Evaluation report

Peer support groups to facilitate self-help coping strategies for people with dementia in extra care housing

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Summary

This project involved the evaluation of three peer support groups for people in the early stages of dementia living in extra care housing. The aims of the groups were to:

- improve people's understanding of memory loss and other issues associated with dementia
- enable participants to learn simple, practical coping strategies to deal with memory loss and other issues associated with dementia
- help participants maintain or even reduce the level of care needs as practical coping improved
- reduce social isolation and feelings of loneliness, increase social networks and interaction, and improve wellbeing of participants
- Be sustained beyond the lifetime of the project itself and become an intrinsic part of the housing provision where they were located.

Five standard measures were used to collect data on participants' physical functioning, social relationships, wellbeing, expectations of the group and orientation in time. Individual semi-structured interviews were carried out with participants at 6 months and at 9 months.

The evaluation also comprised the collection and analysis of information from a variety of people involved in setting up and maintaining the peer support groups. Views collected included those from: members of staff from Housing 21, key stakeholders from the project advisory group, Mental Health Foundation staff, participants in the groups, and the group facilitator.

Overall, the evaluation found positive impact of the peer support groups on participants' wellbeing, social support and practical coping strategies. Participants improved in their communication abilities and in managing their memory and their lives. There was some deterioration in the independent living skills of participants over time as rated by the IADL scale. However, the high level of physical frailty and impairment among group members meant that practical coping skills as assessed by the domains on the IADL were unlikely to improve.

Staff and stakeholder interviews revealed perceived benefits to extend beyond group members to include staff, families, friends, other residents in the housing scheme and the housing provider. Findings also showed the need for the peer support groups to become more embedded within the scheme, with dedicated staff time and resources towards encouraging meaningful activities.

While staff and volunteers who were interviewed agreed that attending the groups had brought in real changes and benefits for the people who attended the groups, they also expressed concerns about the sustainability of the group after the facilitator and volunteers involved had moved on. In spite of these concerns, two of three groups succeeded in being sustained after the facilitator left. In these two locations, volunteers were involved in co-facilitating the groups. However, it is uncertain whether the two groups will be able to continue after September 2014.

On the basis of the findings of this small-scale evaluation, a number of recommendations can be made for a variety of stakeholders.

For group facilitators:

Support is needed by a trained facilitator particularly when working with people with dementia, who may also have other significant impairment and disability. Future groups would also benefit from keeping inclusion criteria flexible, as the groups are also helpful for those who do not have memory problems in terms of reducing social isolation and increasing wellbeing. Facilitators should also give consideration to the cultural and ethnic diversity of residents, staff and themselves to ensure groups are accessible and to understand what skills and techniques may be needed to address memory and recall in relation to historical and cultural memory that may not be shared between participants and staff/facilitators.

For carers:

While it may be difficult for family members who live far away or work during group times to attend the peer support groups, regular conversations with the group facilitator allows family members to understand their relative with dementia better and also increases conversation topics to discuss with them further reinforcing learning from the group. Carers and family members benefit from seeing their loved ones engaging more with the housing community and having a better quality of life in the housing scheme. We recommend for carers of people living with dementia to become involved themselves as much as possible with peer support groups and in instance where direct attendance is not possible, to speak regularly with the group facilitator to discuss learning..

For housing providers:

A more embedded approach to peer support groups in housing schemes is needed if the groups are to become sustainable although working in collaboration with local services may help sustain groups. Groups should be viewed as part of the scheme rather than as an external activity coming into these schemes. There needs to be a shift in the work culture from a primary focus on only maintaining residents' independence to one maintaining residents' connectedness. That is, there is a need to support an organisational culture and environment which focuses on community engagement and meaningful activity and supporting relationships. Cultural and ethnic diversity within extra care housing settings, between staff, carers and residents also needs to be considered in terms of provision of care and particularly when promoting community engagement.

For housing staff:

Frontline staff and housing staff need training in understanding how peer support groups work and how activities like these can enhance residents' lives. They should be motivated and supported by management in terms of time allocated to take part or to support such activities. Staff are vital in sustaining groups like these, especially where the range of disability and impairment requires extra levels of support.

For other residents:

Future peer support groups for people with dementia in extra care housing schemes should consider inclusion of other residents who do not have dementia or memory problems. Doing this would begin to tackle stigma associated with having dementia. In addition, a mixed group may attract individuals who do not want to categorise themselves as having dementia or a memory problem.

For research and policy:

There is little research available on the effectiveness of peer support models in the UK, and peer support for people with dementia in particular. Based on the positive findings of our groups, future research activities are needed in this area. In addition, further exploration around cultural sensitivity and diversity is needed, particularly when participants, housing staff and facilitators may not share the same historical and cultural background.

For commissioners:

In our present financially constrained times, the social and financial value of employing peer-support and self-help approaches in housing schemes should encourage commissioners and housing providers to support such approaches.

While thinking about replicating this work in other locations, it would be useful to conduct a needs assessment study to understand the level of current knowledge and awareness among staff and address any gaps through awareness raising or a specific training course.

