AN AUSTRALIAN GOVERNMENT INITIATIVE

ALZHEIMER'S AUSTRALIA EARLY STAGE DEMENTIA SUPPORT AND RESPITE PROJECT

FINAL REPORT ON THE NATIONAL EVALUATION

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Executive summary

In 2000, the Australian Government Department of Health and Ageing began funding Alzheimer's Australia to run time-limited groups in every Australian State and Territory. The groups offer support, information, education and problem-solving for people with early stage dementia, together with their carers/family members or supporters. The groups are part of the *innovative Early Stage Dementia Support and Respite Project*, presented as the *Living with Memory Loss* (LWML) program.

Evaluation of the effectiveness of such a project presents many problems. This is best illustrated by the fact that 30 years of research, even with traditional carer-alone groups, consistently reports high levels of participant satisfaction but there is rarely improvement in outcome measures over time. The methodology for the current evaluation was devised in consultation with Alzheimer's Australia staff who present the LWML program. The methods involved administering a multi-facetted questionnaire just before the start of the LWML groups, at the end of the program, and then three months and 15 months later. Questionnaires were completed by both carers/supporters and people with memory loss, using a method which maximised the chances that participants were able to process the material. A sub-sample of participants (wait-list control group) filled in two 'pre-group' questionnaires before the program started. These questionnaires were used to determine whether any improvements in the main sample could be attributed to the groups, or to change which would have occurred anyway.

There is sufficient evidence to conclude that what is quite a low-cost and brief intervention has a significant clinical impact, even though some of the effects were not apparent until the three month follow-up. People with memory loss and their carers/supporters were highly satisfied with the groups. Both frequently stated that what they learned, being able to talk freely and openly with others, and feeling that they were not alone were the most helpful and important aspects of the groups. Qualitative comments by the people with memory loss, including descriptions of their experiences, are presented in this report. They demonstrate that people with early dementia retain considerable insight, confirming one of the basic premises of the LWML program.

The findings of this study extend over and above satisfaction ratings. For participants with memory loss there was a significant improvement in depressive symptoms. A decline in cognitive ability (found for the sample as a whole at the three month evaluation) and increased medication use (for those who were clinically depressed when they started the group) were integrally related to the decline in depressive symptoms.

For carers/supporters, there was a significant decline in stress caused by changed behaviours and an increase in how enriched they were by the caring experience. Furthermore, these results were not due to changes in cognitive or functional status, nor to increased use of health services after the group. The improvements described above were evident at the end of the group and at the three month follow-up.

At the three month evaluation, there was also a significant improvement in carer/supporter mental health and in the likelihood of making legal/financial plans for the future. This latter finding could be due to the passage of time. Whether or not

improvements found at three months would have occurred without attending the groups could not be assessed because the control group did not cover such a long time period.

The only effect remaining at the 15 month follow-up was alleviation of depressive symptoms in a somewhat select sub-sample of people with memory loss, whom we were able to interview at that point. We were not able to adjust for all possible confounders because of the small number of participants. Despite the loss of most effects at 15 months and the long passage of time, carers/supporters remained positive about the groups. The majority endorsed the program strongly, both for other people with memory loss and their carers/supporters.

Regardless, the findings up to three months are important in their own right. The evaluation found improvements during a time period that reflect the early stages of dementia. Assisting people living with early stage dementia is the primary goal of the program. The results are noteworthy because changes in validated outcome measures over time are comparatively rare in the support group literature. They are also clinically significant because the variables included in this study are predictive of other negative events, including physical morbidity, inappropriate medication use, and institutionalisation. The findings strongly suggest that the content of the LWML groups is well-chosen and well-delivered. They also strongly suggest that the groups deserve to continue.

Acknowledgements

We would like to sincerely thank and acknowledge the carers/supporters and people with memory loss from the program. Participating in this evaluation has meant spending a lot of time answering extremely personal questions.

We would like to thank Anna Sarre and Glenys Badger who have both been national co-ordinators of the program during the evaluation. Their enthusiasm and communication with Alzheimer's Australia staff has substantially encouraged and benefited the project.

We also want to acknowledge the efforts of the State co-ordinators and staff who have worked on this evaluation. They have contributed at many levels, giving detailed discussion about the content of the questionnaire, administering questionnaires, and answering follow-up queries. They have been unfailingly helpful and enthusiastic.

We are indebted to Professor Henry Brodaty, who suggested entering all potential confounders into the analysis together. Many thanks to Tony Jorm and Keith Dear who gave invaluable help with the statistical methods. Thanks to Keith Dear specifically for his advice about time varying covariates, and the syntax for the Clinical Dementia Rating scale.

Finally, we acknowledge the role of the Australian Government in funding and supporting this project. The foresight and willingness required to fund innovative projects means that Australia is at the forefront of countries running national group programs which include not only carers, but people with memory loss.

Background

From its inception the core business of Alzheimer's Australia has been to support family members caring for people with memory loss, often in group settings. More recently, several regional associations began running groups for people with memory loss themselves. In 2000, the Australian Government Department of Health and Ageing funded Alzheimer's Australia to present standardised *Living with Memory Loss* (LWML) programs in every State and Territory of Australia. Alzheimer's Australia staff facilitate these LWML programs. They provide support groups for people with early stage memory loss who still retain some insight into their difficulties, together with their family carers/supporters. The groups are normally run once a week, for 6-8 weeks, and people with memory loss and their carers/supporters meet both separately and together. The groups provide information and advice about a range of key issues, including describing what dementia is, how to manage the labyrinth of available services, drug and treatment options, stress management techniques, communication skills, and strategies for coping with changed behaviour. Emotional and social support are also a primary component, with the groups providing the opportunity for carers/supporters and people with memory loss to share their experiences with others going through similar situations, and with understanding staff.

It was a condition of funding that the effectiveness of the LWML groups be independently evaluated. This was a crucial issue. Nearly three decades of research has at best produced equivocal findings on the effectiveness of support groups for informal carers, let alone for people with dementia themselves. Although many studies show that participants are highly satisfied with support groups (Brodaty *et al.* 2000), it is rare for movement to be found on measures which would indicate significant improvement in quality of life, for example mental health. The few studies which do show effects on variables other than satisfaction tend to have much more focussed and intensive programs than support groups. An example is the classic study by Brodaty and colleagues, where carers undertook an intensive two-week residential program (eg. Brodaty and Peters 1991). Effects were still apparent several years later (Brodaty *et al.* 1993).

Those who present support groups have no doubt they assist carers, and the fact that people continue to attend could be taken as a marker of effectiveness. Nevertheless, repeated failure to produce data showing improvement in measures other than satisfaction has led to some scepticism in the literature, best encapsulated in the journal article title: *Support groups for informal caregivers don't work! Refocus the groups or the evaluations* (Lavole 1995). That is, because the quality of research on support group outcomes is generally poor, it is unknown whether inadequate measurement or inadequate programs, or both, are responsible for equivocal findings about their effectiveness (Cooke *et al.* 2001; Pusey and Richards 2001). It was against this background that we planned the evaluation of Alzheimer's Australia's *Early Stage Dementia Support and Respite Project.*

Methodological issues

In order to evaluate the LWML program, a number of logistical and methodological problems needed to be solved.

Firstly, research has generally relied upon informant report because of methodological difficulties interviewing people with memory loss. Using carers as informants assumes that they will be able to accurately report on the internal life of those they care for. While this method is widely used it is not always valid, nor does it respect the rights, opinions and experiences of people with memory loss (Clare *et al.* 2002). In the current study, it was considered vital to include the views of people with memory loss in the evaluation, because they are an integral part of the program. However, this population commonly has difficulties processing and storing incoming information in memory. They tend to have equal difficulty retrieving information from memory even when they have processed it (Bird 2001). See the Procedures section (overleaf) for a description of how questions were presented to people with memory loss in this study.

Secondly, in order to show that support groups have an impact, it is necessary to demonstrate that any improvements or benefits would not have occurred in the normal course of events, without attending the LWML groups. In simple research terms this would involve randomly assigning people with memory loss and their carers/supporters to a control group who do not attend the groups. This control group would be followed over time to see if improvements also occur. However, it was neither ethical nor permissible for Alzheimer's Australia to randomly allocate people with memory loss and their carers/supporters to treatment or no-treatment groups. Another way of determining what happens to people without attending the program would be to randomly allocate participants to wait for a pre-determined time, taking measures at two points before they start the groups. However, randomisation was not possible because it was not acceptable to Alzheimer's Australia to make people wait, but also because it was often not logistically possible. Accordingly we have used the best compromise possible: naturalistic wait-list controls. That is, people who were assessed as suitable for a LWML group but then had to wait three weeks or more before it started. For example, wait-list control participants accepted into the groups may have had to wait a month until the next scheduled group was due to commence.

Thirdly, the evaluation required close collaboration between the research team and Alzheimer's Australia staff, who are generally passionate about the well-being of people with memory loss and their carers/supporters. However, few of these clinicians had research experience, and some did not see the value of research and were anxious about it. In particular, they wanted to protect their clients from questions that might be distressing (eg. asking about suicide in mood scales). The final form of the assessment instrument therefore contains some compromises as a result of a number of meetings with staff from Alzheimer's Australia and many email exchanges soliciting their input. We were aware that adding the evaluation to an already substantial clinical load would be a considerable demand. It is most appropriate here to acknowledge the wonderful efforts of LWML program coordinators and group facilitators in helping us carry out this research. We are enormously grateful (see also acknowledgements).

Central aims of the evaluation

Given the methodological problems, the central aim was to conduct a rigorous assessment of the effectiveness of the LWML groups within the constraints of the situation, balancing the rights of participants, the concerns of Alzheimer's Australia staff, and the need not to compromise the goals of the research. We wanted to cover multiple aspects of the dementia experience while using, wherever possible, validated scales with proven sensitivity for this population. We needed to demonstrate that any results (whether positive or negative) obtained were valid, and not due to methodological deficiencies.

Methods

Ethics

Ethical approval for this project was granted by the Human Ethics Committee of the Australian National University (Protocol no 2001/102), and South Western Sydney Health Service (Project no 03/059).

Study design

This is a repeated measure, wait-list control study, utilising one main study group and a control group. For the main study group, measures were to be given before the groups started, when they finished, and at two follow-up points, approximately three months and 15 months later.

The control group was wait-listed. That is, it was a sample of participants who were accepted into the LWML program but generally waited more than three weeks before it started. These participants completed the research measures when first enrolled, and then just before the group actually started. The control condition was designed to evaluate whether or not change occurs over time without participating in a group.

Procedures

Participants were informed about the evaluation upon enrolling in the LWML program. They were assured that if they did not want to participate it would not affect their involvement with the groups or with Alzheimer's Australia and that they could withdraw from the study at any time. Consent forms were filled in by all willing participants.

Carers/supporters completed their questionnaire alone and sealed it in an addressed envelope, so Alzheimer's Australia staff could not see their answers.

The procedure for participants with memory loss was designed to address the problems inherent in interviewing this population. Firstly, the carer/supporter was asked all factual questions such as age. For questions involving the subjective experience of people with memory loss, a standardised method was devised to maximise the chance that participants would process the questions and maintain them in memory long enough to consider them. It capitalises on the fact that the ability to

read words normally declines quite late in dementia, and that reading and considering text induces processing in this population (Bird and Luszcz 1993).

Each question was expressed as a short statement, for example: I FEEL MISERABLE AND SAD (from the Leeds Depression Scale). The interviewer held up a card with the statement in large letters and asked the person with memory loss to read it aloud. Immediately afterwards, while still holding up the statement, the interviewer asked: "Is that true?" If the respondent unequivocally said "yes" or "no", their response was accepted. If their answer was in any way ambiguous, standardised follow-up questions were asked (with the statement still held in front of them). This enabled a more detailed understanding of how the person with memory loss was feeling, rather than just Yes/No. It also allowed responses to be graded from 1 to 4, consistent with the Likert scoring of the Leeds Scale.

Alzheimer's Australia staff administered the questionnaire to participants because dementia specific communication skills were required. A video tape demonstrating the procedure was made by the research team to ensure that it was done as consistently as possible.

