64	88
No response received but support group exists	19	8	12

Table 3. Location of support groups in New South Wales

Location in NSW	Frequency	Valid percent
Metropolitan	43	31.4
Regional*	39	28.5
Rural*	55	40.1
Didn't respond	3	–
Total	140	100

*No definitions for regional and rural were offered in the questionnaire. Responses were self-selected.

4 Appendix 3: Support Groups in New South Wales

5 <http://www.abs.gov.au/Ausstats>

Funding for support group leaders

Funding for the position of group leader came from a variety of sources and was predominantly government-based. These funding sources (Table 4) reflect the range of professional backgrounds of the leaders of dementia support groups.

Table 4. Funding

Funding Body	Percent
NSW Health	27
Department of Ageing Disability and Home Care	25
Australian Government	24
Home and Community Care	12
Residential Care Facility / Day Centre	8
Local Council	2
Alzheimer's Australia NSW	2
Total	100

Responsibility for public liability insurance of support groups was diverse, often resting with either: NSW Health; the residential/day care facility where the session was held; religious groups such as Anglicare and Centacare who auspice the support group; Alzheimer's Australia NSW; local councils; neighbourhood centres; or recreation clubs.

Development of support groups

During the twelve months preceding this research, the

average number of new members joining support groups across New South Wales was seven per group. The average number of members leaving support groups during the same period was four per group. These figures suggest that viable groups have been growing in size over recent years and reflect a growing trend for people with dementia being cared for at home for longer periods. Such a trend indicates an increased need for carer support.

The vast majority of group leaders (79%) stated they usually or always speak to members before they attend their first group meeting. Best practice (Northen and Kurland, 2001) directs that potential members have the opportunity to be informed about how the group operates, what to expect when they attend and what they would like to gain from their attendance.

Setting

The group setting is significant as "the adequacy and atmosphere of the room in which the group meets has an important impact on the development of relationships and group cohesion" (Northen and Kurland, 2001, p.142). The survey data indicated that support groups were held in a variety of locations (Figure 4), with the local community hall provided as the most common setting. Many of the locations described in the survey data implied a sense of relaxation and informality, which in turn can be the impetus for good social interaction.

Settings such as coffee shops may not always provide a safe and private enough environment to encourage the expression of emotions and thus allow the flow of

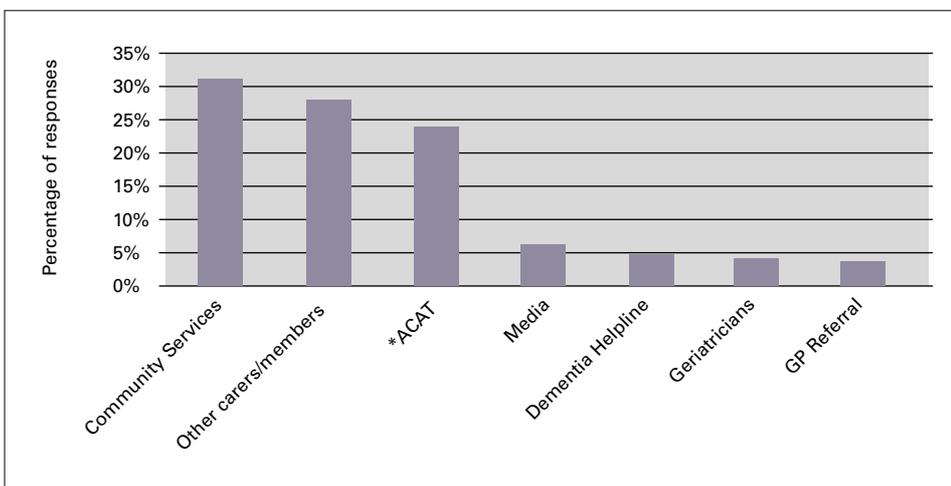


Figure 3. Referral sources

Information on referral sources (Figure 3) indicated that local agencies were the most important source of support group referrals, followed closely by other carers and members. Referrals from doctors were the lowest referral sources reported.

*Aged Care Assessment Team

worthwhile discussion. This may be a question for further research.

While most of the facilities described in the survey data were rent free (92%), the meeting room was often set up by the leader (75%) which meant extra time and physical demands were being placed on that person.

Practical Resources

Most leaders were provided with adequate practical resources to run their groups. Table 5, below, lists the availability of resources to the support groups surveyed.

5.2 Group Membership

The average number of members in each dementia

Table 5. Available resources

Resources	Yes (%)
Coffee / tea making facilities	96
Appropriate comfortable seating	94
Wheelchair access	90
Heating	89
Cooking	87
Attendance book	77
TV / video player	72
Whiteboard / butcher's paper	70
Tea and coffee provided	60
Overhead projector	53

support group surveyed in New South Wales was 13 and the median was 12. The average number of regular members attending a group session was 10.

Cohen et al (2000) suggest the availability of a social network is a component of quality social support and a potential safeguard against depression. On average, group leaders reported that at least three people (approximately one-third of the average group) had contact with one another when they were away from the group. This is a good indication that networks were being formed and therefore a measurable sign of success.

Age and gender of carers

As predicted, most caregivers were female. Females represented 77% of all caregivers, while 23% were male. Of the females, 35% were under 65 years old and 42% were over 65 years old. This is consistent with Australian Bureau of Statistics (ABS) findings (1997)⁶ that report 71% of all carers are female and highlight the traditional role of women as the major carers of men and women.

While the incidence of male carers was less than female carers (Figure 5), there were a significant number of male carers in the over 65 year old group. In fact, the number of older male carers (17%) was more than twice the number of younger male carers (6%).

These figures for male and female carers will be significant measurements for future research as trends develop from the greater incidence of women in the workforce and the consequent increase of males

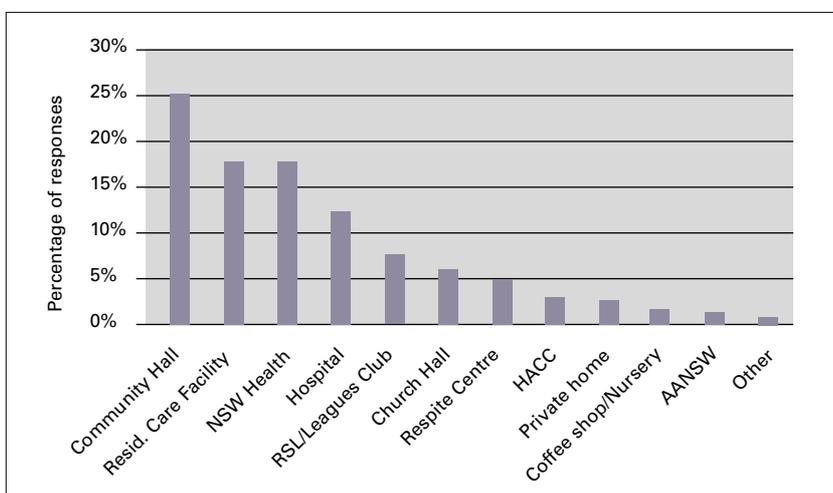


Figure 4. Group Setting

6 <http://www.abs.gov.au/Ausstats>: Special Article – Caring in Australia (1997)

undertaking caring activities in the home. Indeed, ABS Caring in the Community statistics (2000)⁷ for all carers in Australia indicate that the likelihood of women being carers is greatest when they are between 55 and 64 years old, while the greatest likelihood for men for being carers is when they are over 74 years old. The ABS states that this reflects the greater tendency for male carers to assist a partner and for women over 74 years old to be widowed.

Relationship of the group member to the person with dementia

Investigations into the relationship of the carer to the person with dementia were as predicted (Figure 6) with more than half (54.3%) of the carers in spouse/partner relationships and nearly one third (30.4%) being daughters and sons of the person with dementia.