1 Background

Dementia: a growing concern

More than 800,000 people in the UK live with dementia (Alzheimer's Society, 2012a). One in fourteen people over the age of 65 experience the condition and this increases to one in six over the age of 80 and to one third of people over the age of 95 (Alzheimer's Society, 2012). In London, it is said that there is around 64,600 people with dementia and this is currently estimated to increase by approximately 1% every year (NHSL, 2011). By 2021, it is estimated that that there will be one million people in the UK with dementia (Alzheimer's Society, 2013a).

In spite of the increasingly large numbers of people living with dementia, less than half of people (44 %) with dementia in England, Wales and Northern Ireland have a diagnosis, which means a large proportion of people with dementia are undiagnosed and thus likely not to be receiving appropriate treatment and care for their condition (Alzheimer's Society, 2013a).

At present, there is no cure or universally effective treatment for dementia. As age is a risk factor for dementia and as an ageing society witnessing significant increases in the number of people moving into later life, dementia has become a national priority in the UK and is considered a public health concern.

What is dementia?

Dementia refers to a set of symptoms that are associated with the progressive deterioration of the brain and its abilities (Alzheimer's Society, 2013c). The risk of developing dementia increases with age and typically occurs in people over the age of 65. It can be caused by brain changes, such as in the case for Alzheimer's disease, or by brain injury, e.g. through series of strokes. Common symptoms include:

- memory problems;
- difficulties in problem solving, thinking and reasoning;
- problems with communication (following conversations or finding words);
- difficulties with visuo-spatial abilities (judging distances, e.g. on stairs, or seeing objects in three dimensions);
- mood changes (e.g. irritability, anxiety, withdrawal, easily upset, unusually sad);
- problems with motor functioning.

Policy context

Dementia is now a national priority in England, Scotland, Wales and Northern Ireland. In 2009, the Department of Health in England published the first five-year National Dementia Strategy (NDS) with the aims of raising awareness about dementia; improving the lives of people with dementia and their families; and improving the quality of care and treatment that people with dementia and their families receive (Department of Health, 2009). The NDS identifies 17 key objectives, including the introduction of peer support networks, which involves people with dementia offering advice and practical support to others in the same situation; developing new approaches for housing and community support for people with dementia and their carers; and ensuring good quality information and easy access to care, support and advice after diagnosis. Following on from the NDS, the Prime Minister's Challenge on Dementia (Department of Health, 2012) called for action in driving improvements in health and care, creating dementia friendly communities and improving dementia research. The Prime Minister's Challenge also highlighted the need for high-quality information in support for people with dementia and their families and the wider community, a key aspect in models of peer support. At the time of writing, consideration is also being given to establish a housing and dementia working group in recognition of the importance of home for people with dementia, family and carers.

Social isolation and loneliness

It is estimated that 12% of the population over the age of 65 feel socially isolated (Greaves & Farbus 2006) and this number is projected to rise as the as the UK's ageing population increases. As people get older, the risk of being isolated increases with the loss of friends and loved ones through illness and death. The most severely isolated and lonely are those over 75, those who are widowed and those who live alone. Women are at greater risk of isolation because they live longer than men, with older women more than twice as likely as older men to feel trapped in their own homes (Ipsos MORI, 2000).

Isolation can be described as the absence of social contact, which includes, friends, family, community involvement or access to services (Campaign to End Loneliness, 2012). Social isolation is an objective state and is measurable by the number of friends and acquaintances someone has. Loneliness on the other hand is a subjective state and depends on the individual. An individual as well can have different types of loneliness, such as emotional and social loneliness (Weiss, 1973). Emotional loneliness can be described as the absence of a significant other with whom a close emotional attachment is formed (Burholt, 2011). Social loneliness can be described as the lack of a social network or group of friends, neighbours or colleagues.

Recent research by the Alzheimer's Society (2013) examining the quality of life for people with dementia found this group to be exceptionally vulnerable to loneliness and social isolation. It was estimated that 10% of people in the UK general population aged 65 plus are lonely all or most of the time (Victor, 2011). Twenty-four per cent of people over the age of 55 who responded to the Alzheimer's survey (2013) said they felt lonely in the last month compared with 38 per cent of people with dementia and nearly two-thirds (62%) of people with dementia who live alone.

Living alone (de Jong Gierveld et al, 2011) or living in residential care (The Residents and Relatives Association, 2010) are factors which are associated with loneliness, as is poor health (Victor C et al, 2005), reduced mobility (Tijhus et al, 1999) and cognitive impairment (Victor C et al, 2005) – all of which increase an older person's chances of being lonely; these aspects are common amongst people with dementia. Another explanation for why people with dementia feel lonelier than the general population is that it is a consequence of the deteriorating social abilities which are common to people with dementia (Holwerda et al, 2012).