Measures

Separate questionnaires were designed for the person with memory loss and their carer/supporter. A literature search, clinical experience, and input from those presenting the LWML program produced a multi-facetted instrument which covers as much as possible of the memory loss experience, and also gives valid clinical and scientific outcome measures. Validated outcome measures are, the Beck Depression Inventory (BDI), the 12 question version of the General Health Questionnaire using the 'Chronic' scoring method (GHQ: Donath 2001; Goldberg and Hillier 1979), the Leeds Self Assessment of Depression General Scale (Snaith *et al.* 1976), and the Carer Stress Scale associated with challenging behaviour (Bird *et al.* 2002). The questionnaire also included an item asking whether plans for the future had been made. For the end of group assessment, participants were asked to rate their satisfaction with the LWML program.

Validated explanatory measures included the Abbreviated Mental Test (MacKenzie *et al.* 1996), the Clock Drawing Test (Sunderland *et al.* 1989), the Clinical Dementia Rating (Morris 1993) and an adaptation of the Guidelines for the Rating of Awareness Deficits (Verhey *et al.* 1995; Verhey *et al.* 1993). Other explanatory measures included items on service and medication use.

Medication use

It was essential to examine psychotropic and cholinesterase inhibitor use by the people with memory loss to determine whether it changed over the evaluation period and, if so, whether such changes could explain any improvements found in the evaluation. We asked carers/supporters to record the medications and dose per day that people with memory loss were taking across all time periods. However, it is not a simple matter to investigate the amount of medication taken and change over time. There were three main problems.

First, problems arise when attempting to compare the dose across various brands of antidepressants, antipsychotics, anticonvulsants and benzodiazepines. To give an example, a person may have changed the brand, while staying on the same class of medication. That is, they may have changed from Cipramil to Zoloft - two different types of antidepressants. Particular issues complicate the conversion of different medications into common equivalencies, including the plethora of brand names given to similar and often identical chemicals, and the variation in opinion as to the exact equivalency that should be given to a particular chemical. Issues such as half-lives further cloud this domain of enquiry.

We therefore calculated drug equivalencies by converting antipsychotics to chlorpromazine, antidepressants to amitriptyline, and benzodiazepines to diazepam using established dosage equivalencies published in the Victorian Drug Use Advisory Committee's "Psychotropic Therapeutic Guidelines" (2000; 1996/1997). Various other sources were also used (Preston 2002; Preston and Johnson 2002; Preston *et al.* 2002). Note that Avanza (Mirtazapine - a tetracyclic antidepressant), Venlafaxine (Efexor – an SNRI antidepressant), and Luvox/Faverin (Fluvoxam. Maleate – an SSRI antidepressant) could not be converted into amitriptyline equivalency doses, and Seroquel (Quetiapine Fumarate – a new type antipsychotic) could not be converted into chlorpromazine dose. In these instances, the person was recorded as taking the class of drug, but the actual amount was recorded as missing. Rivotril (Clonazepam) is described as an anticonvulsant but is more often prescribed as a benzodiazepine and hence was converted to diazepam equivalency doses. Different types of anticonvulsant cannot be converted into equivalents. However, only four participants were taking an anticonvulsant at any point in the evaluation and nobody changed brands.

Second, it was not meaningful to express the average dose taken because large standard deviations result from including people not on medications that are taken in large amounts (ie milligrams). We therefore used the drug equivalent dosages to generate a 'change' variable identifying people whose use of a class of drug (eg antidepressants) increased, did not change or decreased. Being able to investigate increases and decreases in medication use is much more sensitive than looking at whether or not a person is taking a medication.

Third, information about medications was often missing, particularly about the dose taken. Using a 'change' variable meant that we could code a medication as increased if someone was not previously taking a drug but started taking it at a later time period, even though the dose was missing. Similarly when a person stopped taking a drug, the drug was coded as reduced. Missing data was therefore limited to situations when an individual did not answer the question, or they stated that the person was taking the drug, but did not clearly indicate how much and/or how often.

People who were taking a medication as needed (PRN) were recorded as taking the drug but the dose was recorded as missing. This was only relevant for benzodiazepines.

Statistical methods

The main sample

STATA (version 7) was used to conduct most of the statistical analysis. For continuous outcome variables, XT regression was used to evaluate main effects of change across measurement points. For binary outcome measures (eg making future plans), logistic regression was used to evaluate main effects of change over measurement periods. The logistic regression analysis was clustered by the individual's identification number. Outcomes (such as depression) were used as dependent variables and a measure defining the evaluation periods (start of group, end of group, three and 15 month follow-ups) was used as the independent variable.

We used statistical methods which allowed us to determine whether a range of covariates, individually or combined, could account for change in outcome measures. Covariates were simultaneously used as independent variables in the analysis. The standard errors were adjusted to take into account the repeated measures design. That is, the analysis was clustered by the participant's identification number. The 'xi' procedure available in STATA was used to compare the start of group to the other time periods. Adjusted mean scores were generated for each analysis.

Covariates for the carers/supporters included lateness (described overleaf), service use, medication use and level of cognitive ability (both referring to the person with memory loss), and whether or not they continued on to further LWML groups. For the people with memory loss, covariates included lateness, activities of daily living (ADLs), insight, level of cognitive ability, medication use, whether they went on to attend further LWML groups, and an interviewer measure (described below).

The interviewer measure

As previously noted, Alzheimer's Australia staff interviewed the person with memory loss. The possibility that the results could be influenced by having the same staff member conduct the start of group and follow-up interviews needed to be considered. Consequently, a variable identifying situations where the start of group interviewer conducted subsequent interviews was generated. Table 1 shows that more than half of the end of group evaluations, and more than a third of the three month and 15 month follow-up evaluations were conducted by the start of group interviewer. Accordingly this measure was used as a covariate in the analysis investigating outcomes for the person with memory loss.

Table 1: The number (and proportion) of end of group and follow-up questionnaires conducted by the start of group interviewer.

	EG	**FU1**	**FU2**
n (%)	45 (54%)	30 (36%)	17 (35%)
Missing (n)	*4*	*4*	*3*

EG=End of group, FU1=3 month follow-up, FU2= 15 month follow-up

'Lateness': The timing of the completion of questionnaires

Our aim was to have questionnaires filled in upon completion of the group, and three and 15 months after the groups finished. However, practical difficulties meant that there was considerable variation in timing. Table 2 shows how overdue the questionnaires were (mean number of days) at the end of group, three month and 15 month follow-ups. On average the end of group and 15 month follow-up questionnaires were less than two weeks late, and the follow-up questionnaires were less than four weeks late (as indicated by the mean scores). However, the large standard deviations reflect considerable variance. For example, the end of group questionnaires incorporated responses over a month after the groups finished.

Table 2: Mean (and standard deviation) number of days late: the timing of the completion of the end of the group, three month and 15 month follow-up questionnaires for the main sample.

	Carer/supporter	**Person with memory loss**
EG	13.8 (13.9), n=87	10.6 (10.7), n=84
FU1	27.6 (31.6), n=87	26.6 (33.4), n=84
FU2	10.3 (88.6), n=58	14.4 (93.9), n=52

*EG=End of group, FU1=3 month follow-up, FU2= 15 month follow-up

Consequently, we generated a variable we have labelled 'lateness' which defines each questionnaire as being early, on time, late, or very late. Table 3 shows the definition of the lateness categories for each time period. We included this 'lateness' measure as a covariate in all statistical analyses presented in this report unless otherwise stated. The analysis therefore statistically adjusts for the variation in the timing of the completion of questionnaires.

Table 3: Definition of 'lateness' categories for the start of group, end of group and follow-ups.

	Early	**On time**	**Late**	**Very late**
SG	More than 14 days before groups started	14 days or less before groups started	NA	NA
EG	NA	within 14 days of groups finishing	15 to 27 days after groups finished	28 days or more after end of groups
FU1	More than 14 days before due date	14 days before or after the due date	15 to 60 days after due date	61 days or more after due date
FU2	More than 60 days before the due date	60 days before or 29 days after due date	30 to 120 days after due date	121 days or more after due date

SG=Start of group, EG=End of group, FU1=3 month follow-up, FU2= 15 month follow-up

Statistical methods for the wait-list control sample

For the wait-list control sample, repeated measures analysis of variance was used to investigate the significance of any differences between the mean scores on continuous measures from two pre-group questionnaires. A lateness measure was simultaneously used as a covariate in this analysis. This lateness measure was 42 minus the number of days between the two pre-group questionnaires. Including this measure in the analysis means that the time between the two pre-group questionnaires (for the wait-list control group) parallels the time between the start and end of the groups for the main sample, which was usually 6-8 weeks.

When describing the wait-list control analysis the following terminology will be used. For the wait-list control group, "time 1" is the first pre-group questionnaire and "time 2" is the second pre-group questionnaire. For the main sample, "time 1" is the start of group questionnaire and "time 2" is the end of group questionnaire.

Changes occurring between time 1 and time 2 in the control sample (who had not attended the groups) could theoretically explain changes occurring in the main sample (who had attended the groups). Therefore the outcome measures for the wait-list and main sample participants at time 2 were used as response variables in an analysis of variance, while group (wait-list vs main sample) outcome scores at time 1 and the lateness measure were entered as factors/covariates. This enabled us to investigate whether the wait-list and main sample time 2 scores were significantly different after adjusting for lateness and time 1 scores. That is, we could determine whether changes in the main sample could have occurred without attending the groups.

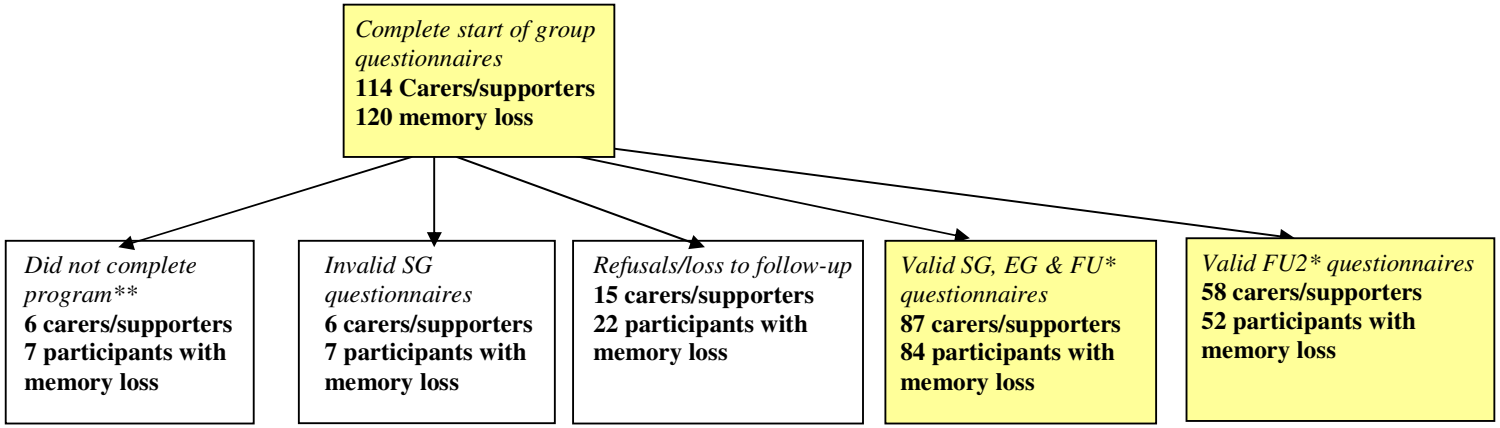
The sample

The response rate for the main sample participants

The participants for the main sample were recruited from groups across New South Wales, Victoria, South Australia, Queensland, Tasmania, and Western Australia. The main sample groups were run from December 2001 through to December 2002. Data collection was concluded in late July 2004.

Figure 1 is a flow chart showing the number of participants who completed the start of group questionnaires. This figure shows that 87 carers/supporters and 84 participants with memory loss had valid data through to the three month evaluation. Between the start of the group and the three month follow-up, 14% of carers/supporters and 18% of participants with memory loss withdrew from the evaluation, and/or were lost to follow-up. Overall, 24% of carers/supporters and 31% of participants with memory loss who filled in a questionnaire at the start of group were not included in the three month follow-up sample analysis given in this report. We also have data at the 15 month follow-up for 58 carers/supporters (57% of those with valid questionnaires up to the end of the groups), and 52 (49%) participants with memory loss.

Figure 1: The number of participants in the main sample who started the evaluation, did not complete the groups, were lost to follow-up, and completed valid questionnaires through to follow-up.