While only 2.1% of respondents were friend/neighbour carers, this small percentage could be a significant measurement for comparison with

future studies. Social changes emerging in current household arrangements indicate that a more diverse interpretation of the family unit, such as an increase in the number of people living alone and people choosing to have less children, mean that the friend/neighbour carer value has the potential to increase.

In hindsight, a variable for gender could have been included in the Phase I survey as it would have provided a more specific interpretation of the results. Research for Phase II will, however, incorporate this data into the Project.

Diversity amongst members

Half (50.4%) of the support groups surveyed were reported by their leaders as having some members from culturally and linguistically diverse (CALD) backgrounds. In all, 28 CALD backgrounds were reported (Table 6). The dominant CALD member group population was Italian, with Polish, German, Dutch and Chinese following strongly. In addition, six ethno-specific groups were reported, i.e., Italian,

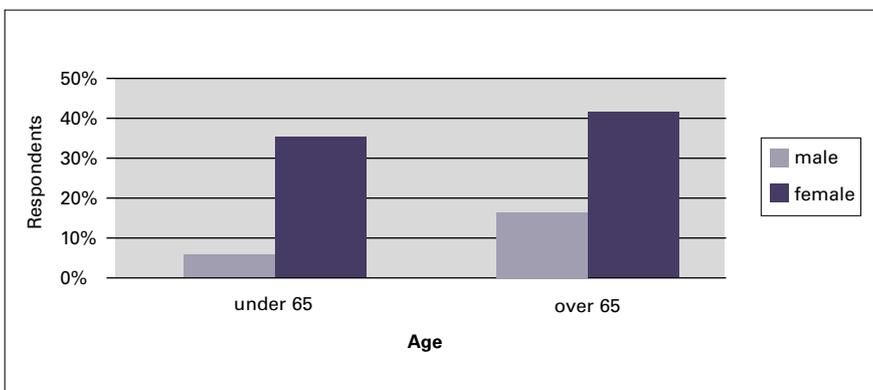


Figure 5. Age and gender of carers in dementia support groups in New South Wales

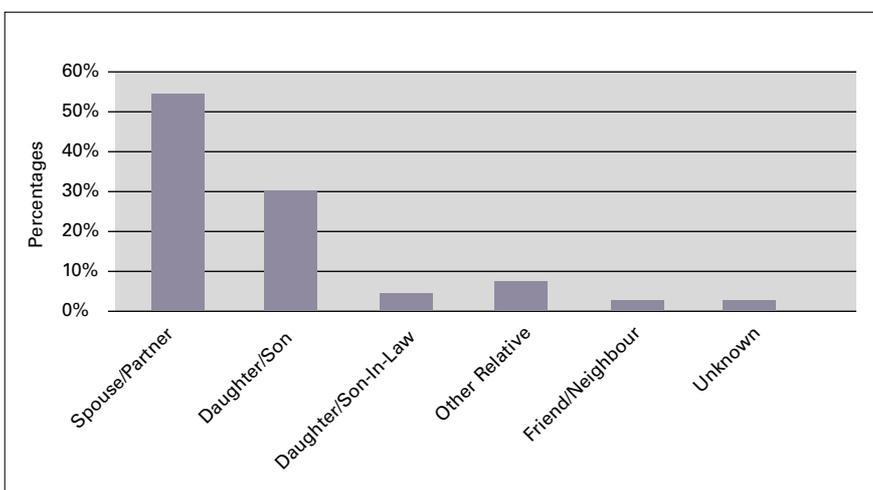


Figure 6. Relationship of member to person with dementia

7 [http://www.abs.gov.au/Ausstats/4436.0/Caring in the Community, Australia](http://www.abs.gov.au/Ausstats/4436.0/Caring%20in%20the%20Community,%20Australia)

Polish, Portuguese, Korean, Arabic and Chinese. Previously, support groups were predominantly homogenised and Anglo-centric. Findings presented in Table 6, however, push the view that there should be more acknowledgement of ‘differences’ amongst carers, i.e., 50.4% of the 133 groups that responded said their membership included carers from CALD backgrounds. Even though some groups reported only small numbers of people with CALD backgrounds, this finding highlights the cultural and linguistic differences that group leaders need to consider.

While the survey identified four specific male support groups that are ongoing, no specific groups were identified for females, former carers, gay people, Aborigines or Torres Strait Islanders. The varied experiences of these carers must be acknowledged so that support groups can accommodate their particular needs in their caregiving role. Groups for these specific carers may exist that are currently not linked to Alzheimer’s Australia NSW.

5.2.1 Description of person being cared for by member

Age and gender of person with dementia

The people with dementia being cared for by support group members were predominantly over 65 years old. The difference in numbers between males and females in both categories was small (Figure 7) with 2% more females than males aged under 65 and 6% more females than males aged 65 and over.

General ‘stage’ of dementia

Leaders were asked to determine which ‘stage’⁸ (i.e., early, middle or late) they believed the carers in the group were experiencing in relation to the person they cared for. The results (Figure 8) indicated that 71% of males and 76% of females being cared for were in the middle to late stages of the dementia process. This is often a time when all those affected by dementia – the carer, the family and the person with dementia – experience high stress levels. In fact, many people with dementia are not placed in formal care until the later stages of dementia, when behavioural changes or physical changes such as incontinence do not allow their carer to continue providing care at home. The reported dominance of mid to late dementia experienced by those being cared for by support

Table 6. Culturally and linguistically diverse backgrounds

Cultural / language background	Number of responses
Italian	24
German	13
Polish	11
Dutch	8
Arabic	6
Greek	6
Chinese	5
Spanish	5
Filipino	5
Vietnamese	3
Russian	3
Maltese	3
Sri Lankan	2
Fijian	2
Indian	2
Hungarian	2
Mandarin	2
South African	2
Lithuanian	2
Armenian	1
Macedonian	1
French	1
Ukrainian	1
Japanese	1
Tagalog	1
Egyptian	1
Croatian	1
Canadian	1

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

group members, and the reported 79% who live mostly in a home environment, not only reflects the high needs of family carers in support groups across New South Wales but may also indicate the period when support groups are most needed or most effective for participants.

Evidence was also reported by group leaders (10%) of support groups having members who were caring for people with conditions other than dementia. These cases were found in regional and rural areas where there may not be enough local carers of people with dementia for a specific group. This highlights the diversity of carer needs that some leaders must confront in their role.

5.2.2 Former carers

It was noticed that a small number of respondents (2%) specified that their person with dementia was deceased. These respondents were the former carers

of people with dementia. Their ongoing attendance at support groups indicates the need to investigate this particular cohort and assess whether they utilise the group session to meet their social needs or if the group provides them with an opportunity to continue their caring role by supporting other carers. More importantly, we must ask whether their specific psychological and social needs are being met. This is an area for future research.

5.3 Characteristics of leaders

Nearly half (42%) of the group leaders have been leading their group for more than five years, with 16% of these people leading for over 10 years. 15% had been leading their group for less than one year, 23% for between one and two years and 20% for between two and five years.

As can be seen in Table 7, most support group leaders in New South Wales were female health professionals.