The value of peer support for people with dementia

A national inquiry into the mental health of people in later life undertaken by Age Concern and the Mental Health Foundation, which included evidence from people with dementia, found that social relationships and meaningful activity were important factors which positively affected the mental health of older people (Age Concern & Mental Health Foundation 2006). A number of reports published by the Joseph Rowntree Foundation (2007; 2009; 2013) have also emphasized the importance of social wellbeing and promoting social needs in purpose built planning. Increasingly over the last few years a growing number of people with dementia in the UK are becoming actively involved to influence polices and services which affect them (JRF, 2012).

In the last 10 years 'Alzheimer's Cafes' have been established in the UK, which is a service model that originated from the Netherlands. These cafes, usually taking place on a weekly basis in community settings, provide practical support and advice to people with dementia (usually in its early stages) and their family carers. Although the cafes are informal and relaxed in their atmosphere with refreshments provided, and do not involve any clinical services or interventions, the sessions have some structure involving a talk or film followed by discussion on a particular topic, such as 'living with dementia' or 'available help'. The model has been adapted for use in sheltered housing by various organisations: one project, a partnership between the Sanctuary Group and the Cambridge branch of the Alzheimer's Society (Moore, 2009) and another project collaboration by the South London Family Housing Association, Alzheimer's Society Southwark, South London and Maudsley NHS Trust (SLAM) and OASIS (Hough & Brims, 2009). Although both projects have been described in the literature neither have been formally evaluated.

Following from the Prime Minister's Challenge (Department of Health, 2012), the Healthbridge evaluation led by the Department of Health (2013) assessed 40 services which supported people with dementia and their carers. The evaluation included services that were set up around a peer support network model (i.e. group or individual support by people living with dementia for other people in a similar position). The wellbeing and quality of life of those using the services were assessed. The results included the following positive aspects from the peer support networks: meeting people who shared a common experience, feeling valued, socialising and interacting with others with dementia leading to decreased isolation, increased confidence which emerged from discussions around struggles and triumphs and developing new interests. Peer support networks also played a role in people receiving a diagnosis and it tackled stigma which can prevent people from getting a diagnosis.

A flexible self-management programme which included handling family relationships, maintenance of healthy lifestyle, psychological wellbeing and techniques helping to cope with memory loss was attended by six people living with early dementia and qualitatively evaluated. Participants reported enjoyment and benefits from the programme, despite some memory difficulties also being reported (Martin et al, 2013). Recommendations for facilitators included placing emphasis on activity, relationships and social interaction.

Dementia in purpose-built accommodation for older people

One third of people living with dementia live in care homes (Alzheimer's Society, 2007) and more than 80% of care home residents in the UK have dementia or significant memory problems (Alzheimer's Society, 2013b). The Dementia 2013 report (Alzheimer's Society, 2013) showed that fewer than half of carers (41%) felt the quality of life for people with dementia living in care homes was good.

It is estimated that among those who live in extra care housing around 25% have a diagnosis or are believed to have dementia (Dutton, 2009). This estimate is similar to findings from a recent report from Housing 21 (Stewart & Keogh, 2014) which looked at 67 of their extra care housing schemes and found just over 21% of tenants surveyed had a diagnosis of dementia (11.7%) or were suspected of having a dementia (9.5%).

Extra care housing schemes provide housing, care and support for older people while helping them also maintain a level of independence. These schemes are designed to meet the needs of people who are physically frail, and/or may have mental health conditions which include dementia (Morrison, 2013). Residents in these schemes have their own self-contained accommodation and the care and support is not always based on site and rather comes through staff from care providers, unlike residential care homes where residents do not have self-contained accommodation and staff are available on site 24 hours a day (Riseborough & Fletcher, 2008). Across all accommodation options, it is essential that there is the provision of services which meet the needs of people with dementia (Alzheimer's Society, 2012).

2 Project overview

This project involves the evaluation of three peer support groups for people in the early stages of dementia living in extra care housing. The aims of the groups were to:

- improve people's understanding of memory loss and other issues associated with dementia;
- enable participants to learn simple, practical coping strategies to deal with memory loss and other issues associated with dementia them. It was also hoped that the groups might;
- help participants maintain or even reduce the level of care needs as practical coping improved;
- There was a strong focus on social interaction among participants, with the expectation that it would reduce social isolation and feelings of loneliness, increase social networks and interaction, and improve wellbeing of participants;
- Be sustained beyond the lifetime of the project itself and become an intrinsic part of the housing provision where they were located.

The groups were modelled on a peer support approach which can be defined as the help and support people with lived experience of a mental illness, learning disability or physical health condition provide to one another (Mental Health Foundation, 2014). The support may be social, emotional or practical but the most important aspect is that it is reciprocal and mutually provided. This differs from common self-help approaches whereby individuals manage themselves through employing skills, strategies and methods to control symptoms (Mental Health Foundation, 2014).

Groups ran in three extra care housing schemes of Housing 21 in London. In two of the schemes (Group A and C), Housing 21 is both landlord and care provider. The third scheme, the site of Group B, Housing 21 is the care service provider and a separate organisation manages the housing. A recent Housing 21 report (2014) revealed that for two of the schemes where groups were running, there was a much higher prevalence of dementia than the overall national prevalence (21%) across all Housing 21 models (Table 1). These two schemes also showed a high proportion of tenants with medium to high dependency needs living there.