*SG=Start of group, EG=End of group, FU1=3 month follow-up, FU2= 15 month follow-up
**Refers to participants who only attended one or two sessions or who withdrew from the groups

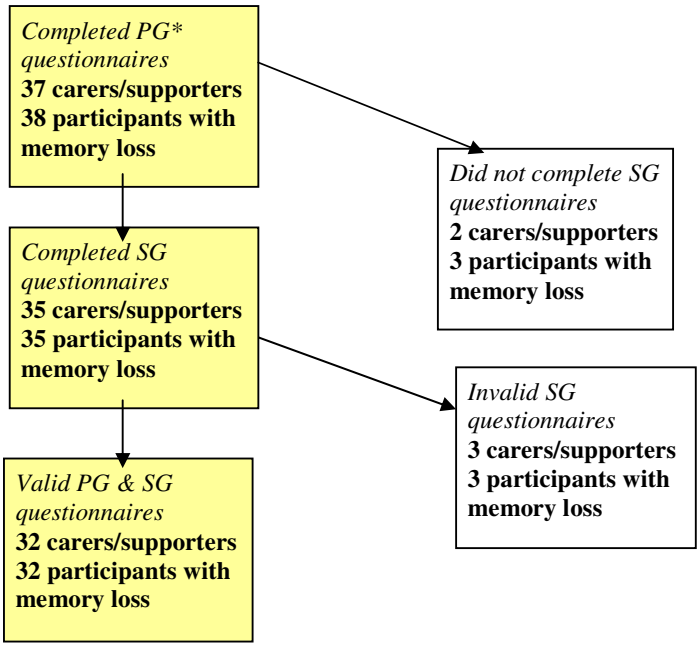
The left box shows those who only attended one or two sessions. This does not necessarily indicate that they "dropped out" or were unsatisfied with the LWML groups. For example, some participants only planned to attend a few specific sessions or may have left because of illness. Some participants filled out start of group questionnaires after the groups had already started. These participants were excluded (shown as 'invalid' in Figure 1) from the study, as their responses may have been be influenced by exposure to the first few sessions.

Table 4: The proportion of people attending 41 LWML programs, who participated in the evaluation (main sample) through to the three month follow-up.

State	Carers/supporters	Person with memory loss
NSW	44.7%	44.8%
SA	45.5%	48.3%
VIC	27.9%	29.7%
TAS	50.0%	60.0%
WA	20.9%	25.6%
QLD	33.3%	22.2%

Table 4 shows that participants came from 339 carers/supporters and 231 people with memory loss who attended 41 groups from six Australian States during the evaluation, though participation rates varied across States, ranging from 22.2% to 60%.

Figure 2: Participants in the wait-list control sample who did or did not complete valid pre and start of group evaluations, or who did not complete the groups.



*PG=Pre-group, SG=Start of group

**Refers to participants who only attended one or two sessions or who withdrew from the groups

The response rate for the wait-list control participants

Figure 2 shows wait-list control participants, those who completed two pre-group questionnaires. Two carers/supporters and two participants with memory loss completed the start of group questionnaires after the groups had started and could not be used in the analysis for reasons described in the previous section. The present study incorporates into the analysis the 32 wait-list carers/supporters and participants with memory loss who filled in valid questionnaires.

Socio-demographic characteristics of the main sample

This section describes the socio-demographic characteristics of the main sample. The aim of this report was to evaluate the efficacy of the LWML programs, not to report overall service demographics. Accordingly, this section describes only the characteristics of the participants who completed valid questionnaires up to three month follow-up. This is the sample for whom we later present findings on the main outcome measures. Table 5 shows the breakdown of participants by State. A larger proportion of participants came from groups run in New South Wales, Victoria and South Australia.

Table 5: The number (and percent) of participants in the main sample by State.

State	Carer/supporter		Person with memory loss	
NSW	38	(43.7%)	30	(35.7%)
SA	15	(17.2%)	14	(16.7%)
VIC	17	(19.5%)	19	(22.6%)
TAS	7	(8.0%)	6	(7.1%)
WA	9	(10.3%)	11	(13.1%)
QLD	1	(1.1%)	4	(4.8%)
total	*87*		*84*	

Table 6 (overleaf) shows a breakdown of the carers/supporters by sex, age, education and their relationship to the person with memory loss. This table shows that a larger proportion of carers/supporters (70.1%) were female. Female participants also tended to be younger, and analysis of variance indicated that the difference was significant ($p<.001$). This age difference is largely due to the participation of daughters (20% of female carers/supporters) in the evaluation. By contrast, no sons of a person with memory loss completed the evaluation.

Most carers/supporters attended the LWML groups with a spouse who had memory loss, and resided together in the general community when they started the groups. A small number of the female carers/supporters had current employment (10 spouses and 9 daughters/sisters of the person with memory loss). Most participants had completed some post high school education and reported good or excellent physical health.

Table 6: Socio-demographic characteristics of the carers/supporters at the start of the group (for the main sample).

			Male	**Female**
	Sex		26 (29.9%)	61 (70.1%)
	Age	<50	0	10 (16.4%)
		50-64	2 (7.7%)	19 (31.1%)
		65-74	9 (34.6%)	17 (27.9%)
		75+	15 (57.7%)	15 (24.6%)
Relationship to person with memory loss				
	Spouse		25 (96.2%)	45 (73.8%)
	Son/daughter		-	12 (19.7%)
	Friend		-	2 (3.3%)
	Sibling		1 (3.8%)	2 (3.3%)
Residence				
	In general community		23 (88.5%)	55 (90.2%)
	Unit in retirement village		3 (11.5%)	6 (9.8%)
Living with the person with memory loss				
	Yes		25 (96.2%)	48 (78.7%)
	No		1 (3.8%)	13 (21.3%)
Currently employed				
	Yes		1 (3.8%)	19 (31.1%)
	No		25 (92.3%)	42 (68.9%)
Post school education (including trade/university/college etc)				
	None		5 (19.2%)	14 (23.0%)
	1-2 years		-	22 (36.1%)
	3+ years		18 (69.2%)	22 (36.1%)
	Missing		*3 (11.5%)*	*3 (4.9%)*
Physical health				
	Poor		1 (3.8%)	1 (1.6%)
	Fair		6 (23.1%)	13 (21.3%)
	Good		18 (69.2%)	31 (50.8%)
	Excellent		1 (3.8%)	16 (26.2%)

Table 7 shows the socio-demographic characteristics of the participants with memory loss. Men and women were fairly equally represented, and tended to be a similar age. They were largely living in private residences in the community and a large proportion had a post-high school qualification. Most participants had a diagnosis of Alzheimer's disease or dementia unspecified. Most carers/supporters reported that the participants with memory loss had good or fair physical health.

Table 7: Socio-demographic characteristics of the participants with memory loss at the start of the group (for the main sample).

		Male	**Female**
Sex		44 (52.4%)	40 (47.6%)
Age	<50	0	0
	50-64	10 (22.7%)	6 (15.0%)
	65-74	12 (27.3%)	9 (22.5%)
	75+	22 (50.0%)	25 (62.5%)
Residence			
At home, in general community		37 (84.1%)	32 (80.0%)
Unit in a retirement village		4 (9.1%)	4 (10.0%)
Hostel		-	1 (2.5%)
Missing		*3 (6.8%)*	*3 (7.5%)*
Physical health			
Poor		2 (4.5%)	-
Fair		8 (18.2%)	10 (25.0%)
Good		19 (43.2%)	23 (57.5%)
Excellent		12 (27.3%)	4 (10.0%)
Missing		*3 (6.8%)*	*3 (7.5%)*
Education			
No post school education		15 (34.1%)	21 (52.5%)
University/college		12 (27.3%)	9 (22.5%)
Trade		8 (18.2%)	3 (7.5%)
Other		3 (6.8%)	2 (5%)
Missing		*6 (13.6%)*	*5 (12.5%)*
Diagnosis			
Alzheimer's disease		25 (56.8%)	29 (72.5%)
Dementia unspecified/ memory loss		7 (15.9%)	6 (15.0%)
Vascular/stroke related, or multi infarct dementia		5 (11.4%)	1 (2.5%)
No diagnosis		3 (6.8%)	
Missing		*4 (9.1%)*	*4(10%)*

Findings for the people with memory loss

What problems does memory loss cause for you?

Participants with memory loss were asked, "What problems does having memory loss cause for you?" Interviewers wrote down the response of the people with memory loss. At the start of the group a response was recorded for 78 (93%) participants. Only three people could not answer the question when asked. For instance, one participant responded, *I don't know about that*. Three people stated that they didn't have, or could not think of, any memory problems.

The most frequent problems mentioned by participants (n=46, 59%) related to practical skills and/or tasks, such as problems doing household chores, driving, forgetting to do things, losing items, being slow, or not being able to do hobbies. Eighteen (23%) participants specifically mentioned forgetting names of places or people.

Distressing emotions were frequently mentioned by participants (n=28, 36%). Examples are: frustration, anger, disbelief, anxiety, panic, feeling sad, useless, confused, vulnerable, upset, embarrassed, afraid, stupid, annoyed, and loss of confidence.

> *Anxiety, this feeling of anxiety overwhelms me. I don't feel as confident when I am anxious.*
>
> *I feel useless…..*
>
> *I hate having to ask people to repeat things for me. I'm afraid of not being able to remember, of getting worse, of becoming senile. I just go blank sometimes and then panic and feel so stupid.*

Communication, relationships and concern for others were also common concerns (n=14, 18%).

> *Problems with all the family. I can't be told anything. I know I am being difficult. Then I feel sad about the arguments. I think I am right most of the time but I am never right, I was never like it. If don't get my way I go on like I don't know what…*
>
> *I have to make lists. My daughter and son have more or less taken over. They won't even let me do the shopping. I'm not being ungrateful, but I would like to do some things, some times.*
>
> *I find that other people don't know how to handle it, that sometimes makes it a bit more awkward in a group of people.*
>
> *My wife worries about it plenty……*

Orientation (to place, date or time) problems were mentioned by nine people (12%).

> *Confusion in shopping centres and open parkland, I get lost easily in new environments…*
>
> *I got lost going to my sister in law's at a roundabout, I asked a couple of builders for help…...*

Nine people (12%) also responded with a comment meaning that they needed to rely on others.

> *Feeling uncomfortable, not being able to remember….I don't find it a big problem because I always have my husband around .*

One person responded:

> *It bloody affects everything….*

Depression

Table 8 shows the mean scores on the Leeds Depression Scale (adjusted for lateness) across evaluation periods for the main sample participants with memory loss. This table shows that there was no significant difference in depression scores at the end of the groups, but on average participants were less depressed at the three month follow-up.

Table 8 also shows the mean depression scores after simultaneously including 'the interviewer' variable previously described. Depression scores for the group as a whole remained significantly lower at the three month follow-up after making these adjustments. That is, being interviewed by the same person did not account for the decreased depression symptoms for the person with memory loss.

However, Table 8 also shows that improvements were statistically accounted for by a number of time varying covariates, level of dementia (CDR), level of capacity in activities in daily living, and insight. That is, taking into account participants' capacity in the above areas over time statistically accounted for the improvement in depression symptoms at the three month follow-up. We cannot therefore attribute the average improvement in depression symptoms to group attendance. Declining cognitive and practical capacity might be expected to increase depressive symptoms, but loss of insight might mask this.

Analysis of variance indicated that there was no difference between the intervention (mean 3.91, se .30, n=84) and the control group (mean 4.08, se .50, n=32) in depression scores at time 2 after adjusting for symptoms at time 1 and lateness (p=.772).

Table 8: Adjusted mean (and se) scores on the Leeds depression scale at the start of group, end of group, three month and 15 month evaluation periods.

Group and sample	SG	se	EG	se		FU1	Se		FU2	se	
Wait-list control†	3.75	.61	3.88	.65							
Main sample											
TO 15 MONTHS, n= 51	3.91	.42	4.02	.42					3.76	.45	
TO 3 MONTHS, n=84	4.27	.35	4.06	.33		3.14	.36	**			
Adjusted for: same interviewer	4.27	.37	4.45	.35		3.42	.36	*			
Adjusted for: insight, adls, CDR	4.27	.34	4.52	.32		3.58	.34				
Clinical sub-sample (Leeds>6)											
TO 15 MONTHS, n=10	9.20	.87	6.74	.84	*				3.76	1.0	***
Adjusted for: same interviewer	9.20	.94	6.68	.92	*				4.00	1.0	***
TO 3 MONTHS, n=20	9.52	.69	6.85	.65	**	5.13	.70	***			
Adjusted for: CDR, insight adls continuing in monthly LWML group	9.52	.69	7.61	.72	*	6.18	.78	**			
Adjusted for: same interviewer	9.52	.77	7.58	.69	*	5.72	.72	***			
Adjusted for: use of (yes/no) antidepressants and cholinesterase inhibitors	9.52	.86	8.24	.77		6.52	.86	**			
Adjusted for: change in antidepressants and cholinesterase inhibitors	9.52	.88	8.22	.84		6.84	.98				

SG=Start of group, EG=End of group, FU1=3 month follow-up, FU2= 15 month follow-up

†The data for the wait-list control is adjusted to represent a time period (42 days) parallel to the time between starting and finishing the group. These two measures are both pre-group and indicate change that would have occurred anyway, whilst not attending the program.