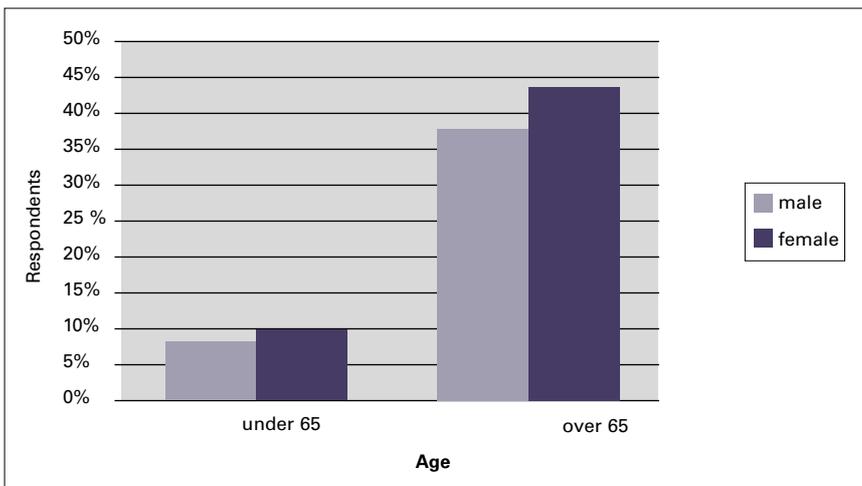


Figure 7. Age and gender of people with dementia

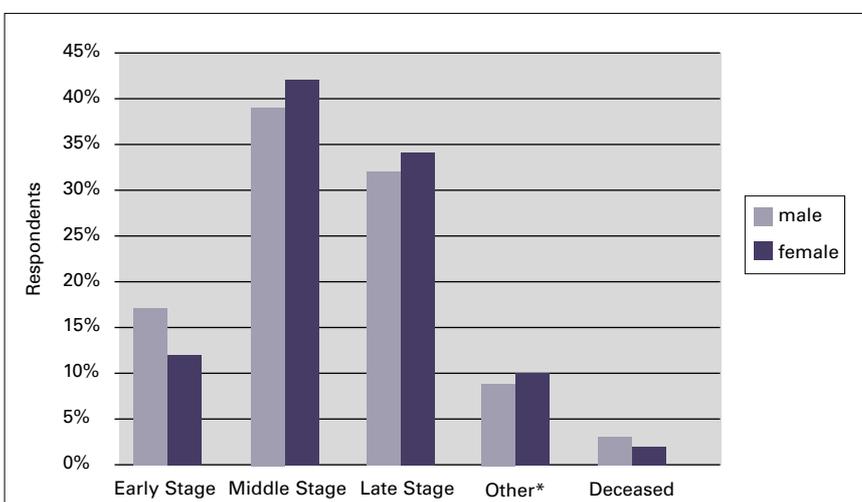


Figure 8. General 'stage' of dementia

(percentages provided to highlight trends)

* Other includes: Frail aged, stroke, Down Syndrome, developmentally delayed and a range of physical disabilities

10% of leaders were male and 1% were males and females sharing the leader's role. Those who did not respond as health professionals were volunteers.

While half of the respondents have their role as leader included in their overall job description, there seems to be some uncertainty surrounding the actual processes and procedures involved in their role as a support group leader. It would appear that very little structured supervision is given and that any assistance provided by workplace peers is informal.

Table 7. Snapshot of an 'average' support group leader in New South Wales

> Female (89%)
> Health professional (86%)
> Leads the group as part of overall job description (54%)
> Does not have a specific job description for role as group leader (76%)
> Has very little structured supervision for the role of leader (90.3%)
> Has access to a computer, the Internet and email facilities (77%)
> Spends up to two hours preparing for the session (85%)
> Gets some assistance preparing the session - mostly in the form of informal discussions with colleagues (57%)

Leaders' perception of the purpose of support groups

The leader's perception of the purpose of the support group strongly affects the way a group is run and is integral to understanding the context of each leader's group.

Following is a sample of how some leaders described the purpose of their group:

- *To facilitate the group, to support carers, provide information, organise guest speakers*
- *To provide emotional support and up to date education and information for carers of clients suffering from any form of dementia*
- *Provide education, support and information – encouraging carers to seek community services and gain support from each other*
- *To listen, support, inform, educate and advocate for carers and facilitate discussion.*

The underlying purpose of a support group appeared to be to provide an opportunity for carers of people living with dementia to experience support, education and information about services within a group setting. The notion of 'support' was referred to at length in the responses. Typically, 'support' was depicted as a type of assistance that aids group members in their caring role. This type of support was based on the mutual aid model of sharing and socialising with peers, as well as support from their leader.

Primary keywords used to describe the purpose of the group (Figure 9) were 'support', 'education', 'information', 'mutual aid', 'sharing', 'socialise',

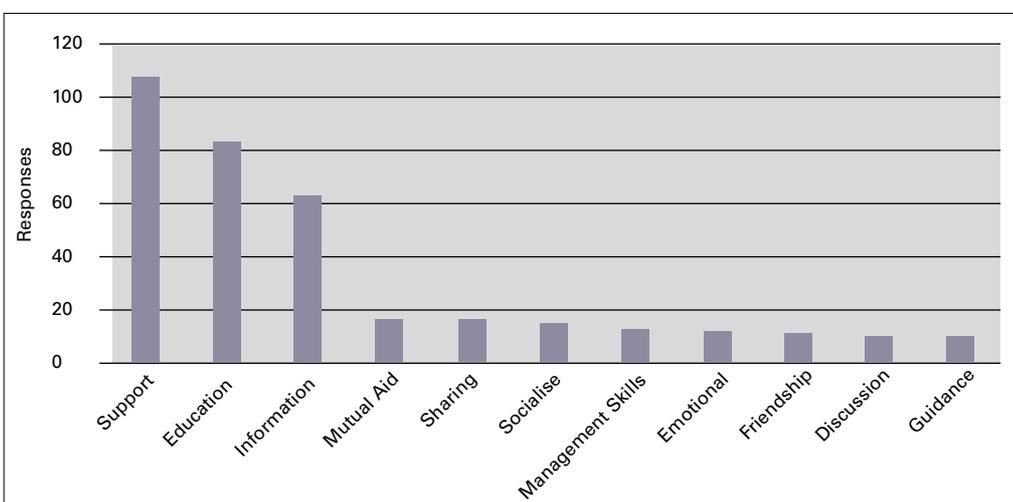


Figure 9. Keywords used to describe the purpose(s) of the group

'management skills', 'emotional', 'friendship', 'discussion' and 'guidance'.

The dominant themes of 'support', 'education' and 'information' were identified as the indicators of the perceived purpose of support groups. Other themes such as 'mutual aid' and 'sharing' suggested a strong social perspective. There were, however, very few responses that promoted a notion of support for the carer's own health and wellbeing through skills training, unless this was implied in the generic term 'support'.

Leadership style

Support group leaders participating in the Project were asked to describe their leadership style by choosing three (only) descriptors from a list of twelve specific leadership characteristics (Table 8).

From the choices provided, 'empathic', 'flexible' and 'accepting' were the most popular descriptors of leadership style. While the results were dependent on self-perception and not external analysis, they informed the research as to how group leaders saw their role and affirmed the expressed purpose of a support group to be one of mutual support and assistance.

Table 8. Leadership style

Perceived style of leadership	
Empathic	23%
Flexible	19%
Accepting	13%
Information Oriented	11%
Casual	9%
Organised	8%
Encouraging of Difference	5%
Structured	4%
Challenging	3%
Opinion Seeking	2%
Directive	2%
Analytical	1%

Skills audit

An audit of core skills and the knowledge base critical for effective support group leadership provided insight into the level of expertise that leaders believed they brought to the group (Table 9).

Knowledge about dementia ranked highly in the 'skilled' and 'very skilled' categories. Communications skills ranked mostly in the mid-range of 'some skill' and 'skilled' categories. Group leadership skill, while also in the mid-range level of 'skilled', had the lowest score overall.

Job satisfaction

A significant majority of group leaders (94%) reported that they found their role always or usually satisfying and 6% reported sometimes satisfying.