Table 1 Prevalence of dementia and level of dependency

Housing Scheme	Prevalence of dementia % (diagnosed and suspected)	Medium/High dependency needs
Group A	40%	73%
Group B	Not available	Not available
Group C	75%	83%

Each group ran once a week for six months and was led by an experienced facilitator; after this point, it was hoped that the groups would become self-sustaining or be sustained through local support. Each week there was a different focus or activity, with the aim that people would learn to support themselves and one another through the challenges of living with dementia while also having fun and enjoying themselves. Group members participated in activities including: creative writing, learning techniques to remember names, healthy living to keep minds active, preparing to go into hospital, stress and relaxation, using technology to help, and learning about what is around locally. Starting dates of the groups were staggered so that any learning from findings in Group A could be used in the development of Groups B and C, see Figure 1.

There are two separate but linked arms to the evaluation: (a) an outcomes evaluation, led by the Mental Health Foundation, a UK charity with extensive research experience in mental health in ageing populations and dementia; and (b) a process evaluation, led by Survivor Research, an independent collective of researchers with lived experience of mental distress and/or of using mental health services. The outcomes and process parts were designed as separate to ensure maximum impartiality of evaluation. The outcomes evaluation examines the impact of the peer support group on individuals with early stage dementia and the process evaluation explores the processes of setting up and maintaining peer support groups of this type. Final reports from these two evaluations are provided below.

A summary of the outcomes evaluation was published in a case study for the Housing Learning and Improvement Network (Chakkalackal, 2013) and presented at their extra care housing and dementia conference in February 2014.

Ethical approval for the study was obtained from the Social Care Research Ethics Committee.

3 Outcomes evaluation

3.1 Aims

The aims of the outcomes evaluation were to assess:

1. The impact of the peer support groups for people with early stage dementia on mental health and wellbeing of group participants plus any family members or carers who attend.
2. The impact of the peer support groups for people with early stage dementia on independent living skills of group participants.
3. Whether people participating in the groups are able to live with the same level of care and support.
4. Sustainability of the peer support group after the departure of the group facilitator at 6 months.

3.2 Methodology

The outcomes evaluation is based on a mixed methods design; both quantitative and qualitative data were collected from group participants and analysed using SPSS and Excel.

Study design

Quantitative data were collected at three time points: baseline (T1), at 6 months (T2) and at 9 months (T3). At 6 months the group facilitator withdrew and the hope was that groups would become self-sustaining. Qualitative data were collected at T2 and T3. Figure 1 provides a timeline of the outcome evaluation data collection.

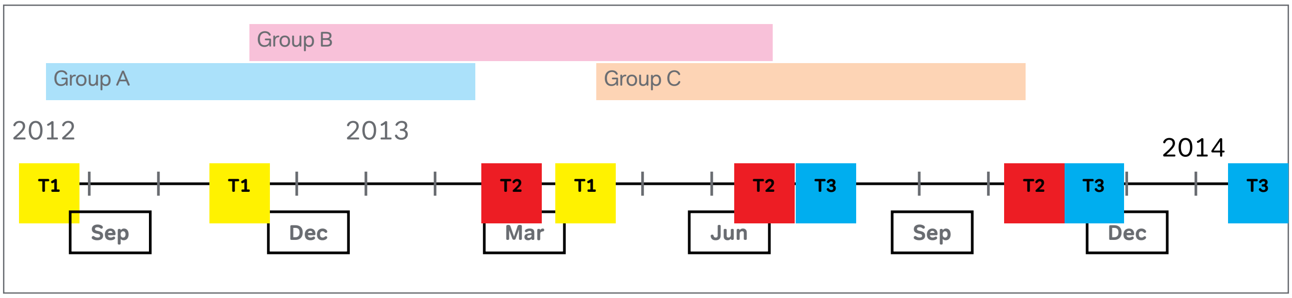


Figure 1. Timeline of outcomes evaluation data collection

Quantitative measures

The following five measures were used to collect data on participants' physical functioning, social relationships, wellbeing, expectations of the group and orientation in time.

1. The Lawton-Brody International Activities of Daily Living Scale (IADL; Lawton & Brody, 1969) to assess practical coping skills associated with independent living. The IADL is a validated instrument in the assessment of independent living skills in older adults. It is used to identify how a person is functioning

at the present time across 8 domains (i.e. food preparation, housekeeping, laundering etc.). Summary scores range from 0 (low function, dependent) to 8 (high function, independent). The outcome evaluation team slightly adapted the measure to provide more complex detail about participant ability; however, the form of the scale was maintained for analysis purposes (see appendix).

2. The Short Warwick-Edinburgh mental well-being scale (sWEMWBS; Stewart-Brown et al 2009), a measure of positive mental wellbeing (see appendix).

3. A social relationships questionnaire developed by the outcome evaluation team to ascertain the level of social support and social networks of participants (see appendix).

4. A participant expectations questionnaire developed by the outcomes evaluation team to collect information on participants' perception of the impact of the group on social support, loneliness, understanding memory loss, and novel activity.