* p<.05, **p<.01, ***p<001, comparing the start of group with other evaluation periods

A cut-off (6/7) was used to identify participants with levels of depression likely to be of clinical significance (Snaith *et al.* 1976). About a quarter of participants (24%) had a clinical level of depressive symptoms at the start of the group. In this clinical sub-sample there was a significant reduction in symptoms at the end of the group, which was still evident at the three month follow-up. These findings were also not accounted for by cognitive ability, insight and activities of daily living or continuing on to participate in other LWML groups.

In the clinical sub-sample, there was significant improvement in depressive symptoms at the end of the group and at the three month follow-up after adjusting for the interviewer bias described previously. Further, amongst the 10 participants in this sub-sample from whom we were able to obtain data after 15 months, symptoms were still significantly lower more than a year after they finished the groups. Therefore possible bias resulting from the interviewer conducting both interviews cannot account for the reduction in depression found for the people with memory loss.

The possibility that medication changes could account for the improvement in depression symptoms for the people with memory loss also needed to be investigated.

We specifically investigated the role of antidepressants for obvious reasons and cholinesterase inhibitors because, if effective, a remission in cognitive decline might be expected to lift mood.

We included measures identifying whether or not participants were taking antidepressants and cholinesterase inhibitors (at each time period) as covariates in the XT regression analysis of the clinical sub-sample. The use of these drugs statistically accounted for the reduction in depression at the end of the group (p=.154) but not at the three month follow-up (p=.007). However, including the more sensitive "change" medication variable in the analysis statistically accounted for the reduction in depressive symptoms at the end of the group (p=.252) and the three month follow-up (p=.051).

The wait-list sample was too small to determine whether change would have occurred over time in a clinical sub-sample.

Medication use

We were interested in investigating the use of medications over time. As described above, they were a key confounding variable, but they are also a possible outcome of attending the groups. This section describes medication use over the evaluation periods.

Table 9 shows the proportion of participants with memory loss *in the evaluation* who were taking antidepressants and cholinesterase inhibitors, and the number of participants whose use increased, stayed the same or decreased.

Logistic regression was used to determine whether there were increased odds of taking antidepressants or cholinesterase inhibitors at the end of the group and at the three month follow-up. The use of antidepressants (OR=2.18, se .83, p=.040) and cholinesterase inhibitors (OR=1.62, se .32, p=.013) was more likely at the end of the group. However, the odds were not significantly different at the three month follow-up compared to the start of the group for both antidepressants (OR=4.26, se 3.38, p=.064) or cholinesterase inhibitors (OR=1.62, se .49, P=.110).

Table 9: The use of antidepressants and cholinesterase inhibitors by participants with memory loss over the evaluation period.

Medication and sample	SG	EG	FU1	FU2
Antidepressants				
TO FU1 N°. on drug	29/73 (39.7%)	36/77 (46.8%)	35/75 (46.7%)	
N°. missing	11	7	8	
TO FU2: N°. on drug	15/48 (31.3%)	17/48 (35.4%)		15/45 (33.3%)
N°. missing	3	1	4	7
Change relative to SG (n)				
Decrease	-	1	1	
No change	-	59	56	
Increase	-	5	7	
N°. missing	-	19	20	
Cholinesterase inhibitors				
TO FU1: N°. on drug	54/73 (74.0%)	61/77 (79.2%)	60/76 (79.0%)	
N°. missing	11	7	8	
TO FU2: N°. on drug	38/48 (79.2%)	38/48 (79.2%)		34/45 (75.6%)
N°. missing				
Change relative to SG (n)				
Decrease	-	2	3	
No change	-	59	56	
Increase	-	9	12	
N° missing	-	14	13	

SG=Start of group, EG=End of group, FU1=3 month follow-up, FU2= 15 month follow-up

Given that use of these medications had significantly increased by the end of the group, and that changes in medication use accounted for depression in the clinical sub-sample, it is likely that the groups had an effect on medication use and that this in turn was associated with a reduction in depressive symptoms.

Measures of cognitive ability

The insight of participants was measured on a scale from 0 to 4, where 0 represented no recognition of having memory problems and 4 represented unprompted, spontaneous mention of having memory problems.

Cognitive ability was assessed using the clock drawing test. Level of dementia was assessed using the Clinical Dementia Rating scale (CDR) with administration slightly modified, as necessary, to assist carers in answering the questions. It is important to note that this item represents the abilities of the person with memory loss as perceived by the carer/supporter. The items cover capacity/impairment in the domains of memory, orientation, judgement and problems solving, community affairs, home and hobbies and personal care. For each question, a participant is assigned a score of 0 (none), 0.5 (questionable), 1 (mild), 2 (moderate) or 3 (severe). CDR scores were calculated using a scoring method devised by Gelb and St. Laurent (1993). The score is based on calculating the median of the six questions, but places an emphasis on the importance of memory, which is considered the primary question.

Table 10 shows the mean scores for participants on the cognitive measures. Participants with memory loss only showed a significant decline on the CDR after 15 months. In contrast, there was no change over time on the insight or the clock drawing items. This could reflect selective loss to follow-up in that those who stayed in the study to 15 months were the people who did not experience marked cognitive decline and who retained insight. However, given that the carers/supporters reported that the people with memory loss participants had deteriorated cognitively, the findings may simply indicate that the clock item is less sensitive to change. A change in the nature of behaviours (reported later) also indicates that there had been deterioration.

Table 10: Mean scores (and standard errors) on various cognitive measures over the evaluation period for the main sample.

Measure and sample	**SG**	**se**	**EG**	**se**	**FU1**	**se**		**FU2**	**se**	
Insight										
TO 15 MONTHS, n= 50	2.67	.19	2.61	.19				2.70	.20	
TO 3 MONTHS, n=81	2.71	.14	2.69	.13	2.79	.15				
Clock ♣										
TO 15 MONTHS, n=51	7.69	.40	7.91	.40	-			6.83	.43	
TO 3 MONTHS, N=84	7.03	.36	7.12	.36	-					
CDR (carer rated)♣ ♣										
TO 15 MONTHS (not adjusted for lateness), n=47	.80	.05	.86	.06				1.09	.09	***
TO 15 MONTHS	.81	.07	.88	.07				1.06	.08	**
TO 3 MONTHS (not adjusted for lateness), n=78	.87	.04	.90	.05	.99	.04	**			
TO 3 MONTHS	.90	.06	.90	.05	.95	.06				

SG=Start of group, EG=End of group, FU1=3 month follow-up, FU2= 15 month follow-up

♣The clock drawing item was not included in the three month follow-up questionnaire.

♣♣ 0= none, .5=uncertain, 1=mild, 2=moderate 3=severe

* p<.05, **p<.01, ***p<001, comparing the start of group with other evaluation periods

Findings for carers/supporters of people with memory loss

General mental health

The GHQ has become one of the main questionnaires for measuring non-psychotic mental illness in the community (Donath 2001). In the current study, the 12 question form of the GHQ (using the chronic scoring) showed good internal consistency at the start of the group (Chronbach's Alpha=.86), confirming that it was a meaningful scale for this sample.

Table 11 shows mean mental health scores at each period for participants in the main sample and in the sample completing questionnaires at the end of group and 15 month follow-up. A significant improvement was evident in general mental health in the main sample at three month follow-up, but not at the end of the groups.

Donath (2001) investigated the GHQ (using the chronic scoring method) in Australian samples and found that a threshold of 3/4 was optimal to identify participants with mental illness. Table 11 shows the mean scores for a sub-sample of participants scoring above this cut-off at the start of the group. The mean scores for this sub-sample were significantly lower at three months. Table 11 also shows that adjusting for potentially confounding variables (service use, CDR –level of dementia, attending monthly LWML sessions post group) only makes a minimal difference to the mean scores.

There was no significant difference in general mental health of participants between the start of group and the 15 month follow-up in the main sample as a whole or in the clinical sub-sample. That is, on average the mean scores were the same as the levels obtained at the start of the groups.

For the wait-list control sample, there was no significant change in the GHQ between the first questionnaire (mean 4.06, se .41) and the start of group questionnaire (mean 3.72, se .45) (n=32, p=.120). There was also no difference in symptoms between the wait-list control group (mean 4.04, se .41, n=32) and the intervention sample (mean 4.32, se .24) after adjusting for symptoms at time 1 and the lateness of the second questionnaire (p=.573). This means that there was no difference between the wait-list and main sample in movement on the GHQ between time 1 and time 2.

However, the change in GHQ scores was not apparent until three-month follow-up. The mean length between questionnaires for the wait-list sample was 42 days, roughly the length of the LWML groups. The wait-list results therefore only enable us to draw conclusions about changes in the main sample which had occurred by the end of the groups. The improvement in mental health scores is worth drawing attention to, but we cannot state unequivocally that it is not due simply to the passage of time. Overall, the results on the GHQ, while significant, must be treated with caution.

Table 11: The General Health Questionnaire mean scores (and standard errors) across evaluation periods for the carers/supporters of people with memory loss.

Group and sample	SG	se	EG	se	FU1	se		FU2	se
Wait list control†, n= 32	4.06	.41	3.72	.45					
Main sample									
TO 15 MONTHS, n=57	4.42	.39	4.20	.39				4.07	.40
TO 3 MONTHS, n=84	4.78	.35	4.50	.34	3.86	.36	**		
Adjusted for: service use, CDR, continued on to monthly LWML groups	4.78	.35	4.39	.34	3.87	.35	**		
Clinical sub-sample: (C-GHQ > 3)									
TO 15 MONTHS, 31	6.31	.45	5.81	.45				5.62	.48
TO 3 MONTHS, n=52	6.39	.43	5.95	.43	5.05	.43	**		
Adjusted for: service use, CDR, continued on to monthly LWML groups	6.39	.43	5.88	.42	5.12	.43	**		

SG=Start of group, EG=End of group, FU1=3 month follow-up, FU2= 15 month follow-up
†The data for the wait-list control is adjusted to represent a time period (42 days) parallel to the time between starting and finishing the group. These two measures are both pre-group and indicate change that would have occurred anyway, whilst not attending the program.
* p<.05, **p<.01, ***p<001, comparing the start of group with other evaluation periods

Depression

The Beck Depression Inventory showed good internal consistency at the start of the group (Chronbach's Alpha =.88). For the main sample, there was no significant association between BDI scores and the measurement period when the questionnaires were completed. Mean scores and standard errors are shown in Table 12.

Scogin et al. (1988) showed that a cut-off greater than or equal to 4 on the BDI adequately identified clinical cases of depression in a sample of older ($\geq$60) adults. This cut-off was used to determine participants likely to have a clinical level of depression before they started the LWML program. Table 12 shows that depression symptoms were not significantly associated with the measurement period in this sub-sample. However, there was some indication of significant improvement in depressive symptoms at the end of the group, although this was not maintained through to follow-up.

XT regression was also used to look at the mean depression scores across measurement periods. There was no significant change from the start of the group to the end of the group or the three month follow-up in terms of depression symptoms. That is, BDI scores did not change significantly over time. This applied equally to a sub-sample reporting clinically significant levels of symptoms (n=29).

For the wait list control sample, there was no significant change on the BDI between the start (mean 2.72, se .51) and the end (mean 3.14, se .55) of the 42 day period (n=29, p=.437). Univariate analysis of variance was used to determine whether the

pattern of association over time was different for the wait-list and intervention samples on the BDI. There was no difference in depression symptoms at time 2 between the intervention sample (3.42, se .26) and the wait-list control group (3.54, se .43; p=.827).

For the 15 month follow-up, there was no association between depression and measurement periods in the main sample as a whole However, there was an indication in the clinical sample that those participants (exactly half) who went on to participate in the 15 month evaluation were less depressed by the end of the LWML groups than at baseline. It is possible that participants who improved were more likely to participate at 15 months but this is speculative.

Table 12: Beck Depression Inventory mean scores (and standard errors) for the carers/supporters across the evaluation periods.