Following is a representative sample of how respondents described their satisfaction with their role as support group leader:

- *Seeing positive social interactions among members*
- *Receiving 'good' feedback from group members*
- *Group cohesiveness – leading a group that has a clear identity and 'life'*
- *Being able to share their knowledge and experience.*

These reported levels of carer satisfaction may be evidence of the group leaders' effectiveness (see Literature Review, Chapter 3). The social element of the support groups, together with the exchange of knowledge and experience, confirm that a mutual aid model is operating.

When asked to rate the level of difficulty they experienced in running their support groups the majority of leaders (80%) stated they found their role as group leader sometimes difficult; 16% stated that they found their role never difficult; and 4% stated that they found it usually or always difficult.

Identifying future needs of leaders

Respondents' feedback on what they needed to further develop their capacities as dementia support group leaders was dominated (35%) by their request for further group leadership training. This included

training in: group process and dynamics; meeting the needs of demanding/difficult members; balancing group and individual needs; and identifying ways to foster energy and maintain direction in the group. This feedback correlated with the findings from the skills audit (Table 9).

Another request (17%) was for the opportunity to meet more regularly with other leaders for planning and debriefing. This reflected the isolation felt by many leaders, both physically and professionally, not just in rural areas but also amongst volunteer leaders who comprised 14% of the sample.

The number of respondents who had access to a computer, the Internet and email facilities was quite high (77%), however, information about the frequency and ease of access to these facilities was not recorded, nor was the computer literacy of the group leader.

Although this preliminary record of Internet access lacks detail and makes planning difficult for service providers, it will still assist service providers to develop improved communication with and amongst leaders.

The need for more time was a constant theme (15%) in responses throughout the survey. Many support group leaders stated that they were time poor and that they needed more time to prepare for support group sessions as well as to follow-up on concerns that arose in group sessions. This feedback echoed the evidence that many of the leaders were undertaking this position as part of a wider job description and often needed to fit it in around other demands.

Other requests from group leaders were for: educational resources (14%); research updates (topics unspecified) (13%); more contact with Alzheimer's Australia (3%); and more staff (3%).

Table 9. Leader skills audit

Group leadership skills	Unskilled %	Some skill %	Skilled %	Very skilled %
Maximise interactive discussion in group	-	32	57	11
Handle 'difficult/high needs' members	2	46	40	12
Help members learn and apply new ideas	2	32	53	13
Knowledge about the processes of a well functioning group	1	38	47	14
Balance 'individual' and 'group' needs	-	37	49	14
Communication skills	Unskilled %	Some skill %	Skilled %	Very skilled %
Capacity to respond to the spoken and unspoken themes in the group	1	27	58	14
Capacity to understand and communicate what is happening in the group at various levels, including the 'here and now'	1	32	53	14
Respond to members in terms of their current needs (emotions, concerns, reactions)	-	26	55	19
Use of knowledge	Unskilled %	Some skill %	Skilled %	Very skilled %
Knowledge about the impact of dementia	1	8	60	31
Knowledge of the impact of stress, anxiety and depression on carers	-	12	59	29
Knowledge of dementia services available	-	11	47	42
Knowledge of the impact of a chronically stressful situation on individuals and families	1	19	49	31

Session plans

A high percentage of group leaders (79%) reported that they attend their support group sessions with a prepared session plan. Leaders stated their preference for the dominant influence on their program planning from a range of five specific choices (Table 10).

Table 10. Program planning

Influence on program planning	%
Carer requests	49
Own knowledge	19
Annual carer needs analysis	18
Plan from one group to next	8
Availability of speaker	6

A mutual aid model was confirmed. Nearly half (49%) of group leaders stating that their first consideration for planning comes from carers' requests, that is, specific group participants.

The remaining preferences were stated in the following order: own knowledge, annual carer analysis, plan from one group to next, and availability of guest speaker.

Session content

The four most nominated session themes used as content for the group session were:

- General group discussion – 22.7%
- Guest speaker – 17.5%
- Social outing – 16%
- Informal education – 13.6%

These and the other themes reported (Figure 10) indicated a sociable, informal model where members are supported in a group environment.

'Information' and 'Informal education' needs were acknowledged and 'Guest speaker' visits included a range of topics from dementia to physiotherapy.

Guest speaker topics (Table 11) list the most frequently recorded to least recorded.

There was considerable thought put into planning for topics that were concerned with the management of people with dementia, including administrative and financial issues. There was some evidence that topics relating to the wellbeing of carers and the risk of depression or anxiety amongst carers did not identify strategies or psychological coping skills that carers could use to lessen or prevent these conditions. Also, very few group leaders expressed a planned way for members to apply and integrate learning from the session into their daily lives.

Session structure

The majority of groups surveyed meet monthly for approximately two hours. Session outlines for these group meetings showed a considerable level of uniformity. Generally, a typical mutual aid model was

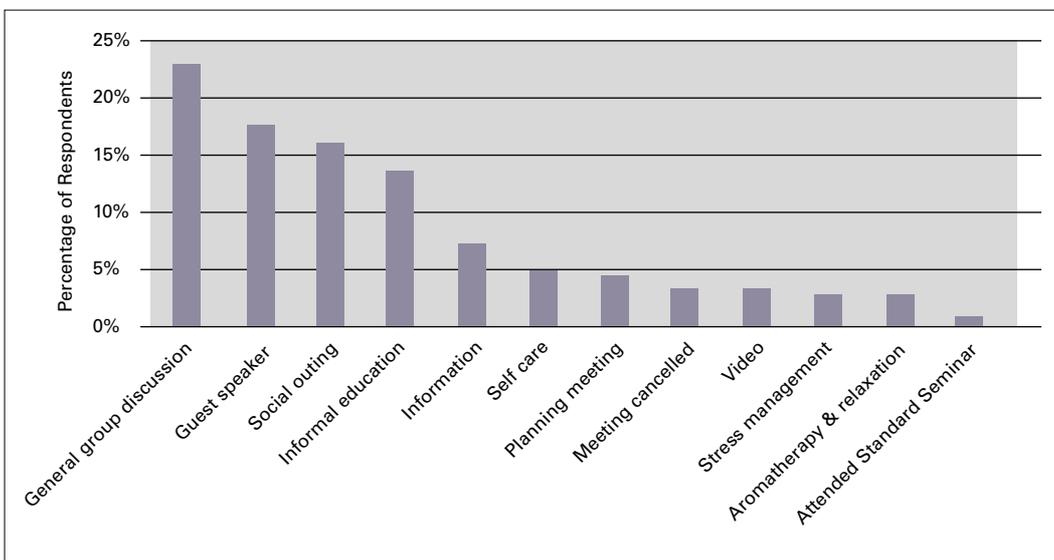


Figure 10. Session themes

found, based on the building of strong social and emotional connections between members as well as education and information to assist carers and to enhance their knowledge of dementia and services. The coffee/chat session correlates strongly with the high response rate for 'general group discussion' in the session themes. The success of this approach was perhaps the reason for increased member

numbers and thus the impetus for outside contacts. This denotes the strength of the social element in these groups and connections for mutual support.

The session structure consistently found in the dementia support groups surveyed is outlined, using a compilation of responses, in Table 12.

Table 11. Guest speaker topics

Guest speaker topics	
1. Dementia	15. Occupational therapy
2. Finance / legal	16. Health
3. Community resources	17. Assertiveness
4. ACAT services	18. Self care
5. Residential care referral and placement	19. Mental health
6. Centrelink	20. Continence
7. Activities of daily living	21. Nutrition
8. Advocacy	22. Music
9. Coping	23. Activities
10. Grief and loss	24. Funerals
11. Medication	25. Art therapy
12. Respite	26. Peer support
13. Aged care	27. Physiotherapy
14. Palliative Care	

Table 12. Session structure

first half hour	<ul style="list-style-type: none"> - **Informal greeting, welcome 'cuppa' - Formal: minutes from last meeting, follow an agenda
second half hour	<ul style="list-style-type: none"> - **Informal discussion of each person's situation, group sharing experiences, 'sharing/caring' time - Discussion: information, services - Guest speaker
third half hour	<ul style="list-style-type: none"> - **Guest speaker, discussion (sometimes continued from second half hour) video, more formal issues sometimes presented - 'Caring/sharing' - problem solving - Informal group discussion
fourth half hour	<ul style="list-style-type: none"> - **Cup of tea/wrap up

** Highest number of responses for that time slot

Needs analysis of group members

Leaders recorded their perceptions of how well carers' needs were being met by support groups by responding to a Likert scale of: 'need not met'; 'need sometimes met'; 'need met well'; 'need met very well' (Table 13).