5. Participants' orientation in time was assessed by asking them: the current time, the day of the week, today's date and the season of the year.

Participants completed the questionnaires with the assistance of the project researcher. For example, the researcher administered the questionnaires to participants by reading the questions to them and then manually recorded individual item responses on the measures.

Qualitative data collection

Individual semi-structured interviews were carried out with participants from all groups at 6 months (T2) and at 9 months (T3). In these interviews participants were asked open ended questions which included: what strategies or approaches they may have learnt in the group to help manage memory or memory loss; what, if any, memory aids did they receive from the facilitator and have these made a difference in their day-to-day life; and whether they have started doing new things as a result of coming to the group. Please see appendix for interview schedules at T2 and T3.

Procedure

The group facilitator selected participants assessed as suitable for the group activities based on their level of cognitive and physical functioning. These participants were approached by the researcher about being involved in the evaluation following the facilitator's introduction. Easy-read information sheets and consent forms were used with participants. Verbal consent and the signature of a witness were used in the instance where a participant was unable to sign.

Limitations

There are several limitations to this study. As a result of the small sample size and additional confounding factors, such as death, hospitalisation or people moving away, the findings on the quantitative measures were limited. Initially, the plan was to include a control group of tenants in the same or different housing schemes who were not participating in the groups. This proved difficult as the participants turned out to be very varied with a range of abilities and limitations. Thus residents not participating were likely to be quite different from the participants and would not be a suitable control group. As an alternative, it was decided to use normative data from the housing provider on residents' care plans and wellbeing, if available. However, due to logistical difficulties, this was not possible. Consequently, apart from participants self-reports, the evaluation was not able to address one of the aims relating to the level of care and support.

3.3 Results

3.3.1 Participants' characteristics

Across all three groups, a total of 21 participants agreed to participate in the evaluation. There were 9 participants in Group A, 6 in Group B and 6 in Group C. Across all groups, 13 females and 8 males participated. The mean age was 83 years (SD=9.56) with the youngest aged 66 years and the oldest aged 97 years. Table 2 shows the gender and age for each group.

Table 2: Breakdown of gender and age by group

Group	Total	Gender		Mean age years (range)
		Female	Male	
Group A	9	7	2	84 (67–97)
Group B	6	3	3	81 (66–95)
Group C	6	3	3	83 (70–95)
Total	21	13	8	83 (67–97)

Ethnic or cultural background data collection was not among the original purposes of the evaluation. Retrospective personal communication with facilitator revealed that about one third (8 out of 21 participants involved in the evaluation) were non-UK born. Places of origin of group attendees included the Caribbean (5), Ireland (1), South Africa (1), Nigeria (1), France (1), and India (1). According to the facilitator, all participants of group A were UK born, at least two participants of group B (33.3% of 6) were born outside the UK, whereas most if not all six participants of group C were non-UK born. The researcher also noted that the participants in Group C were more ethnically diverse than those in Groups A and B.

All groups maintained a consistently high attendance rate during the six months with the group facilitator. The facilitator led a total of 24 sessions for each group. Table 3 shows the number of sessions attended for each group.

Table 3: Group attendance

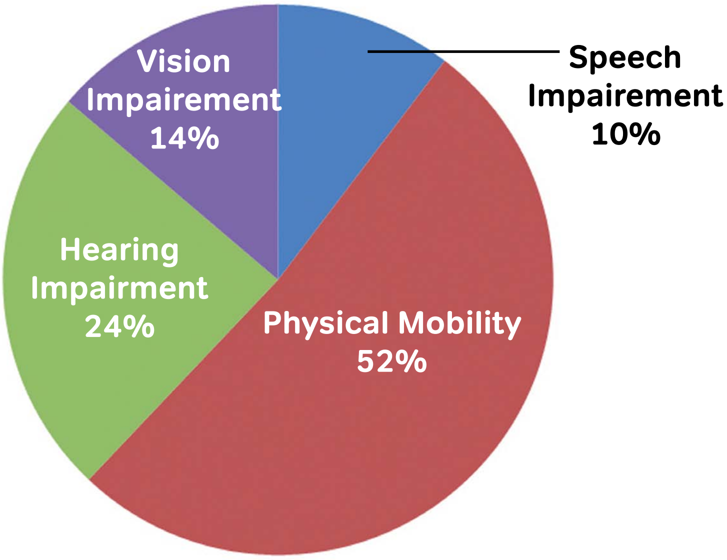
Group	Number group members	Total number of sessions	Number of sessions attended	%
A	10	206	163	75%
B	6	144	117	81%
C	6	144	106	74%

The numbers of participants involved in the research throughout the course of the evaluation can be seen in Figure 2. One participant did not wish to participate from the start and two participants stopped during the course of the evaluation. The remaining loss of participants at T2 and T3 was due to: participants' being unwell, going into hospital, moving away, death, and no longer coming to the group.

Figure 2 Numbers of participants over the course of the evaluation

More than half of participants involved (51%) had physical mobility issues and nearly a quarter (24%) of the sample had significant hearing problems (Figure 3).