Group and sample	SG	se	EG	se		FU1	se	FU2	se
Wait-list controls†, n=29	2.72	.51	3.14	.55					
Main sample									
TO 15 MONTHS, n=48	3.63	.52	2.98	.53				4.19	.55
TO 3 MONTHS, n= 75	3.64	.53	3.49	.52		3.80	.55		
Clinical sub-sample (BDI> 3)									
TO 15 MONTHS, n=18	7.18	.84	5.80	.85	*			5.97	.86
TO 3 MONTHS, n=29	7.01	1.04	5.89	1.02		7.82	1.08		

SG=Start of group, EG=End of group, FU1=3 month follow-up, FU2= 15 month follow-up
†The data for the wait-list control is adjusted to represent a time period (42 days) parallel to the time between starting and finishing the group. These two measures are both pre-group and indicate change that would have occurred anyway, whilst not attending the program.
* p<.05, **p<.01, ***p<001, comparing the start of group with other evaluation periods

Changed behaviours

Carers/supporters were asked at baseline about behaviour change and given examples of common behaviours in early dementia which often cause stress to those exposed to them. They were asked to nominate up to four such behaviours and asked to rate the degree of stress each caused them (on a scale from 0=no stress to 5=extreme stress). At the end of group and in the three month follow-up questionnaires, they were reminded of the behaviours they had reported at baseline and asked to again rate the degree of stress they caused. This measure has excellent test-retest reliability over time (Bird *et al.* 2002).

At 15 month follow-up we expected the behaviours to have changed somewhat, so carers were asked the question in the same way as the start of group questionnaire; that is, they were not reminded of the behaviours they had reported earlier.

Before the groups started carers/supporters (in the main sample) identified 213 behaviours (2.4 behaviours per person) that were causing them difficulty and then rated how stressed they felt. Carers were also given the opportunity to record new behaviours that were causing them stress at all follow-up time periods. At the end of

the group 279 behaviours (3.2 per person) were listed, and at the three month follow-up 345 behaviours (4.0 per person) were identified by participants

Table 13 shows how carers responded to this question at the start of the group, roughly classified into behaviour or symptom themes. Some carers listed multiple, conceptually different behaviours as one behaviour; others listed the same behaviour several times as different behaviours. For this reason, Table 13 ranks behaviours in order of frequency per person, though some distinct behaviours were described consistently enough to provide some idea of the number of carers reporting them. For example, at the start of the group 18 carers (21%) of those answering this question reported repetitive questions as occurring; 6 (7%) reported apathy or withdrawal, and one (1%) reported incontinence.

Table 13 demonstrates that some carers made no distinction between direct symptoms of dementia, for example aphasia or forgetfulness, and BPSD (eg., aggression). There was some consistency over time in the manifestations of dementia which were stressful (for example aggressive outbursts and repetitive questions) but it is clear that some frequencies had changed. This may be because certain behaviours which are unlikely to change have become so commonplace as to barely rate a mention, for example misplacing objects - ranked fifth at the start of the group, and fourteenth 15 months later. It may equally be that other behaviours or symptoms are more salient as the disease progresses. For example, inability to recognize family members is not present at start of the group but fifth in frequency of carers reporting it as a source of stress 15 months later.

Table 13: Changed behaviours listed as stressful by carers/supporters at the start of the group. Behaviours are ranked in order of frequency of occurrence at the start of group (SG) and 15 month follow-up (FU2).

	Rank Order	
Behaviour/manifestation of dementia	**SG**	**FU2**
1 Angry outbursts/verbal aggression/mood swings	1	1
2 Repetitive questions	2	3
3 Misplacing/losing objects	3	14
4 Communication problems-receptive/expressive aphasia [1]	4	4
5 Rejection of help/reminders [2]	5	19
6 Lowered standards of tidiness (including clothing)	6	26
7 Apathy/loss interest in activity/withdrawal	6	14
8 Memory problems/forgetting things	6	2
9 Repetitive speech other than questions	9	8
10 Inconvenient behaviour [3]	9	8
11 Anxiety/obsessive anxiety about specific things[4]	11	19
12 Socially inappropriate (including sexual) behaviour	11	8
13 General irritability/intolerance (without outbursts)	11	8
14 Lowered standards of personal hygiene [5]	14	8
15 Unable to carry out simple tasks	14	5
16 Slowness/lack of urgency or increased urgency	14	19
17 Sleep problems/disturbed diurnal rhythms	17	5
18 Saying things which are not true/confabulation	17	19
19 Impaired planning of tasks or priorities	17	8
20 Seeking reassurance through shadowing/frequent telephoning etc	17	14
21 Frustration/distress when unable to accomplish tasks	21	19
22 Increased dependence not otherwise specified	21	14
23 Suspicious/jealous	21	19
24 Getting lost	24	19
25 Depressive symptoms including frequent crying	24	14
26 Incontinence/Loss of toileting skills	24	27
27 Dangerous behaviour [6]	24	8
28 Miscellaneous behaviours and irritations [7]	28	28
29 Miscellaneous other direct symptoms of dementia [8]	29	29
30 Violence	0	26
31 Visual agnosia (mostly failure to recognise family)	0	5

[1] Includes reading and/or writing

[2] Usually when person with memory loss insists on trying to do tasks they can no longer accomplish

[3] For example: hoarding rubbish, leaving car lights on, mixing dirty and clean laundry

[4] For example: leaving the gas on, being left alone, money

[5] For example: failure to wash, wearing same underwear for weeks

[6] For example: Leaving house unlocked, not eating, leaving dog locked in car in summer

[7] A diverse group. Examples include: 'selfishness', being impervious to logic, 'being right all the time', asking to come home (nursing home resident at 15 month follow-up)

[8] (Other than aphasia and memory). Includes: confusion, gait disturbance, spatial disorientation

Stress from changed behaviours (listed at the start of group) over time

We investigated behaviours and symptoms listed at the start of the group, to determine whether there was any change over time in how stressful carers found them. Table 14 shows that carers were significantly less stressed at the end of the group and this decrease in stress was maintained at the three month follow-up. These results were still significant after taking into account service use, the CDR, and whether they went on to attend at least one monthly LWML post-group session and the use of psychotropic medications and cholinesterase inhibitors (by the person with memory loss).

For the wait-list control participants, 74 behaviours were named at time 1 and then followed up at time 2. Repeated measures analysis showed no change in the stress associated with these behaviours over the mean 42 day period (adjusted for late or early questionnaires) between time 1 (mean 2.87, se .13) and time 2, (mean 2.69, se .14; p=.179). Univariate analysis of variance indicated that at time 2 the main intervention group had significantly lower mean stress caused by behaviours identified at time 2 (1.93, se .15) than the wait-list control group (2.60, se .15) after adjusting for lateness and stress at time 1 (p<.001). The wait-list control sample is of relevance here because change in the intervention sample had occurred by the end of the groups. The findings indicate that the improvement in the intervention group would not have happened without attending the LWML groups.

Stress from behaviours per person (using all behaviours listed)

We also looked at the average level of stress for participants, across all behaviours reported. This means that any new behaviours identified by carers/supporters at later time points as difficult to handle were incorporated in the analysis. Table 14 also shows the average stress per carer/supporter associated with these behaviours. In the main sample carers/supporters were less stressed by the end of the group and this was maintained at the three month follow-up. This finding was significant after adjusting for service use, medication use (by the person with memory loss), level of dementia, and whether or not they attended at least one monthly post-LWML group session. However, at the 15 month follow-up there was no significant change on this measure compared to the start of the group.

The wait-list control sample findings support the argument that this improvement was a result of attending the groups. Repeated measures analysis of variance was used to investigate the change over time, in mean stress levels across all behaviours listed by participants in the control group (n=30). There was no difference between the stress wait-list participants reported between completing the first questionnaire (mean 2.79, se .20) and the start of group questionnaire (mean 2.54, se .19, p=.105).

The main sample participants (mean 1.98, se=0.11) reported significantly lower stress scores than the wait-list sample (mean 2.48, se=.19) at time 2 after adjusting for the lateness of the interviews (p=.035). This analysis indicates that overall stress was significantly lower at the end of the groups than at the start for the main sample, and that the wait-list control group did not experience the same reduction.

Table 14: Mean (and standard error) stress associated with changed behaviours across the evaluation periods. Means stress scores are given per carer/supporter and for behaviours identified as stressful just before the start of the groups.

STRESS♣ FROM BEHAVIOURS IDENTIFIED BEFORE THE START OF GROUP AND THEN FOLLOWED-UP OVER TIME	**SG**	**se**	**EG**	**se**		**FU1**	**se**		**FU2**	**se**
Wait-list control† 74 behaviours,	2.87	.13	2.69	.14						
Main sample										
TO 3 MONTHS, n=209 behaviours, 81 participants	2.73	.12	1.87	.11	***	1.82	.12	***		
Adjusted for: service use, cdr, continued on to monthly LWML groups	2.73	.12	1.88	.11	***	1.84	.12	***		
Adjusted for: service use, cdr, continued on to later LWML groups, use (yes/no) of antipsychotic, antidepressant, cholinesterase inhibitor, benzodiazepine, anticonvulsant medications for person with memory loss	2.73	.12	1.94	.11	***	1.88	.12	***		
Adjusted for: service use, cdr, continued on to later LWML groups, change in dosage of antipsychotic, antidepressant, cholinesterase inhibitor, benzodiazepine, anticonvulsant medications for person with memory loss	2.73	.12	1.98	.12	***	1.95	.13	***		
MEAN BEHAVIOUR STRESS♣ PER PERSON										
Wait-list control†	2.79	.20	2.54	.19						
Main sample										
TO 15 MONTHS, n= 51	2.72	.15	1.98	.15	***				2.60	.16
TO 3 MONTHS, n=81	2.63	.13	1.96	.13	***	2.04	.14	**		
Adjusted for: service use, cdr, continued on to later LWML groups	2.63	.13	2.00	.13	***	2.04	.13	**		
Adjusted for: service use, cdr, continued on to later LWML groups, use (yes/no) of antipsychotic, antidepressant, cholinesterase inhibitor, benzodiazepine, anticonvulsant medications for person with memory loss	2.63	.14	2.06	.13	***	2.06	.13	**		
Adjusted for: service use, cdr, continued on to later LWML groups, change in dosage of antipsychotic, antidepressant, cholinesterase inhibitor, benzodiazepine, anticonvulsant medications for person with memory loss	2.63	.14	2.03	.14	**	2.07	.14	**		

SG=Start of group, EG=End of group, FU1=3 month follow-up, FU2= 15 month follow-up

♣ on a scale from 0=no stress to 5=extreme stress

†The data for the wait-list control is adjusted to represent a time period (42 days) parallel to the time between starting and finishing the group. These two measures are both pre-group and indicate change that would have occurred anyway, whilst not attending the program.

* p<.05, **p<.01, ***p<001, comparing the start of group with other evaluation periods

Because of the way the question was constructed (carers were asked to rate stress associated with the behaviours they had reported at baseline), it was not possible to determine whether the reduction in stress occurred because the behaviour had ceased or diminished, and/or because carers had more understanding of it. In either case a decrease in stress is an excellent outcome, because stress caused by changed behaviour is a major reason for family members giving up and surrendering care to residential facilities (Morriss *et al.* 1996).

Making plans for the future

Participants were asked, "Have you made financial and/or legal plans for the future in case the memory loss of the person you care for or support gets worse?" Table 15 shows the proportion of carers/supporters who responded, "Yes we have." at the start of the group, the end of the group and at the follow-ups. For the main sample there was no difference in the likelihood of carers/supporters responding, "Yes we have." at the end of the group. They were, however, more likely to have made plans at three month follow-up.

There was increased likelihood of making plans at the 15 month follow-up compared to just before the start of the group, evident prior to adjusting for the lateness of the interview. However, adjusting for "lateness" accounted for the increase in the likelihood of making plans for the future. This suggests that the passing of time is strongly related to making plans, and we cannot directly attribute any change to the groups (particularly because we have no control group with comparable data over such a long stretch of time).

Table 15: The proportion and odds ratios (comparing the start of group to other time periods) of making legal or financial plans for the future across evaluation periods.