The carers' needs were described in five broad dimensions:

- **Emotional** dimension of need – group provides an environment where members can have the opportunity to express and process their feelings related to their experiences
- **Social** dimension of need – group provides an opportunity for participants to develop networks and friendships to share with others in similar circumstances
- **Psychological** dimension of need – group provides opportunities to learn skills and strategies to help manage change
- **Educational** dimension of need – group provides access to education, both formal and informal, within the group
- **Informational** dimension of need – group keeps members informed about a range of relevant community, health, financial, library and web resources.

Overall, responses to this section of the questionnaire were very high (95%). While all dimensions of need reported 'need met well' as the highest response, variations were recorded across all dimensions of need.

The social dimension of need scored highest in 'need met very well' and was the only need category devoid of a 'need not met' response. The data and literature reviewed for the Project confirmed that this was one of the main characteristics of a successful support group (Table 13).

The emotional, informational and educational dimensions of need were reported by leaders to be 'need met well'. This perception was replicated in other areas of the data.

The psychological dimension of need was the category most identified commonly as 'need sometimes met', indicating a significant gap in the current support group program.

These findings are important for Phase II of the Project where carers will be asked to describe how well their needs are met through membership of a support group. Survey findings will result in a range of strategies being developed to meet the various needs of carers through the Alzheimer's Australia NSW Group Development Unit.

Phase III of the Project will compare the perceptions of leaders and carers regarding how well carers' needs are met. This will enable service providers to better understand how to measure the effectiveness of support groups and what needs should be prioritised for attention.

Table 13. Dimensions of need

Dimensions of need	Need not met %	Need sometimes met %	Need met well %	Need met very well %
Emotional dimension	0.7	11.2	59.7	28.4
Social dimension	–	14.1	52.6	33.3
Psychological dimension	0.7	26.7	54.1	18.5
Educational dimension	0.7	13.4	58.2	27.6
Informational dimension	0.7	12.6	61.5	25.2

Assistance for support group leaders

Leaders were asked whether there were any other ways Alzheimer's Australia NSW could assist them in their roles as dementia support group leaders. This question drew a response rate of 54%, with the most dominant requests being for ongoing access to current information, education about dementia and more leader skills training. Other requests for assistance included more time in general, a greater role for advocacy, more workshops and web-based assistance.

The responses were generally encouraging of the work of Alzheimer's Australia NSW and most respondents expressed their appreciation for the support they received from Alzheimer's Australia NSW.



Challenges for group leaders

The size of the groups and finding time to prepare before meetings.

The mixture of carers at different stages in their caring role, diverse personalities and expectations of carers.

Grief and sadness expressed by carers.

When multiple complex issues arise in one meeting.

Inconsistent attendances due to carer pressures.

Ensuring each member of the group feels adequately supported.



It is satisfying seeing the overall improvement in the carers' physical and emotional wellbeing.

6. Discussion

Positive findings from Phase I of the *Quality Support Group Research Project* have enhanced our knowledge of the operation and structure of dementia support groups in New South Wales.

The literature review of research studies in Australia and overseas, as well as this survey of support group leaders in New South Wales, will enhance the development of service provision for all dementia support groups.

Funding for support group leaders

Our findings indicate that there are three major funding bodies for the leaders of dementia support groups in New South Wales: NSW Health; the NSW Department of Ageing Disability and Home Care (DADHC); and the Australian Government. As these organisations and other funding bodies promote support groups as a component of their service for those caring for people with dementia, they would benefit from current information on the status and requirements of dementia support groups in New South Wales.

How dementia support group leaders perceive their groups

One of the main objectives of Phase I of the Project was to investigate the perceptions of leaders with regard to their group.

Previous research about dementia support groups in New South Wales (Alzheimer's Association NSW, 1991) has provided little information about the status of leaders. Research produced by Toseland and Rossiter (1989) in the United States of America and Kitwood (1997) in Great Britain has, however, highlighted the impact of the leader upon a group and the importance of effective group leadership skills training.

Support group leaders influence the development of the group through their perception of the group's purpose, the needs of its members and the content and processes implemented to reach articulated outcomes. They are aware that the social needs of carers are critically important and that increasing isolation from social contacts is a common experience for carers and people with dementia. For the support group leader to acknowledge and respond to these

needs in a practical way is beneficial for the carer and has positive implications for the person with dementia and other family members.

Our survey results indicate that most of the dementia support groups in New South Wales operate to meet many of the social needs of members. In their responses, leaders emphasised the importance of providing a social support outlet for family carers while also providing education and information, particularly service information. It appears that the strength of these groups is currently in these areas and that this may be the core reason for their ongoing growth and increase in membership.

At least one-third of the members in the support groups surveyed maintain regular contact with one another outside regular meetings. Our findings also suggest that the local community network and other carers and/or members are effective referral tools for these support groups. This has positive implications for the marketing and community awareness programs that Bird and Parslow (2001) have stated should be paramount for raising the penetration rate of the target population of all people affected by dementia in New South Wales.

The survey data indicates that while many of the social needs of carers are being met, opportunities exist to better meet their needs for psychological support and skills development. This finding confirmed those reported by Depp et al:

Support groups are most often unstructured, led either by a professional or peer, and focus on enhancing emotional support among members. Usually, coping skills are not explicitly taught and no opportunity for role playing or skill acquisition and practice are incorporated in the sessions. Rather the emphasis is on emotional sharing and peer support (2003, p.23).

Quality dementia care acknowledges the unique contextual differences amongst people with dementia. Should carer support also embrace the "person-centred care" approach (Kitwood, 1997), rather than a one-size-fits-all approach? If so, this could be achieved by considering the differences that exist between carers in dementia support groups.

Many leaders used the terms 'support' and 'education' to describe the purpose of their support group. There was strong evidence that the promotion of friendship and sharing through mutual aid is the prime motivator to facilitate this purpose. It appears that 'support' is primarily understood as being to provide carers with social contact with peers, as well as to provide information and education to assist carers in their caring role. There is little evidence that this level of 'support' assists the carers of people with dementia to manage their own ongoing life changes more effectively, or to cope with chronic stress and carer burden.

Mental health issues that affect dementia caregivers

Significant mental health issues that affect caregivers of people with dementia were identified in the research reviewed. These issues require management and skills beyond those currently available in the mutual aid model for an ongoing support group (Pusey and Richards, 2001; Bourgeois et al, 2002; Sorenson et al, 2002). In their current form, dementia support groups in New South Wales do not appear to be a prime resource for assisting carers to learn substantial skills to cope with their own significant mental health needs.

Support group leaders reported that 'carer requests' were the most dominant impetus for their work when planning a program. It therefore appears that the voices of family carers' are taken into account in session planning processes. Optimum effectiveness when using carer feedback for session planning is only gained, however, when leaders know their carers are consistently being given ongoing education and skills training pertinent to their individual needs. Without this knowledge, their requests have the potential to be limited and reactive and only partially meet their needs.

The literature reviewed highlighted the clinical needs of carers as arising from the higher risk of depression, stress and anxiety they face, and increased levels of morbidity. If the gap between what is known in clinical terms and the carers' own knowledge can be reduced, it will enable greater support for them in their role as carers.

