Best Practice in Dementia
Carer Support Groups: an evidence based model

The Quality Support Groups Research Project
Support groups for carers of people with dementia

a core service of Alzheimer's Australia NSW for over two decades
Dementia support groups...

*directly* assist the carer

*indirectly* assist the person with dementia
Alzheimer’s Australia NSW provides assistance to support group leaders

- skills training
- practical aids for programming
- educational resources
Consequently ........

Support groups provide a valuable line of communication between Alzheimer’s Australia NSW and carers
Until 3 years ago...

Little documented evidence and only anecdotal evidence available to confirm the popularity and effectiveness of these groups in NSW
Social Changes

- ageing population
- changes in family structure
- emergence of female labour market
- educated ‘baby boomer’ cohort
Quality Support Groups
Research Project

investigates in a measurable way the characteristics of dementia support groups and their effectiveness in providing support to carers.
Core findings

1. Ongoing support groups are an effective means of meeting the needs of carers of people with dementia

2. The skills of the group leader are important

3. The evidence from our research findings will influence the development of best practice for carer support groups
Methodology

Phase I -  
- literature review
- survey of support group leaders

Phase II -  
- survey of support group members (carers)

Phase III -  
determine quality standards
Data Collection

- Over 350 self-completed questionnaires
- 12 telephone interviews
- 4 focus groups
What we found:

The Group

- 220 support groups in NSW
- Most dementia specific (90%)
- Few specific carer groups – such as men only groups, sons and daughters, CALD groups
- Average number in each group - 10
The support group leaders

- 89% Female
- 86% Health professionals
- Time poor
- 94% described their role as ‘always’ or ‘mostly’ satisfying
The group members

- 75 % Female
- Female spouse (49 %), male spouse, daughters, son, daughter in law, friend
- Average length of membership - 3 years
Diversity

- Diversity in culture and language
- Diversity in the relationships
- Diversity in the stages of dementia
- Diversity in type of dementia
- Diversity in living arrangements
- Diversity in carer’s other responsibilities
- Diversity in the gender of members **NOT** significant as 75% female
Literature Review

- Change of focus in research at end 1980s
  - call for a new approach to recognise distress and anxiety experienced by the carer of a person with dementia
This acknowledgement of the physical and emotional stress of carers and the dearth of information about dementia support groups in NSW was the initial spur for the research.
Physical and Emotional Stress

Is your caring role physically stressful?

Is your caring role emotionally stressful?
Grief & Loss

- Grief after the diagnosis
- Grief at the loss of the known personality of the person with dementia
- Grief at the loss of the relationship
- Grief and loss through the transition of care
- Grief and loss at death
- Grief over the loss of the carer’s former identity
Outcomes from Group Membership

- Phase I - reported that social needs of carers appear to be met but no direct proof of psycho-emotional needs being met

- Phase II - emotional burden of caring for someone with dementia can be significantly relieved

- Education and Information

- Relieves ‘isolation’
Reasons for non-attendance

- Stigma
- Practical issues time, venue
- Respite constraints
- Carer need was met with short term attendance
- Some carers do not like informal/social aspect
Mutual Aid

- Not given enough kudos
- Trust and reciprocity develops through friendships
- Former carers
- Group cohesion
Good Leadership Skills
vital for optimum quality outcomes

- Carers described leaders as ‘empathic’, ‘flexible’ and ‘accepting’

- Carers and leaders expressed desire for more group leadership skills training
Effective partnerships:

1. Alzheimer’s Australia NSW partners with leaders through education

2. Leaders partner with group members to inform and educate, develop mutual aid

3. Trust and reciprocity between members grows
*Policy and Advocacy
- Diversity must be acknowledged
- Flexibility required to coordinate services

*Information Technology
- Increasing demand → virtual ‘support group’

*Community Awareness
- stigma
- advertise support groups more widely
A Simple Mathematical Theory

In 2007 the number of people with dementia living in Australia = 220,000

1/3 reside in NSW = 70,000 (approx)

Half of these people would have one carer = 35,000 carers

Dementia support groups in NSW = 220

With an average of 10 members per group = 2200 members
Therefore the current support group network does not include over 30,000 carers!!
In Conclusion...

The Quality Support Group Research Project provides a new interpretation of dementia support groups across the state.

A foundation to develop evidence based practices for effective partnerships in dementia care.
**Carers are the final arbiters of what counts as 'success'**

(Nolan, Ingram and Watson 2002)
We were often told there was ‘life after dementia’. I think it is important to learn to have a life with dementia. Dementia journeys can be long and to wait over 11 years is a long time not to have a life. To have a life with dementia has helped me through our long journey (carer)
To read Phase I and II of the
Quality Support Groups Research Project

www.alzheimers.org.au

National Dementia Helpline 1800 100 500