Group and sample	**SG**	**se**	**EG**	**se**	**FU1**	**se**		**FU2**	**se**	
Wait-list†, n=32	60.0%		68.6%							
Main sample										
TO 15 MONTHS n=58 (%, se)	62.1%	.06	63.8%	.06				81.0%	.05	
Odds ratios (unadjusted)	1	-	1.08	.29				2.61	1.09	*
Odds ratios adjusted for lateness	1	-	.98	.30				2.35	1.17	
TO 3 MONTHS n=87 (%, se)	59.8%		66.7%		77.0%					
Odds ratios adjusted for Lateness	1	-	1.52	.39	2.29	.89	*			

SG=Start of group, EG=End of group, FU1=3 month follow-up, FU2= 15 month follow-up
†The data for the wait-list control is adjusted to represent a time period (42 days) parallel to the time between starting and finishing the group. These two measures are both pre-group and indicate change that would have occurred anyway, whilst not attending the program.
* p<.05, **p<.01, ***p<001, comparing the start of group with other evaluation periods

For the wait-list control participants, the future plans measure at the start of group was entered as the dependent variable in a logistic regression, with group, lateness and future plans at the first questionnaire they completed entered as independent variables/covariates. The odds (OR=0.71, se .80) of having made future plans at the time they did their second questionnaire were not significantly different for the main sample than the control group after adjusting for lateness and having made plans at time 1 (p=.590). Therefore there was no difference in the likelihood of making plans between the sample who attended the LWML group and a sample who did not.

Service use

Carers/supporters were asked to indicate the number of times in the last two months they had used the following services: GP, support group (other than the LWML group), individual counselling, telephone support, day respite or activity centre, respite in their own home, and residential respite. For each evaluation period, we calculated the average level of use of GP, support services, respite services and home help services (0=did not use, 1=monthly or less and 2=two to three times a month or more). In the main sample, Table 16 shows that there was generally no significant change over time after adjusting for lateness. At the end of group support services were less frequently used, but this is probably related to the end of the weekly LWML groups.

Table 16: Mean level (and standard error) of service use♣ for the main sample across evaluation periods.

Services and sample	**SG**	**se**	**EG**	**se**		**FU1**	**se**	**FU2**	**se**
General Practitioners									
TO 15 MONTHS, n=53	1.14	.07	1.22	.07				1.04	.08
TO 3 MONTHS, n=84	1.14	.06	1.20	.06		1.10	.06		
Support services									
TO 15 MONTHS, n=51	.51	.09	.26	.08	*			.53	.09
TO 3 MONTHS, n=81	.61	.07	.38	.07	*	.47	.08		
Respite services									
TO 15 MONTHS, n=51	.18	.04	.21	.07				.27	.08
TO 3 MONTHS, 81	.22	.07	.23	.06		.27	.07		
Home help									
TO 15 MONTHS, n=51	.33	.10	.44	.10				.46	.10
TO 3 MONTHS, n=82	.35	.08	.46	.08		.49	.09		

♣0=did not use, 1=monthly or less and 2=two to three times a month or more
SG=Start of group, EG=End of group, FU1=3 month follow-up, FU2= 15 month follow-up
†The data for the wait-list control is adjusted to represent a time period (42 days) parallel to the time between starting and finishing the group. These two measures are both pre-group and indicate change that would have occurred anyway, whilst not attending the program.
* p<.05, **p<.01, ***p<001, comparing the start of group with other evaluation periods

Medication use

These data represent medication use by people with memory loss, reported by the carers/supporters in the evaluation, regardless of whether the person with memory loss was participating in the study. Table 17 shows the number of people with memory loss taking various drugs at each time period. About three quarters of the people with memory loss were taking cholinesterase inhibitors and about a third were taking antidepressants. Only a small proportion of people with memory loss were taking antipsychotic, benzodiazepine or anticonvulsant medications at any point in the study, and there were few changes to medications over time, in terms of increased or decreased dosage.

Logistic regression was used to determine whether there were increased odds of taking antidepressant or cholinesterase inhibitors at the end of the group and three month follow-up. The people with memory loss were more likely to be taking cholinesterase inhibitors at the end of the group (OR=1.75, se .43, p=.023) and at the three month follow-up (OR=2.26, se .78, p=.018). There was no significant difference in the odds of antidepressant use at the end of the group (OR=1.45, se .32, p=.090) or the three month follow-up (OR=1.33, se .40, p=.353). These statistics were calculated adjusting for the lateness of the interviews.

Table 17: Medication use by people with memory loss over the evaluation periods, reported by the carers/supporters in the evaluation, regardless of whether the person with memory loss was participating in the study.

Medication and sample	SG	EG	FU1	FU2
Antidepressants				
TO FU1: N° on drug	33/82 (40.2%)	40/86 (46.5%)	39/84 (46.4%)	
N° missing,	*5*	*1*	*3*	
TO FU2: N° on drug	17/55 (30.9%)	19/57 (33.3%)		17/51 (33.3%)
N° missing	*3*	*1*	*4*	7
Change relative to SG (n)				
Decrease	-	1	1	4
No change	-	65	62	34
Increase	-	6	8	5
N° missing	-	*15*	*16*	13
Cholinesterase inhibitors				
TO FU1: N° on drug	59/82 (72.0%)	67/86 (77.9%)	67/85 (78.8%)	
N° missing,	*5*	*1*	*2*	
TO FU2: N° on drug	41/55 (74.5%)	44/57 (77.2%)		39/51 (76.5%)
N° missing	*3*	*1*		7
Change relative to SG (n)				
Decrease	-	2	3	4
No change	-	66	62	33
Increase	-	10	14	12
N° missing	-	*9*	*8*	9
Anticonvulsants				
N° on drug	3/82	3/86	4/85	2/51
N° missing,	*5*	*1*	*2*	7
Change relative to SG (n)				
Decrease	-	0	1	
No change	-	81	78	
Increase	-	1	2	
N° missing	-	*5*	*6*	
Antipsychotics				
N° on drug	3/82	4/86	4/85	6/51
N° missing,	*5*	*1*	*2*	7
Change relative to SG (n)				
Decrease	-	1	1	
No change	-	77	76	
Increase	-	4	4	
N° missing	-	*5*	*6*	
Benzodiazepines				
N° on drug	3/82	4/86	4/85	5/51
N° missing,	*5*	*1*	*2*	7
Change relative to SG (n)				
Decrease	-	0	0	
No change	-	81	80	
Increase	-	0	0	
N° missing	-	*6*	*7*	

SG=Start of group, EG=End of group, FU1=3 month follow-up, FU2= 15 month follow-up

Caring as an enriching experience

Factor analysis was conducted on a range of items representing outcomes expected by LWML staff, for example improved communication, or less embarrassment about caring for/supporting a person with memory loss. No clear factors were evident in these responses. However, one item was of note.

Carers/supporters were asked the extent they concurred with the following statement, "Though caring for or supporting someone with memory loss can be stressful, the experience has also enriched you. Do you agree or disagree?" Response options ranged from 0 (strongly disagree) to 4 (strongly agree). Table 18 shows that participants more strongly agreed with this statement at the end of the group and at the three month follow-up after adjusting for lateness of the interview.

Table 18: Caring/supporting as an enriching experience♣, means and standard errors across the evaluation periods.

Group and sample	SG	se	EG	se		FU1	se		FU2	se
Wait-list control†, n=30	2.37	.15	2.33	.16						
Main sample										
TO 15 MONTHS, n=56	2.44	.13	2.71	.13	*				2.54	.13
TO 3 MONTHS1, n=86	2.49	.11	2.79	.10	**	2.76	.11	*		

♣ 0 (strongly disagree) to 4 (strongly agree)
SG=Start of group, EG=End of group, FU1=3 month follow-up, FU2= 15 month follow-up
†The data for the wait-list control is adjusted to represent a time period (42 days) parallel to the time between starting and finishing the group. These two measures are both pre-group and indicate change that would have occurred anyway, whilst not attending the program.
* p<.05, **p<.01, ***p<001, comparing the start of group with other evaluation periods

For the wait-list control group, there was no change in the response on the measure between time the first questionnaire (mean 2.37, se .15) and the start of group questionnaire (mean 2.33, se .16) after adjusting for days pre/post 42, (n=30, p=.502). There was a significant difference between the main sample (mean 2.76, se .08, n=86) and the wait-list control group (mean 2.28, se .15, n=30) in the endorsement of this item at time 2 after adjusting for lateness and time 1 scores (p=.008). That is, the finding that caring for someone with memory loss was an enriching experience cannot be explained by the results in the control sample. It is likely to be as a result of group attendance.

At 15 month follow-up the enrichment item had reverted to baseline levels.

Satisfaction and comments about the groups

Carers/supporters were asked for comments about the program at the end of the groups and at the 15 month follow-up. People with memory loss were asked about the groups at the end of the program but they were not given satisfaction items at the 15 month follow-up. At any point more than a month or so at most after the end of the groups, it would be of doubtful validity to ask for retrospective ratings of satisfaction.

Responses from all completed questionnaires (main sample) were used to evaluate participants' satisfaction with the groups. This was because some participants completed these questions at the end of the group but did not go on to the follow-up evaluations. It was considered optimal to report comments about the group for all who responded to this question.

The person with memory loss: Satisfaction with the groups

The statements "I enjoy going to the memory loss group", and "Going to the memory loss group has helped me", were held up in front of the participants with memory loss at the end of the groups. The participants were asked, "Is this true?" and the same methods were used to assess their answers as described in the procedures.

Table 19 shows how people with memory loss rated the helpfulness and the enjoyment of the group. This table includes data from all 101 participants (from the main sample) who were a part of the end of group evaluation. Most participants (96.0%) reported that they enjoyed the groups quite often or all/most of the time. The majority (94.0%) also reported that the group helped them quite often or all/most of the time.

Table 19: People with memory loss: satisfaction with the program at the end of the program (main sample, n=101):

	Enjoyed the group?	**The group helped me?**
Rarely or never	2 (2.0%)	5 (4.2%)
Occasionally	2 (2.0%)	1 (1.0%)
Quite often	9 (8.9%)	16 (15.8%)
All or most of the time	88 (87.1%)	79 (78.2%)
Missing	*0*	*0*

People with memory loss: Comments on the groups

People were asked, "What did you enjoy about the memory loss groups?" and, "How did the groups help you?"

We identified themes that were evident in the responses from the 101 participants who were a part of the end of group questionnaires. Seven broad themes emerged. The most frequent response was that they noted the social and communication aspects of participating, being able to talk openly, getting out, developing friendships, being able to laugh with others. These sorts of responses were evident in 67 (66%) of the questionnaires.

> *…showed that I can go out again and mix with people…*
>
> *…being able to discuss my problems…….sharing, there being no embarrassment about it….*
>
> *…talking freely about things, catching up with old friends…*

A large number (n=60. 59%) of participants specifically mentioned that it was helpful knowing that they were not alone, that there were others in a similar situation.

> *…knowing that you are not alone and there must be a lot of it about. To know it's nothing to be ashamed of….*
>
> *It has helped to know I am not alone, but has not helped improve my memory.*
>
> *…meeting people in early stage after only having met people in later stage dementia…. the people and positive talk…. the doctor's talk…*
>
> *I have said yes because I feel it has helped. I think it has helped because you see other people with the same problems…. and it is nice to go to a group like that. It's good to think you are not on your own…*

Learning and the information participants came away with from the groups was mentioned by 46 (46%) participants. Areas of learning mentioned included, where to go, what to do, strategies for remembering, seeing how other people cope, that there are things you can do, information about the disease and its stages, information from the speakers and the video. In contrast to the carers/supporters (presented in the next section) only one person with memory loss specifically mentioned learning about services as having been helpful.

> *The info provided gave everyone that attended a better understanding. the ways to do things positively. There was an understanding, a full attempt to help people in how to cope with the loss, methods and ideas and how they could be of assistance.*

While this 'learning' included formal components of the program, they also mentioned information and strategies learnt from other participants.

> *It helped me a lot, broadened my view, planning, talking about how to remember, meeting other nice people, learning what they do with their life.*

Participants (n=28, 28%) noted that they felt supported, and understood. This category includes both staff and other group members.

> *People were sympathetic.*

Eleven participants reflected about how they felt about others in the group, feeling compassion and watching others change. Others reported feeling relieved that they were not as "bad" as others.

> *It made me feel lucky because I'm better off than some of them.*
>
> *It was wonderful it was lovely seeing everyone get together. People started to blossom a bit….. opportunity to learn from each other and to communicate better outside of group for other members….. can always*

learn something, learning from other people, learning about carers' experience/relationship, growing… amazingly good….

…proud that there are other people trying to change their lifestyle because they have to…

One participant volunteered that it had been beneficial for their partner too.

I look forward to it, [my partner] benefited too.