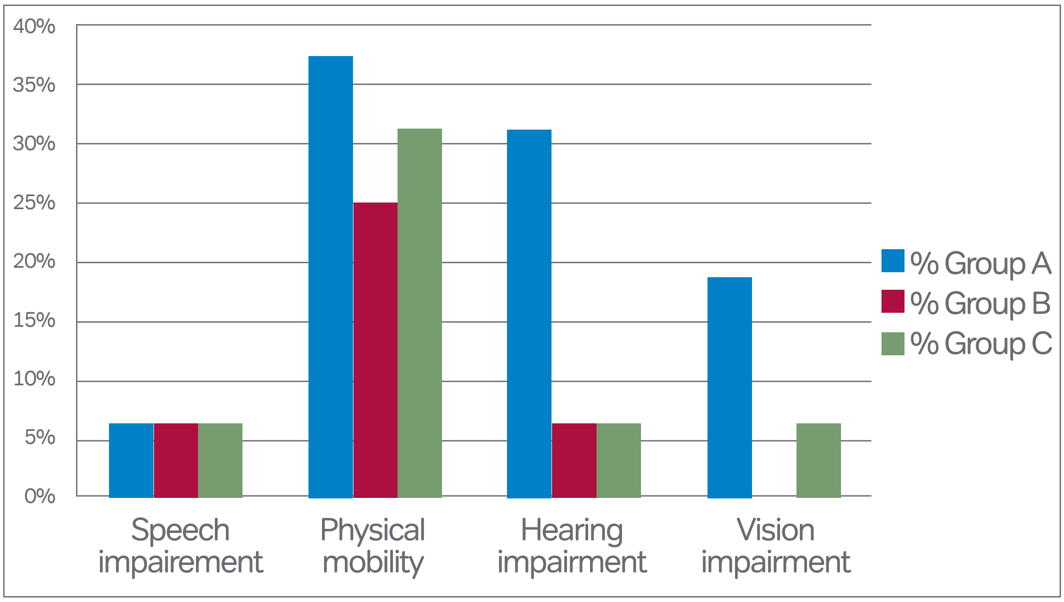
Figure 3. Level of disability and physical frailty of participants in all three groups



*Level of disability was assessed by the Group Facilitator's and Researcher's observations

Group A, the largest group of the three, had the highest percentage of disability and physical frailty amongst group members (Figure 4). In spite of this, the Facilitator found participants in Group B to be the most challenging due to the level of assessed cognitive impairment in the group. Of the six participants participating in Group B, two had a formal diagnosis of a dementia and one had Korsakoff's syndrome.

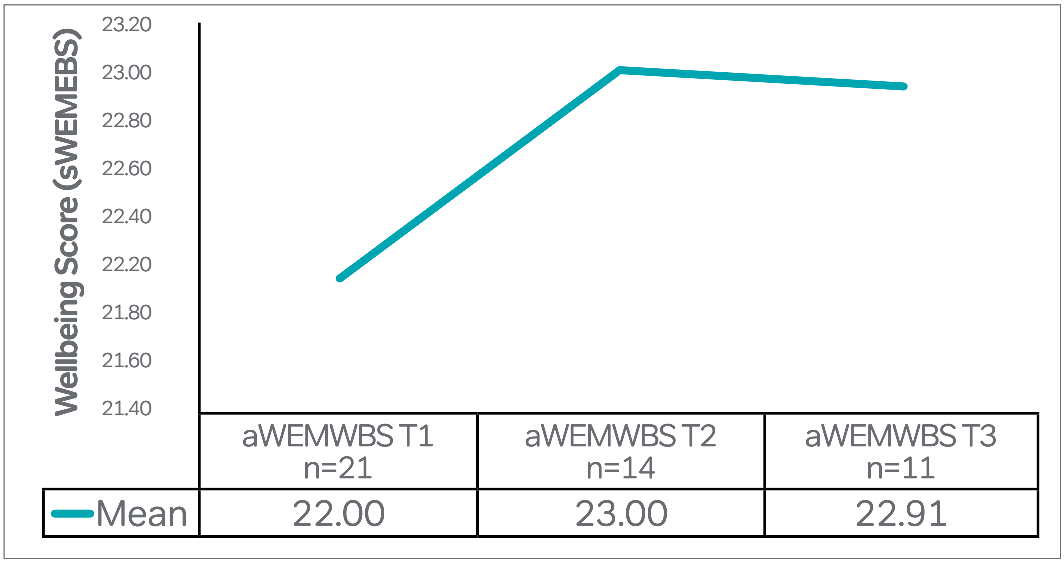
Figure 4. Proportion of participants with physical mobility issues, speech, hearing and vision impairment in each group.



3.3.2 Wellbeing

Following participation in the peer support group, the mean wellbeing scores increased from T1 to T2, although the mean change over time was relatively modest (Figure 5). The mean sWEMWBS score at T1 was 22 (±4.48) and at T2 23 (±5.78). A non-parametric test showed that the change was not significant (Z=-1.26, p=0.206). The relatively small numbers of participants (especially at T2 and T3) may have contributed to the non-significant result. Even though the mean score decreased very slightly from T2 to T3, it was still higher than at T1. A slight decrease in the mean score seen at T3 might be explained by the fact that one of the three peer-support groups was no longer running.