The progression of dementia, and individual differences, results in variable areas of need for both the person with the condition and the carer. The finding from this survey that a high percentage of people in the middle to late stages of dementia were living in the home environment, suggests a large proportion of carers could be faced with managing challenging and chronic distress.

The impact of group leadership on the mental health of carers

Effective group leadership is a core requirement for a support group to achieve its purposes. In their self-assessment, the group leaders described their leadership styles as being predominantly empathic and responsive to the needs of the group members, and that their delivery was casual and informative. Very few leaders stated that their leadership style was challenging or directive. This may suggest that some leaders are apprehensive about the risk of challenging the status quo.

These results correlated with data from the skills audit where leaders rated their skills and capabilities higher in 'knowledge of the impact of dementia and the availability of services', than in 'group leadership and communication skills'. When asked for feedback on what they needed to further develop their competencies as support group leaders, the dominant request was group leadership training. This verifies the value of regular professional development responses and suggests a need for further leadership training.

Session themes were found to be relaxed and informal, with strong elements of mutual aid. A dominant session theme was the regular engagement of guest speakers covering educational/informational topics. Within this framework there are two distinct potential outcomes for the group: firstly, guest speakers for specific interest topics could attract increased numbers in attendance for support groups; on the other hand, consistent reliance on the use of a guest speaker as a major part of the session content can often stifle discussion and interaction at a more emotional and meaningful level. This could be the easier option for those with limited groupwork skills or difficulty addressing strong emotion in a group content.



Use of information technology

The high incidence (77%) of email and Internet resources available to support group leaders and members is particularly pertinent for the development of service delivery in rural and regional areas where high numbers of support groups are located, and has the potential to broaden the scope and range of future training sessions. Effective use of information technology could also alleviate some time constraints that were reported to be a major hindrance to leaders being able to effectively carry out their role. IT also provides increased opportunity for leaders' communication with Alzheimer's Australia NSW, with other leaders and amongst group members.

Diversity amongst carers

Findings revealed that in New South Wales, carers of people with dementia have a wide representation of ages, from under 40 years old to over 85 years old. This diversity in age groups has the potential to contribute to difficulties of program and session planning in a support group context. For example, carers who are under 50 years old and caring for someone with dementia may have needs associated with a younger family, financial security and employment. The needs of someone 80 years old and caring for a person with dementia may include personal health and isolation issues.

The findings indicated that a number of carers under 65 years old (6% of male carers and 35% of female carers), belong to the baby boomer cohort. This group of carers will grow as our population ages. Acknowledgement of their different needs compared to the current generation of carers will be necessary for more targeted services to assist them. These services could include short-term evening sessions to allow for work and time constraints, and fixed term psychoeducational interventions.

Women (75%) are still the major carers for both men and women. This supports Ungerson's (1987) claim that gendered kinship obligations ensure females are more often than not the preferred carer, be they wife, daughter, daughter-in-law or friend.

Although the incidence of male carers was small compared to female carers, the accepted female bias

amongst carer numbers has the potential to change. The increase (more than double) in male carers over 65 years old attending support groups compared with those under 65 years old could have implications for future trends in the content and processes of dementia support groups. Under the right conditions, such as flexible work practices and the eradication of the gendered stigma of undertaking unpaid 'women's work', more men may undertake the carer's role before their retirement years.

Currently, there are four specific men's groups in New South Wales. Little is known about these groups, their similarities and differences to non-gender specific groups and their effectiveness. Further investigation into the needs of male carers of people with dementia would be valuable.

The diversity amongst carers and the need for flexibility in support group planning was evidenced by the dominance of spousal and daughter/son relationships. The prevalence of these varying relationships signifies the different social dynamics and life stages integrated into the caring role and thus the support group.

The friend/neighbour category, while only a very small value (2%), may also present challenges for prospective planning. The more diverse interpretation of the family unit currently emerging includes an increase in the amount of people living alone and people choosing to have fewer children, and suggests this value has the potential to increase.

Former carers too, were evident amongst the group members. These people have unique needs surrounding their grief and loss on multiple levels. In recognising this, support group leaders are taking on another tangent to their role by ensuring former carers are appropriately assisted in the crisis period around the death of their person with dementia and the transitory period from their caring role.

A large number of group leaders (50.4%) reported to have members who had come from culturally and linguistically diverse (CALD) backgrounds. These variances have been acknowledged by six ethno-specific groups. With 52% of Australia's current

population growth coming from net overseas migration (ABS, 2004), the continuing acknowledgement of cultural differences will need to be included in support group planning. Issues reflecting this diversity may include: understanding of cultural difference and myths about dementia; cultural expectations of the caring role and norms around expressing and dealing with strong emotion. Many members are reported to be caring for someone in the mid to late stages of the dementia process. It was acknowledged that this has the potential to be very stressful for the carer, particularly if the person with dementia is living in a home environment, either alone or with their primary carer. Multiple issues relating to ongoing behavioural change, physical deterioration, increasing dependency and cognitive decline in the person with dementia combine with chronic grief, physical and emotional exhaustion, risk of depression and poor health outcomes for the carer. These members need the skills and opportunities to care for their own health and wellbeing as well as that of the person they care for.

Phase I findings suggest a need to strengthen and enhance the structure of dementia support groups across New South Wales. This would help to provide quality assistance to support group leaders and thus to the carers who are the support group participants. These findings, in combination with the findings anticipated in Phase II of the project, will provide a better interpretation of the organisation and effectiveness of quality support groups.





What would assist you to further develop as an effective support group leader?

More training in group processes and developing strategies for maximising everyone's group experience.

Meeting with other group leaders. Updating theory and practice.

Debriefing with a supervisor on a regular basis.

More prepared sessions on topics to draw on if needed.

Time to develop further practice in new skills.

A colleague to reflect my role and actions with.

More skills on group processes.

Database of information. Set activities to help guide leader.

Help in locating people in the community who need this group involvement.



Striking the balance between effective program development and responsible evaluation will be the challenge.

(Monahan 1994, p.699)

7. Recommendations

7.1 Investigative research with carers

Phase II of the *Quality Support Groups Research Project* seeks to hear the voice of carers so that their views may contribute to the development of a better service for all dementia support groups.

We recommend that Phase II of the Project proceed and that the following methodologies be implemented to maximize outcomes:

- A sample of carers be developed to include both the carers who attend a support group and others who no longer attend a support group
- A triangulated form of research be implemented for carers to ensure their voice will be directly heard, e.g., a questionnaire, telephone interviews and focus groups.

Results from Phase II would be analysed separately and then compared with findings from Phase I of the Project, to allow for the continuation of this comprehensive investigation of dementia support groups in New South Wales.

7.2 Development of standards

There is a need to: strengthen the focus of service delivery for dementia support groups in New South Wales; better articulate outcomes to consumers; and, conduct objective evaluations of support groups.

We recommend the development of clear indicators of quality in both the content and process of an effective dementia support group, to assist the creation and implementation of acceptable practice standards.

7.3 Specific program development

There is evidence in our research that the term 'support' is perceived by support group leaders and carers as denoting social and informative assistance. Yet 'support' can also mean the teaching of skills, especially psychoeducational skills, to help carers manage their ongoing life changes more effectively and to improve their own health and wellbeing.

We therefore recommend that:

- Alzheimer's Australia NSW pilot and evaluate different models of delivery for support interventions, including short-term focused

models such as coping with stress; skills for relaxation; and groups for specific sub groups such as daughters and sons, former carers and male carers

- Alzheimer's Australia NSW to develop strategies and resources to disseminate successful models and programs and maintain quality outcomes
- Alzheimer's Australia NSW seeks funding to renew the CALD teleconferencing model to acknowledge the high number of CALD support group members in New South Wales
- Alzheimer's Australia NSW promotes initiatives to establish new ongoing support groups, especially in areas not presently serviced by Alzheimer's Australia NSW
- Alzheimer's Australia NSW develop a strategic plan for the Group Development Unit to integrate the research and drive program direction and development.

7.4 Expand group skills training for leaders

Our survey results demonstrate the need for further development of group skills training for support group leaders. This training would aid the professional development of all leaders, volunteers and professionals, and enable leaders to extend their skill level and target effective outcomes. In addition, competency based training for leaders would increase standards of quality for support groups and thus enhance the support service available to carers of people with dementia. We therefore recommend:

- Further investigation into the training needs of volunteer/non-professional group leaders
- Specific training for new group leaders
- Further development of groupwork and program resources to support group leaders
- Ongoing workshop training for experienced trainers
- Competency based training in line with the National Training System
- Increased opportunities for networking and peer support.

7.5 Identify the different needs of all carers

Our survey has identified a diverse range of carers for people with dementia, including males and females, spouses, daughters, sons, friends, neighbours and people from various CALD

backgrounds. We recommend that further research be conducted to acknowledge the diversity of these carers and to identify their specific needs.

For example, further to the 'feminised' area of care that has been replicated in our research, we recommend a study to identify the different needs of male carers, their perception of their caring role and views on support groups. Bird and Parslow's (2001) previous recommendation to make greater use of Honours, Masters and PhD students could be implemented here. This would help Alzheimer's Australia NSW to establish stronger links with research institutions and increase the organisation's credibility with other professions.

7.6 Identify service gaps

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



One of my greatest challenges as a leader is the range of needs of carers, and just how many of them there are.

The completion of a group session leaves me feeling very humble and privileged.

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6. a) How long does it take you to travel to the group?
 Less than 1/2 hr 1/2 -1 hr 1-2hrs more than 2 hrs
- b) How much time is spent preparing for each session?
 None less than 1 hr 1-2 hrs 3-5 hrs more than 5 hrs
7. a) Do you have any assistance preparing for the group? Yes No
b) If yes, how often? Monthly Bimonthly Quarterly
c) What is the assistance?
 Informal discussions with colleagues
 Formal discussions with colleagues
 Structured supervision
 Other, please specify _____
8. Do you have easy access to:
 A computer The Internet Email facility
9. How do you plan the program content? (Please order 1-5: 1 = the most used; and 5 = least used method of planning.)
__ Carer requests and suggestions
__ Own knowledge of key concerns of carers
__ Annual carer needs analysis
__ Availability of guest speakers
__ I decide from one group session to the next
10. a) How difficult do you find your role as a group leader?
 never difficult sometimes difficult usually difficult always difficult
b) What factors determine this? _____
11. a) How satisfying do you find your role as a group leader?
 never satisfying sometimes satisfying usually satisfying always satisfying
b) What factors determine this? _____
-

WHAT QUALITIES DO YOU BRING TO THE GROUP?

12. How do you perceive your leadership style? (Please tick THREE ONLY)
- | | | | | | |
|------------------------------------|---|-------------------------------------|--------------------------------------|-------------------------------------|--|
| <input type="checkbox"/> Casual | <input type="checkbox"/> Information Oriented | <input type="checkbox"/> Empathic | <input type="checkbox"/> Organised | <input type="checkbox"/> Structured | <input type="checkbox"/> Accepting |
| <input type="checkbox"/> Directive | <input type="checkbox"/> Opinion Seeking | <input type="checkbox"/> Analytical | <input type="checkbox"/> Challenging | <input type="checkbox"/> Flexible | <input type="checkbox"/> Encouraging of difference |

13. Do you think you have sufficient skills / knowledge in the following areas:

This information will be used in developing resources for group leaders. (Please tick appropriate response for each)

Group work skills:

- a) Maximising interactive discussion in the group:
 unskilled some skill skilled very skilled
- b) Skills in handling 'difficult / high needs' members:
 unskilled some skill skilled very skilled
- c) Helping members learn new ideas and apply them:
 unskilled some skill skilled very skilled
- d) Knowledge about the processes of a well functioning group:
 unskilled some skill skilled very skilled
- e) Balancing 'individual' and 'group' needs
 unskilled some skill skilled very skilled

Communication skills:

a) Capacity to respond to the spoken and unspoken themes in the group:

unskilled some skill skilled very skilled

b) Capacity to understand and communicate what is happening in the group at various levels

unskilled some skill skilled very skilled

c) Responding to members in terms of their current needs (emotions, concerns, reactions):

unskilled some skill skilled very skilled

Use of Knowledge:

a) Knowledge of the impact of dementia:

unskilled some skill skilled very skilled

b) Knowledge of the impact of stress, anxiety and depression:

unskilled some skill skilled very skilled

c) Knowledge of the services available:

unskilled some skill skilled very skilled

d) Knowledge of the impact of a chronically stressful situation on individuals and families:

unskilled some skill skilled very skilled

14. What would you need to further develop your role as an effective support group leader?

YOUR PARTICULAR SUPPORT GROUP

15. What is the geographic location of your group?

Metropolitan Regional Rural

16. Is the group primarily for those who look after persons currently in residential care? Yes No

17. How long has the group been meeting?

less than 1yr 1- 2yrs 2-5yrs 5-10yrs more than 10 yrs

18. Do you have to set up the room yourself? Yes No

19. Does the facility have resources required for running a meeting?

Coffee/tea making facilities Heating
 Appropriate comfortable seating Cooling
 Wheelchair access Overhead projector
 TV/video player Whiteboard / butchers paper

20. How do you finance tea/coffee and other resources you may need?

21. Do you maintain an attendance book? Yes No

22. Is there a rental fee for the site? Yes No

23. If so, how is rent financed?

GROUP MEMBERSHIP

24. How many new members have joined in the last twelve months? _____

25. How do members first hear about the group? (Please order 1-6: 1 = the most common; and 6 = least common source of referral)

- GP Referral
- Aged Care Assessment Team
- Dementia Helpline
- Other carers/ members
- Media
- Other, please specify _____

26. Do you speak with potential members before they attend their first group meeting?

- Never sometimes usually always

27. Defining a group member as a person who attends at least half of the meetings in a year:

- a) How many group members do you have in the group? _____
 b) How many people usually attend a typical meeting? _____

28. How many people do you have on your mailing/contact list? _____

29. How many members have left in the last twelve months? _____

30. Do you have any members from culturally and linguistically diverse backgrounds? Yes No

If yes, what is their first language? _____

31. Considering the group members, list the number of males and females in each age group:

	Under 40 years	41-50 years	51-65 years	66-75 years	76-85 years	Over 85 years
Males						
Females						

32. Considering the relationship of the group member to the person being looked after, how many members would be in each category?

Spouse/Partner	Daughter / Son	Daughter / Son-in-Law
Other Relative	Friend / Neighbour	Unknown

33. Considering the persons being looked after, can you indicate the age groups and gender of this group?

	Under 40 years	41-50 years	51-65 years	66-75 years	76-85 years	Over 85 years
Males						
Females						

34. What is the general diagnosis of the person being looked after by each member?

(Please write beside each the number of males and females)

	Male	Female
Early Stage Dementia		
Middle Stages of Dementia		
Late Stages of Dementia		
Other please specify		

35. Estimate how many members of your group have regular contact with each other at times other than support group meetings: _____

SESSION PLAN

36. Do you attend the group with a prepared session plan? Yes No

37. Please list, as best you can, the dominant themes / topics / activities used in the group over the last 12 months.

Month	Dominant Themes / Topics / Activities
July 2003	
June 2003	
May 2003	
April 2003	
March 2003	
February 2003	
January 2003	
December 2002	
November 2002	
October 2002	
September 2002	
August 2002	

38. Give an outline of a typical session for the support group in timed sections.

First 1/2 hour _____

Second 1/2 hour _____

Third 1/2 hour _____

Fourth 1/2 hour _____

Other _____

39. To what extent do you think the group meets the following needs of participants in the group? (In responding, consider the past twelve months)

Emotional – Group provides an environment where members can have the opportunity to express and process their feelings related to their experiences.

need not met need sometimes met need met well need met very well

Social – Group provides an opportunity for participants to develop networks and friendships to share with others in similar circumstances.

need not met need sometimes met need met well need met very well

Psychological – Group provides opportunities to learn skills and strategies to help manage change.

need not met need sometimes met need met well need met very well

Educational – Group provides access to education, both formal and informal, within the group.

need not met need sometimes met need met well need met very well

Informational – Group keeps members informed about a range of relevant community, health, financial, library and web resources.

need not met need sometimes met need met well need met very well

Thank you for your participation and contribution to this work. This will lead to us being able to provide a better service to support groups.

Finally, do you see other ways Alzheimer’s Australia NSW could assist you in your support group leadership role?

Appendix 2 – Information Accompanying Questionnaire

September 9, 2003

Dear Support Group Leader,

As you may have heard we are conducting a research project on support groups, and our first stage is asking you to complete this rather lengthy survey.

As support group leaders you are pivotal to this field. This is the first time that a survey of this nature has been conducted, and there is little knowledge about your role in this critical field. Consequently, we wanted to start with obtaining your feedback, views and perceptions about what you are doing, your priorities and concerns, and the supports you may have in this role.

We apologise for the length of the survey, which we think may take you about an hour. We have included some tea and coffee to assist you in the task.

Thanking you again, and please ring if you have any questions.

Yours sincerely,

Rosemarie Tweedie
Coordinator
Group Development Unit

Enclosures:

Information Sheet

1. Two consent forms
2. Helpful hints
3. Checklist
4. Questionnaire

INFORMATION SHEET

ALZHEIMER'S AUSTRALIA NSW QUALITY SUPPORT GROUPS

RESEARCH PROJECT

CHIEF INVESTIGATOR: Manager, Family Services, Alzheimer's Australia NSW.

PURPOSE OF PROJECT

The purpose of the research project is to become better informed about the operation and structure of support groups in NSW. In order to do this there will be an investigation into the needs of both support group leaders and carers. The outcome of this research will be a clearer understanding of what constitutes quality support groups and how this can be achieved.

In accordance with the **Principles of the AANSW Privacy Policy Procedures** you are ensured:

- The right to privacy.
- Personal details will be managed with diligence and confidentiality.
- AANSW will be open and accountable about these procedures.
- All staff involved in data collection will sign a confidentiality agreement.
- An appointed Privacy Officer shall ensure proper implementation of procedures.

This document is available upon request.

DATA COLLECTION

- You will be asked to take part in a questionnaire/ focus group.

The data collected in this study will be collated and analysed. Some of your words may be quoted from the questionnaire/focus group and used in academic articles written from the analysis. However, all information and opinions provided are confidential and anonymous. Your name will not be recorded except for the information from the cover sheet where you will be assigned a code number. No identifying information about you will be published.

- You may decline to answer any or all of the questions and may withdraw from the study at any time.
- Any questions regarding the study or your part in it can be answered by calling Rosemarie Tweedie (02) 9888 4207 or emailing: groupdevelopment@alznsw.asn.au

- Similarly, if you have any complaints or reservations about the ethical conduct of this project you may contact RNSH Research office on (02) 99268106

This project has the backing of:

Alzheimer's Australia NSW

Macquarie Research Ltd (Macquarie University)

NSW Health

NSH Human Research Ethics Committee

CONSENT FORM – LEADERS

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.
- The aim of the project is to research the processes and needs of leaders and members of support groups.
- My name will only be used to register the completion of the questionnaire and to check that AANSW database information (name, address, location of support group, telephone number and meeting times) is accurate.
- Only identified research team members will see this information as it comes in to the organisation and it will not be available to other AANSW staff.
- Personal details as completed on this form will not be made available to any other parties.
- All information after page one of the questionnaire will be given numerical codes and not be identified.
- 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 Quality Support Groups Project team on (02) 9888 4207 (Rosemarie Tweedie) 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.



HELPFUL HINTS FOR SUCCESSFUL COMPLETION OF QUESTIONNAIRE

We have sent out one questionnaire per group with the assumption that if there are co-leaders they will collaborate in completing the questionnaire i.e. one questionnaire per support group!

To help you complete the attached questionnaire we would like to offer some suggestions to make this task more enjoyable. Your answers are important to us as this research project will not only lead to a greater understanding of support groups but the important role that you, the leader, play. This in turn will eventually lead to greater assistance for support group leaders across NSW.

Please remember:

- This is not a test; there are no right or wrong answers.
- Rather than not answering a question please attempt to make a 'best guess'.
- Feel free to scribble extra remarks or comments throughout the questionnaire if the need arises.
- Make yourself comfortable as we estimate the questionnaire could take up to one hour to complete.
- If you lead more than one support group please phone and let us know if you require extra questionnaires.
- If you also run Living with Memory Loss groups DO NOT fill out a questionnaire for these groups.
- 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
- You may phone Rosemarie or Jean (02 9888 4207) or email: groupdevelopment@alznsw.asn.au to answer any queries you may have with regard to the questionnaire.

We would be pleased if you could return the questionnaire with the signed **white** consent form, in the reply paid envelope by 14th October 2003

CHECKLIST FOR RETURNING YOUR PRE PAID ENVELOPE

Have you remembered to include?

- Completed questionnaire
- The WHITE SIGNED consent form

Appendix 3 – List of Support Groups in New South Wales

Dementia Support Groups in New South Wales

February 2004

*Albury	Galston	North Sydney
Alstonville	Georges Hall	*Nowra
Armidale	Gerrigong	Orange
Ashfield	Glen Innes	*Pambula
*Auburn	Gosford	Parkes
*Ballina	Goulburn	Parramatta
Bankstown	Grafton	Peak Hill
Bateau Bay	Green Hills	Penrith
Bathurst	Grenfell	Port Macquarie
Baulkham Hills	Griffith	Queanbeyan
Bega	Gundagai	*Randwick
Belmont	Gunnedah	Raymond Terrace
Belrose	Haberfield	Rose Bay
Bingara	Hamilton	Sandgate
Blacktown	Hammondville	*Scone
Bondi	Henty	St George
Bondi Junction	Inverell	St Georges Basin
Byron Bay	Kempsey	St Leonards
Camden	Kincumber	St Peters
Camden Haven	Lake Cargelligo	*Sutherland
Canowindra	Lakemba	Tamworth
Cardiff	Leeton	Toronto
*Cessnock	Leura	Trundle
Charlestown	Long Jetty	Turrumurra
Coffs Harbour	Manilla	Tweed Valley
Coledale	Manning	Ulladulla
Concord	Mayfield	Wagga Wagga
Condobolin	Merimbula	*Wallsend
Coonabarabran	Miranda	Waratah
Corowa	Mittagong	Warilla
Cowra	*Moree	Wentworthville
*Cringila	Morisset	West Wyalong
Dee Why	Moruya	Willoughby
Deniliquin	Mount Hutton	Winmalee
Dubbo	Mudgee	*Winston Hills
Erina	Narooma	Wollongong
Ermington	Narrabri	Woodfield
Fairfield	Nelson Bay	Woy Woy
Forbes	Newcastle	Wyong
Forster	North Ryde	Young

* Denotes areas that have more than one support group. We acknowledge that other ongoing dementia support groups may exist that were not investigated as part of this research.