While most of the participants said that they felt better knowing they were not alone and that there were others in the "same boat", 11 (11%) specifically mentioned feeling better, coping better, being less anxious, feeling a sense of relief and acceptance, and increased confidence as a result of attending the groups.

…given me some optimism and understanding…

…things aren't as bad as I initially thought…confidence booster…

…good to hear things that worried me were the same for everybody else…. Given me new insight….The knowledge that I gained was very beneficial to me. I'm not anxious anymore about what will happen. I'm not going to allow it to interfere with me.

The questions about enjoying the groups or how the groups helped were skipped if participants reported that they rarely/never enjoyed the group or thought they helped. These participants went on to be asked about improvements to the groups. However, a couple of statements by these people were recorded for these questions:

I was very self conscious. I didn't want to be conspicuous, I really didn't enjoy it….

It hasn't been any help. I have forgotten what happened….

At the end of the groups people with memory loss were asked if they had any criticisms. Out of the 101 people who filled in questionnaires at the end of the group only a small number of participants were critical when responding to this question. Their comments are recorded below under the following general themes, practical difficulties, group dynamics and the content of the program.

Practical difficulties:
Two people commented that hearing was a problem for them and one person mentioned transport difficulties, difficulties in getting to the groups. Another participant mentioned that the chairs were hard, and another requested more chocolate biscuits!

Group dynamics:
Three participants stated that a particular participant was annoying or dominant in the group. Another noted the repetition in questions and that different levels of dementia

caused difficulties. One participant said that they felt bad/sorry for older people in the group, that they were having so much hassle.

The content of the program:
One of the participants with memory loss stated.

> *…being singled out, focusing on the memory loss was hard, because it wasn't a major problem (prostrate cancer and anxiety much more of a problem)….*

Another person wanted more information on facts about a specific condition (ie vascular dementia) and one person found the sessions on feelings too abstract *airy fairy*. One suggestion was that a presentation by the RTA would have been useful. A participant commented that they did not like the term 'dementia' being used, *it sounds like I am demented.*

Follow-up was mentioned a few times within and after the group, with one participant stating that it would be good to be able to phone others, another stating it was not long enough, and another requesting more follow-up materials.

Carers/supporters: Satisfaction with the groups

At the end of the groups a total of 98 carers/supporters were asked "How helpful has going to the Living with Memory Loss program been"…. "for the person you care for or support?" and "for you?" Table 20 shows that the majority of carers/supporters (79.2%) thought the group was helpful "a lot" or "somewhat" for the person with memory loss. Carers/supporters also tended (85.4%) to report that the group helped themselves "a lot" or "somewhat".

At 15 month follow-up 63 carers from the main sample were asked: "In the year since attending, how helpful would you say the Living with Memory Loss program has been for you?" They were then asked the same question about the person with memory loss.

Table 20 shows that despite some tempering with time, most carers continued to remember the groups as being extremely helpful.

Table 20: Carers/supporters' beliefs [n, (%)] about the helpfulness of the groups at the end of the group and 15 months later.

Carer	**About themselves**		**About person with memory loss**	
Helpfulness	**End of group (n=98)**	**15 mths post (n=63)**	**End of group (n=98)**	**15 mths post (n=63)**
1. Helped a lot	74 (77.1%)	40 (65.6%)	46 (47.9%)	24 (40.0%)
2. Somewhat	21 (21.9%)	19 (31.1%)	30 (31.3%)	24 (40.0%)
3. No difference	1 (1.0%)	2 (3.3%)	18 (18.8%)	10 (16.7%)
4. Somewhat	0	0	2 (2.1%)	2 (3.3%)
5. A lot worse	0	0	0	0
Missing (n)	*2*	*2*	*2*	*3*

Comparing Tables 19 and 20 it could be interpreted that the perception of carers/supporters of how helpful the groups were for the person with memory loss was more negative than the person with memory loss thought the groups were for themselves. However, caution must be taken when directly comparing the responses of the carers/supporters and the person with memory loss. The carer/supporters' responses were collected via a confidential, self-completion questionnaire. In contrast, the person with memory loss was interviewed by Alzheimer's Australia staff. This methodological difference in data collection may have contributed to the difference in mean scores between the carer/supporter and the person with memory loss. Furthermore, a handful of people with memory loss attended groups without a carer/support person. The above ratings therefore do not report a matched sample of carers/supporters and people with memory loss.

At 15 months Carers/supporters were asked: "Thinking about it now, would you recommend (or discourage) people with memory loss to attend the program?" They were also asked whether they would recommend the groups for other people in their situation. Table 21 shows that carers/supporters tended to recommend or strongly recommend the groups for other carers and people with memory loss.

Table 21: The number (and %) of carers/supporters in the main sample (n=63) who would recommend or discourage others from attending the LWML Groups at 15 month follow-up.

Recommend……	**For other carers**	**For other people with memory loss**
Strongly recommend	48 (78.7%)	44 (72.1%)
Recommend	11 (18.0%)	18 (11.0%)
Neither	2 (3.3%)	6 (9.8%)
Discourage	0	0
Strongly discourage	0	0
missing	*2*	*2*

It is intuitively important that participants were satisfied with their experience at the end of the LWML groups. Carers also endorsed the groups for themselves, and for the person with memory loss more than a year later. This strongly reinforces participants' satisfaction and beliefs about the helpfulness of the groups, particularly bearing in mind the stressors involved in caring for a person with memory loss, and the progression of the disease over time.

Important aspects for carers/how it made a difference 15 months after the group

At the 15 month follow-up carers were asked "If the program has made a lasting difference (better or worse) what difference has it made for you?", and "What do you think the important things (if any) have been for you?"

There were 63 questionnaires completed by carers/supporters during the 15 month follow-up. Of these 31 (49%) mentioned information and/learning from the groups. This included speakers, learning from other participants (generally), understanding of the illness and medications.

> *I've often thought back to what other carers said and how they solved problems.*

About a third (n=20, 32%) of the carers/supporters mentioned that realising they were not alone hearing the experiences of others was important and had made a difference.

> *Friends that are in the same boat, different seats, that you can talk to.*

The above quote also demonstrates that social aspects of the groups and the development of friendships, and open communication was also important for carers/supporters. This was noted by 25 (40%) participants.

> *Friendship with people in the same situation and being able to talk over problems. Also all the info on Alzheimers Disease, provided wider info on counselling ….*

> *Made friends and we are able to "cry on each other's shoulders" together as we both know what its like to have a partner with problems*

The services available and how to access them were specifically mentioned by 14 (22%) people as being important. This refers to people who were clearly discussing accessing professional services.

> *Knowing who to contact and when…*

> *Knowledge of various help agencies etc…*

However, there were 11 general comments where people stated that just knowing that help was available when needed, knowing there are others that care, and knowing where to turn to, was important and had made a difference. It was difficult to distinguish carers reporting that they felt supported by staff and other participants, from learning about the availability of services.

> *I can receive help from wonderful people when I need it, it gives me a feeling of security.*

> *…knowing that help is available when I may need it..*

Only a handful of people mentioned specific components of the program, such as the legal knowledge/services (n=3, 5%) were important. Six (10%) people specifically mentioned that knowing what to expect in the future was important.

> *…to give me a better understanding of Alzheimer's and what to expect…*

Seven (11%) carers also specifically noted that they felt more accepting, tolerant or empathetic towards the person they care/for or support.

> *Before [he] went into the Nursing Home I found the program helped me understand what it was like for him trying to cope with everyday living and simple duties like washing and dressing and finding items. This helped me to be more understanding and tolerant.*

> *I am much more accepting of the condition.*

One participant stated:

> *…seeing Mum lose her fear of the unknown about the illness….*

Six people mentioned feeling more confident.

> *It gives me confidence and support for the future so I should have no worries. The comradeship between the staff and other carers…..*

Learning "coping" strategies was directly mentioned by 11 (18%) people. Participants stated that they had learned to cope better in a general sense or mentioned various particular strategies they had learned from other participants and from the groups.

> *I keep thinking back and remember methods of coping that we were taught. I also enjoyed and learned from the experiences of others.*

While some responses represented recurring themes, not all aspects of all comments are classifiable. It is important to remember the trends described in this report reflect individual experiences.

> *The program explained the illness more thoroughly. I feel much less isolated and I no longer feel guilty when doing something for me….Losing my guilty feelings and also the isolation I felt.*

One participant stated that it had improved communication between herself and her father.

> *Support from within the group and Alzheimer's Association prompted Dad and me to talk about memory loss.*

Carers/supporters suggested improvements 15 months after the groups finished

At 15 months the carers were asked, “In the light of your experiences since attending the program what improvements would you make to it?” In the interests of brevity we present the findings for people with memory loss at the end of the groups and the carers/supporters at 15 months.

Similar to the people with memory loss, most carers were positive about the groups, and many complimented the program when asked for improvements. Very few

criticisms were mentioned by more than one or two people with one exception. When asked what could be improved about ten participants mentioned wanting more ongoing support/follow-up or longer sessions.

> *Over the time there has always been interesting and informative topics. Sometimes there is no agenda, and just talking and sharing has been a great support. Much of the information given is not relevant at the time and is forgotten. However, it becomes relevant so an opportunity to have some sort of refresher course would be helpful.*

However, another commented that they *found it depressing listening to everyone complaining*.

One person wrote, *mix up the visits with "home visits*". Another stated, *have the talks etc at a home caring for dementia cases. Let them see what really happens to their loved ones*.

A few people mentioned having more guest speakers (driving was specifically mentioned by one carer/support person), or videos.

The continuity of counsellors was raised by a couple of people, that change had been off-putting. About five carers mentioned that they would have liked to have come together more with the person they cared for/support to find out more about what they gained, and how/whether they participated.

Other suggestions included: being on some kind of mailing list including lists of coping skills and up to date research, more outings as a group, more information about services and activities available for people with dementia. Access/the location of the groups was also raised.

Similar to the people with memory loss a few of the carers mentioned ways of splitting the groups, for instance difficulties having residential with non-residential carers in the same groups.

> *Two ladies found it embarrassing to talk of weekly experiences in front of people who did not live with the people they supported, I would separate the groups into people who have a residential carer and those who live independently as the problems are different and time is wasted discussing aspects of memory loss that are not relevant to the other group.*

It is important to note that we undertook no formal evaluation of particular components of the program. Similarly, criticisms and suggestions from these comments need to be read as suggestions from individual participants rather than representing general beliefs about the groups. This is because there were very few consistent criticisms.

Discussion

Main findings

The methodology for the study was selected to provide as rigorous a level of evidence as possible, given the constraints of running groups with this heterogeneous population. The evaluation has produced results strongly suggesting that support groups, at least those run under the LWML program, do 'work'. That is, it has made a significant difference to those who have attended. The analyses presented in this report demonstrate that the person with memory loss and their carer/supporter were highly satisfied with the groups. This is a commonly found outcome for support/information groups for carers (Brodaty *et al.* 2000), but it is rare for the views of the person with memory loss to be canvassed. It is equally rare to find improvement in measures beyond satisfaction (Cooke *et al.* 2001; Pusey and Richards 2001). It is therefore of some importance that the evaluation shows improvements on validated outcome measures. In summary, these were as follows.

Participants with Memory Loss

For participants with memory loss, there was no effect for the group as a whole on symptoms of depression, but there was an effect for a sub-sample whose scores suggested a clinical level of distress at the start of the group. It was apparent by the end of the group, and was maintained at three month follow-up. Controlling for medication use suggested that this was due to increased use of antidepressants and cholinesterase inhibitors. Given that use of these medications had also significantly increased by the end of the group, it is likely that attendance at the group influenced both results, though we could not clearly distinguish causes and effects.

We were able to collect 15 month follow-up data from 10 (exactly half) of the clinical sub-sample, and they remained non-depressed. Survivors through to 15 month follow-up may be a select sample but the fact remains that the LWML group appears to have produced a lasting effect on their depressive symptoms.

Carers/supporters

1) There was a significant improvement in carer/supporter general mental health (GHQ) apparent three months after the program finished, though not at the end of the group. This was evident both for the sample as a whole, and a sub-sample of people whose scores on the GHQ at the start of the groups suggested a clinical level of distress.

2) There were significant reductions in stress related to behaviour and/or other symptoms which carers found hard to handle. This analysis included mean stress across all behaviours, as well as those identified at the start of the group. Improvements had occurred by the end of the program and were maintained at three month follow-up. They were not due to changes in other factors including medication and service use, nor were the improvements explained by the control group. As such it is highly likely the decrease in stress associated with changed behaviours results from attending the LWML groups.