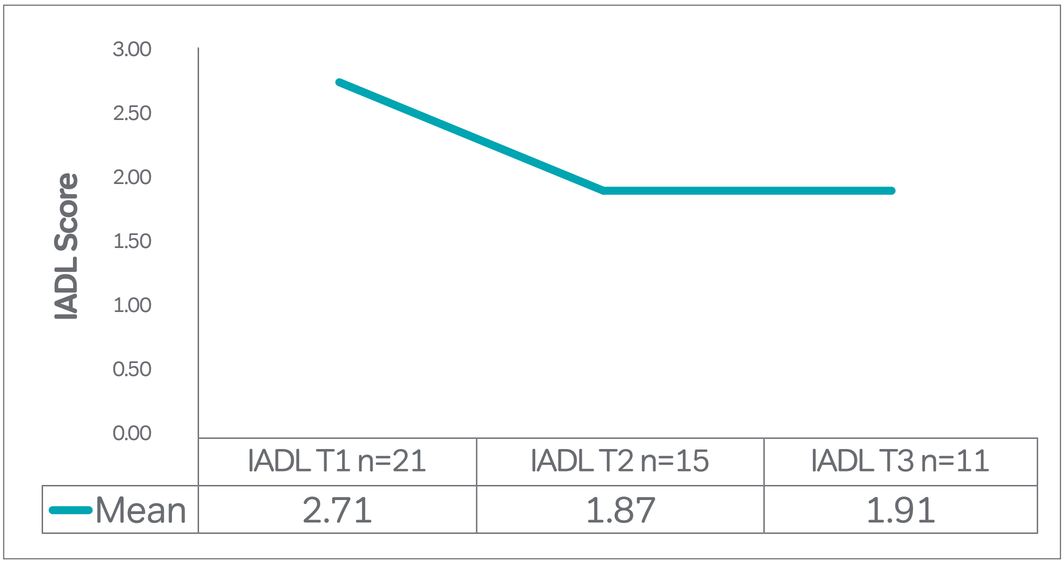
Figure 5 Mean wellbeing scores (sWEMWBS) over three time points



3.3.3 Independent living skills

Based on findings on the International Activities of Daily Living Scale (IADL), we found that physical functioning of participants (n=15) deteriorated slightly after 6 months, and stayed around this level at T3 (See Figure 6). A non-parametric test showed a significant change in the IADL score from T1 to T2 (Z= -2.99, p=0.003). Indeed the median IADL Score at T1 was 1.00 and at T2 it was 2.00. This may be explained by the high level of physical frailty found in those participating in the groups which is unlikely to improve over time.

Figure 6 Participants' mean IADL scores over time



3.3.4 Participants' orientation in time

The majority of participants (85%) could accurately recall time of day at T1 and many (65%) were using an aid such as a clock, watch or calendar to help them keep orientated in time. At T2, more participants were able to recall the month and season of the year than at T1 or T3; 50% and 60%, respectively. At T3, more participants (25%) could recall the date than at T1 or T2, and 50% used an aid to do so (Figure 7).

3.3.5 Perceived social support

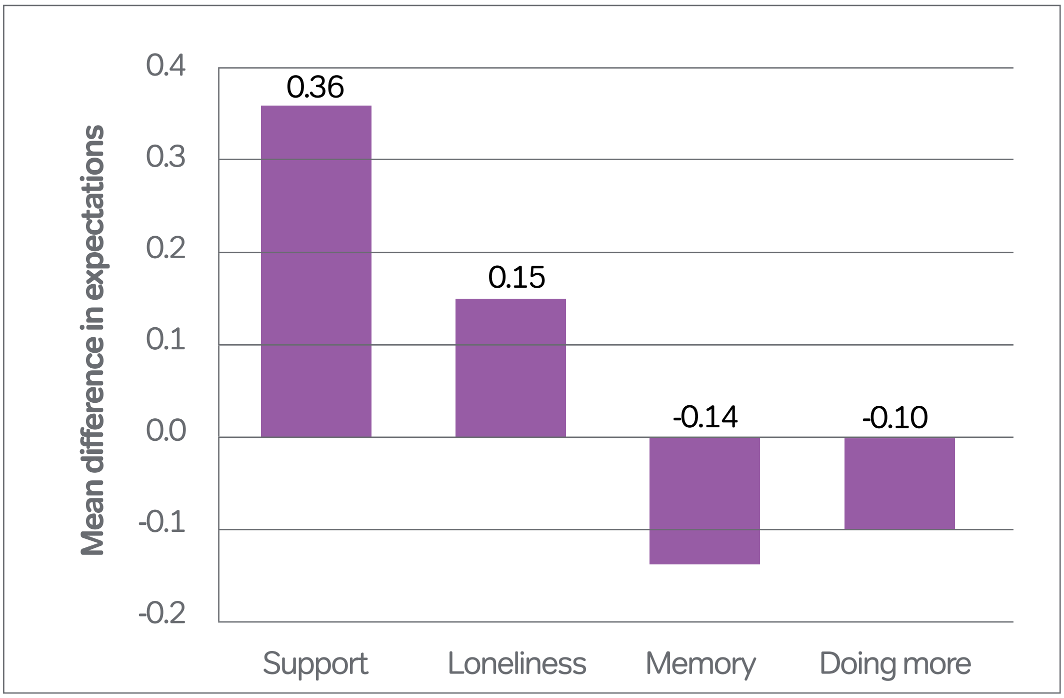
Participants were asked to gauge the level of social support both inside and outside their housing scheme on the measure of social relationships. No change was seen comparing respondents' answers between T1 and T2 (n=15) on the item of to whom they would speak if something was worrying them. The majority said they would speak to a member of their family about personal matters over other tenants in the housing scheme.

Participants were asked how many people they knew by name living in their housing scheme. While the same number of participants could recall names of people at both T1 and T2, participants at T2 could recall more names of people living in their scheme, and particularly they could recall more names of other group members as well as the facilitator's name at T2. One participant also described using the photo book album, which they had created in the group to help them remember names. From these findings it would appear that participants had more awareness and improved recall, possibly as a result of participation in the group.

3.3.6 Participants' expectations

Figure 7 shows the mean differences between participants' expectations before attending the group (T1) and their experiences of the group (T2) on the four items of the participants' expectations form. A positive value on an item reflects that on average participants benefitted more from the group than they expected to at T1; zero would reflect no difference between expectation and experience, and a negative value reflects that on average, participants' experiences of the group were less beneficial than they expected.

Figure 8. Mean difference in expectations between T1 and T2



Participants felt they had benefitted more than they expected in terms of supporting each other (item#1) and feeling less lonely (item# 2). However as far as understanding more about memory loss (item#3) and doing more things (items #4), participants felt they did not benefit from attending groups as much as they had thought they would. It is unclear why participants felt they had not understood more about memory post participation in the groups, though findings on the item of doing more things (item#4) may be partially explained by the deterioration in scores of the IADL over time. It is likely that participants were unable to do new activities due to their level of disability rather than a lack of interest.

3.3.7 Qualitative findings

Individual interviews were carried out at T2 following the departure of the group facilitator, and at T3, three months after the facilitator had left.

At T2, the interview explored whether participants had learnt or used any strategies for managing their memory or memory loss after participating in the group; whether they were using any equipment that the facilitator had given them, such as a clock or calendar, or if they were using anything that they had made during the group, such as the photo book of names or a hospital bag; and whether they had started doing new things as a result of coming along to the group. Fourteen participants spoke about their experience at T2.

Impact of the groups on memory

Despite the findings on participants' expectation of understanding more about memory (item#3) interviewees spoke of how the groups had helped them understand more about the brain and that it had increased their understanding of memory and memory loss. They spoke of using different cognitive strategies, which they had learnt during the group, to help them remember things such as names, dates and numbers.

> *You learn more through association. Like the telephone, if you want to remember numbers like the pin number you make a number on the telephone keyboard like the L shaped on the left or right. (Participant#7)*

> *I'm remembering more things now because I'm thinking more about it. What I'm doing at the time and what I should say. (Participant#8)*

Participants also realised the importance of keeping the brain 'active' in order to keep the mind alert and improve their concentration skills. They spoke of doing activities such as Sudoku puzzles, word searches and reading books to help keep their mind sharp.

> *Certainly keeping the brain active, I'm a great word searcher learning to keep your brain much more active. (Participant #3)*

The majority of participants (n=8) spoke of using aids such as clocks, watches, calendars and tablets to help them keep orientated in time.

> *It's quite a good clock it tells you the date and the time. I'm glad I got it because I can never tell what day is what. (Participant#5)*

One participant even spoke about using the photo album that they had created during the group to help them remember the names of other people in their group.

> *Now I know them all and they're good. (Participant#6)*

Confidence to do new things

Many participants reported increased confidence and greater sense of self, as a result of participating in the groups, which gave them the support to do new things, such as talking to more people, going out on their own and even going downstairs to use the tenants' room. This positive finding on doing new things is in contrast with participants' expectations' on doing more things. It would appear that participants were able to do new things although this was not expected.

> *I'm feeling much more determined with how I want to do things. Before I went to the group I always thought I was going to have an addled brain but it's not like that at all. Going to the group and listening and learning they've shown me how to point myself to the future. (Participant#3)*
>
> *"[The group] seemed like nothing at all, but in the last few meetings, I noticed how useful the group could be in getting things done, teaching people how to manage themselves [their memory]" (Participant#18)*
>
> *I never used to go downstairs till the group started (Participant#21)*

Improved communication skills

Group members also spoke about learning practical coping strategies which helped them improve their communication with others, this included:

- Allowing people to finish when they are speaking and minimising interruptions;
- Patience;
- