Dementia Cafés:
An evaluation of their effectiveness in supporting carers of people with dementia

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Session Outline

- SLHD Dementia Cafés Model
- Aims of the research
- Methodology
- Findings to date
- Where to from here
SLHD cafés
SLHD Dementia Café Model

- Informal
- Doing things together
- “Normalising”
- Access to information and advice when needed
- Low cost
Aims of the research

- To establish whether attendance at the Cafés reduces carer stress
- To ascertain whether attendance at the Cafés increases awareness/use of support services
- To identify what carers perceive as the key elements of a successful Café
- To compare the support provided by the Dementia Café with other service types
Methodology

• Invitation sent to 93 carers who had attended a Café in past 12 months (Jan-Dec 2012)

• 40 people initially agreed to participate

• Participants were sent questionnaires at 2 different points in time approx. 4 months apart
  – General questionnaire
  – Zarit Burden Interview (short form)
  – Quality of Life-AD(Alzheimer’s Disease) Measure

• 32 participants responded
General questionnaire

- 23 questions
- Carer demographics
- Attendance at Cafés
- Important elements of the Café
- Social connections made
- Support service types accessed by carers
- Opinion of the Dementia Café
Zarit Burden Interview (short form)

- 12 questions scored from 0-4 related to perceived carer burden

- Eg. Do you feel that because of the time you spend with your relative you don’t have enough time for yourself?
  - Never -0; Rarely-1; Sometimes-2; Quite frequently-3; Nearly always-4

- Total score possible score = 48

- Higher score = greater burden
Quality of Life – AD (QOL-AD)

- Rates the QOL of the person with dementia as perceived by the carer at the present time

- 13 dimensions scored from poor – excellent

- Eg Physical Health – poor=1; fair=2; good=3; excellent=4

- Total possible score = 52.

- Higher score = better QOL
Results – General questionnaire

- 50% participants have attended 7 times or more
- 80% plan to continue attending
- 66% of carers are partners
- 80% are the primary carer
- 75% live at home with the person
- 66% are female
Questionnaire results cont’d

- 33% found out about the services they use through the Café
- 40% started using services as a result of discussing them with others at the Café
- Almost 50% say the Café provides “more” or “much more” support than other services they access
- 75% gained info at the Café about support services
Questionnaire results cont’d

- 81% made a connection with others at the Café
- 50% have contact with others outside of the Café
- 88% rated their experience of the Café as above average or excellent
- 84% reported that the Cafés have impacted positively on their quality of life
- Most relevant aspects of the Café for carers
  - “Opportunity to talk to Health Professionals”
  - “Opportunity to meet others”
  - “Outing for myself and my relative”
Comments

“I feel more confident to ask for support when I need it.”

“A great meeting – terrific. The informality is excellent.”

“The dementia cafes have given me a life.”

“It’s a very important outing for the people with dementia, they are comfortable being with others having the same disability.”

“I think it is a lifesaver for me as I have been feeling overwhelmed and alone in regard to support and advice on dementia.”
Suggestions for improvement

“Have the cafes on a more regular (fortnightly) basis.”

“Have regular excursions away.”

“More people in council constituents should be encouraged and invited to come along.”

“Sometimes it’s hard to speak to others at the cafe as I don’t know who has the dementia ... Some sort of introduction to the other carers would be nice.”

“Guest speakers.”
### Zarit Burden Interview

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<td>37-48</td>
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- **Mean score:** 23.1
- **Median score:** 23
- **Range:** 5 - 36

**NSW Health**

**Sydney Local Health District**
# Quality of Life - AD

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- **Mean Score:** 25.07
- **Median:** 25.5
- **Range:** 18 - 43

*NSW Government Sydney Local Health District*
What’s next?

- 2nd stage questionnaires have been sent
- Analysis of themes in open responses
- Statistical analysis of results
  - eg. Correlations (comparing baseline and 4 months ZARIT score and QOL - AD)
- Final reporting to DCRC by August 2013
Project Team

- Project Leader: Jane Palmer
- Project Co-ordinator: Anne Tunks
- Project Officers: Stephanie Ingram/ Evelyn Argall
- Research Consultant: A/Prof Vasi Naganathan
Questions?
Thank you

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