3) For the BDI, there were no changes over the evaluation periods for the group as a whole, but the clinical sub-sample remains of interest. There was improvement in BDI scores by the end of the program in a clinical sub-sample whom we were able to track

through to 15 month follow-up. This may be a survivor effect; that is, those who were less depressed at the end of the group were more likely to be available to long-term follow-up. Nevertheless, it appears that on average, depressive symptoms were alleviated for this sub-sample, at least for a time after attending the group.

4) At the three month follow-up (though not by the end of the LWML groups), carers/supporters were more likely to have made legal/financial plans for the future. While this may be related to group attendance, the results at the 15 month follow-up indicate that this finding is more likely to be due to the passage of time. That is, the timing ('lateness') of the questionnaires explained the increased likelihood of carers/supporters making plans between the start of the group and the 15 month follow-up.

5) As well as formal scales such as the BDI and the GHQ, we included questions based on outcomes LWML staff expected to come out of the groups, for example less embarrassment about the disease, or improved communication. These outcomes were somewhat diverse, and analysis of change on each individual question would have risked producing results purely by chance. We therefore conducted a statistical procedure called Factor Analysis to try and identify underlying factors and construct scales from the items. Unfortunately, no clear factors were evident, but a single item was of note. There was a significant increase in carers/supporters' endorsement of a statement about their role being an enriching experience. Significant change was evident at the end of the LWML program, and was maintained at three month follow-up. It could not be explained by change over time in the control group.

6) At the 15 month follow-up, 58% of the original sample was available to complete questionnaires. By this time, none of the improvements had been maintained. Mean scores on most measures were not significantly different from those found at the start of the groups. It should however be noted, first, that carers had not deteriorated. Secondly, though some of the same phenomena were reported by carers as causing stress, different behaviours and symptoms associated with progression of the disease were becoming prominent. Thirdly, at 15 month follow-up, carers remained extremely positive about the LWML program, and the majority strongly recommended it for other carers and for other people with memory loss. The clarity and detail of recollections about how the groups had helped suggests that the program had been a salient experience.

Robustness of results

The analysis statistically adjusted for a range of covariates, factors which individually or in combination might affect or account for any improvements found. For instance, these included service use, deterioration in the abilities of person with memory loss, lateness of questionnaires, medication use, attendance at LWML groups after the formal groups finished. Changes apparent by the end of the groups – carer/supporter stress about changed behaviour, carers/supporters' perception about caring, depression symptoms for a clinical sub-sample of people with memory loss - can therefore confidently be associated with attendance at the LWML program. One caveat is that the effect on depressive symptoms of people with memory loss has been mediated by increased medication use.

For findings not apparent until three month follow-up (carer/supporter GHQ scores) some caution is required. The period between questionnaires for our wait-list control group was 42 days, roughly the length of the LWML groups. That is, in general we know that no changes occurred over 42 days without the LWML intervention, but we do not know what would have happened over a longer period, such as three months. It remains likely that it was the LWML groups rather than the passage of time which led to the improvement in general mental health at three months. However, we cannot be as confident about changes over longer time periods as we are with improvements which were evident at the end of groups.

One improvement was maintained through to 15 month follow-up; those of the clinical sample of depressed people with memory loss from whom we were able to collect data. Because of the small number we were not able to adjust for all possible confounders.

The mean scores for all other measures were not significantly different at the 15 month follow-up than they were before participants attended the LWML groups. Regardless, it is important to make the point that the result for carers/supporters post group and at three month follow-up is a major finding in its own right, especially given the general failure in the literature in most support group studies to find effects in any measure other than satisfaction. A failure to demonstrate maintained improvement more than a year later is scarcely surprising. Many things happen over the dementia journey, and it would be naïve to expect a 6-8 week program, meeting one day a week, to still have measurable effects over a longer period. The scores on the CDR, and the nature of some of the behaviours/symptoms causing stress to carers/supporters at 15 month follow-up, confirm that there had been some deterioration in the person with memory loss.

It is also important to note that carers/supporters were not worse than they had been before attendance at the LWML groups, and remained extremely positive about the program. They recommended it for other carers/supporters and people with memory loss, the majority endorsing it strongly. As noted, this is a common finding. It is much more significant for participants to be still enthusiastically endorsing a short program 15 months after it finishes.

Methodological considerations and potential limitations of the study

The main potential limitations of the study are *sample* and *response bias*.

Potential for sample bias

There are four aspects of sample bias to consider in this study. Firstly, by definition, those with memory loss who attended the groups were at a relatively early stage. At a clinical interview, they showed sufficient insight to be able to discuss their difficulties before enrolling in the groups. Our cognitive and insight measures reflect this (see Table 10) as do the qualitative comments by participants reported in the Results section. They spoke with feeling both about living with their own memory loss, and about how the LWML program helped them.

The high levels of insight found in this study are of particular interest in that they challenge a popular view that people with dementia have little or no awareness. They

tend to confirm the assertion of Clare *et al.* (2002) that awareness is a variable of clinical importance in designing interventions. It could be argued that a high level of awareness makes this an elite group. However, the actual proportion of people with dementia who retain insight into their problems is still unknown because methodological problems have confounded this area of research (Clare *et al.* 2002). It is worth highlighting that it was never an aim of the LWML program to provide help for all people with memory loss and their carers/supporters. Its objectives are to provide assistance at the earliest possible stage after diagnosis.

A second possible source of sample bias is the notion that people who choose to attend support groups may be in themselves a select group. For instance, the main sample was highly educated and women carers/supporters were over-represented. However, it has been noted elsewhere that Alzheimer's Australia may serve a moderately well-educated population with English as its first language (Bird and Parslow 2001). An over-representation of women as carers has been a feature of the literature for decades. The sample is therefore roughly representative of the core Alzheimer's Australia population. Service access issues and whether the groups would be of benefit to a less well-educated population is beyond the brief of this evaluation.

The third possibility for sample bias is that the results in this report reflect responses from 22-60% (varying across States) of the participants who attended LWML groups during the study period. A plausible explanation for the range in response rates was that some States were more diligent than others in approaching participants to take part in the evaluation. All eventually filled their quota but some took much longer to do so.

A final possible source of bias is that those who did not like the groups may have dropped out of the evaluation. However, attrition was not high up to the three month follow-up. By 15 month follow-up nearly half the sample had been lost, scarcely surprising given the fact that dementia is a progressive disease.

In summary, we acknowledge the potential for these biases to have influenced the results of this evaluation. However, a substantial number of people were assisted, showing improvement on validated outcome measures as well as satisfaction. Those carers/supporters whom we were able to track at 15 months still felt almost as strongly as they had immediately after attending the LWML groups that it helped them and the person they cared for.

Potential for response bias

For carers/supporters of people with memory loss, the potential for response bias was minimised as the questionnaires were completed in private, and sealed in envelopes. They were not seen by Alzheimer's Australia staff. It is also unlikely carers/supporters would be biased by remembering their responses from the previous administration. The questionnaires included a large number of items (most on a Likert Scale), and there were substantial time intervals between the completion of the start of group, end of group and follow-up questionnaires.

The feelings of the person with memory loss were directly canvassed because their voice needs to be heard, even thought this rarely occurs. Their opinions about the

groups and their needs are clearly of considerable consequence. Further, their participation makes the program unusual and informant reports on the inner life of people with dementia/memory loss may not always be valid - dependent upon a number of variables including nature and quality of the relationship (Clare *et al.* 2002). The methodology used to canvas their beliefs, experiences and feelings was based on a large literature on the inherent difficulties for this population in processing incoming information, and retaining in memory the concepts being measured long enough to consider them in depth. Standardised administration by staff with dementia specific skills was required. However, there is the potential for response bias because participants may have wanted to please the staff administering the questionnaire, or the staff themselves may have exaggerated change.

The possibility that people with memory loss would remember the answers they gave on previous administrations weeks or months before is, by definition, highly unlikely. The chance that staff administering questionnaires remembered previous responses and doctored them in the desired direction is extremely slim. In any case, we statistically controlled for situations where the same person administered questionnaires at the start of the group and at follow-up time points. This did not change the findings.

Finally, though selection of instruments was satisfactory on the whole, it is matter of regret that we used the shortest form of the General Health Questionnaire and deleted an anxiety measure from the carer/supporter questionnaire in order to allay concerns that it was too long. It is not possible to specifically identify anxiety from the short form of the GHQ, and it may be that the distress apparent on this measure and stress associated with behaviour was manifested more as anxiety than depression. In a recent study, symptoms characteristic of arousal were as salient as depressive symptoms amongst carers of people with memory loss (Caldwell and Bird 2004). We take full responsibility for the decision not to measure anxiety.

Comment on the program

Cooke *et al*. (2001) noted that poor results from psychosocial interventions, including support/information groups, has led to calls to improve the content of programs. They argued that components with known effectiveness need to be incorporated. Unfortunately, these calls have generally been little heeded. In contrast, the LWML program is based on an intimate knowledge of the needs of carers/supporters built up by Alzheimer's Australia over many years. Social support and training in practical problem solving, specifically identified by Cooke *et al*. (2001) as likely to be effective in improving carer well-being, are core components of the program. This may explain the positive results.

The concept of providing support groups for people with dementia is relatively new. The content for people with memory loss was planned based on a pioneer program developed in the United States (Yale 1995), and experience gained in those Australian State Associations which had run such groups for some years. It was beyond the scope of the evaluation to investigate the effectiveness of individual course components. However, the positive results in this study suggest that the content, which involves a great deal of mutual support, sharing problems, and being able to speak openly about them to people who understand, is important. This was strongly endorsed by

participants with memory loss and their carers/supporters, in their comments about the groups (reported in the Results).

Finally, the relative cost-effectiveness of the LWML program is a noteworthy feature. It is short (2 hours, once a week for 6-8 weeks) and it is delivered in a group setting. Although some carers/supporters continue to use the services of Alzheimer's Australia afterwards, our results show that this concentrated burst of information, social support, and problem solving is effective in itself.

Clinical implications

Increased capacity to cope with changed behaviour is of great clinical importance. Behaviour which is hard for family members to accept and understand is a major predictor of their giving up and allowing those they care for to go into residential care (Morriss *et al.* 1996). This is both costly financially but also marks the effective end for many couples of married life, often a very abrupt end given competition for residential care places and the need to make instant decisions when a bed becomes available (Bird and Parslow 2001). Problem behaviour often also leads to overuse of psychotropic medication, itself expensive and with the potential for harmful side-effects (Bird *et al.* 2002).

Our data do not allow us to determine whether the improvements in stress were because of a decline in behaviour, because carers/supporters understood and accepted it more, or because they had learned better ways of dealing with it. It is likely to be a mix of all three; behaviour problems in dementia are often an interaction of behaviour and carer response, and changes in carer behaviour often affects behaviour of the person with dementia (Bird *et al.* 2002). Whatever the mechanism of change, the improvement in stress was clear and highly likely to be a direct result from attending the LWML programs.

The improvement in scores for the sub-sample of participants with memory loss who reported depressive symptoms of a clinical level at the start of the group, is also of importance - beyond the obvious benefits to quality of life. The findings showed both that this was statistically accounted for by increased use of anti-depressants and cholinesterase inhibitors. The increased use of these medications was more likely after attending the groups. That is, though the causal pathway is not clear, it is possible that group attendance influenced both the use of medication and depressive symptoms. Depression increases the risk of a number of adverse outcomes for this population, including physical morbidity (Bird and Parslow 2001) further cognitive decline (Bassuk *et al.* 1998) and institutionalisation (Steeman *et al.* 1997). Depression in the person with memory loss is also a major source of distress for family members – in some instances it is worse than effects of difficult behaviour (Teri 1997).

That is, apart from the benefits to quality of life and morbidity, two predictors of institutionalisation improved following attendance at the LWML programs.

Conclusions

Research canvassing the opinions and experiences of both people with dementia and their carers/supporters is rare and methodologically difficult. Despite these difficulties, the results of this evaluation are a strong endorsement of the content and method of delivery of the LWML programs. This evaluation found improvements on validated measures up until the three month follow-up, a period reflecting the early stages of dementia. Assisting people living with early stage dementia is the primary goal of the program. For a brief time-limited, group intervention, the positive results are important given the rarity in the literature of improvements over and above the satisfaction of participants.

Collectively, these are strong findings. The *Living with Memory Loss* program appears to be delivering well chosen material very effectively, and it has a significant effect on those who participate in it.

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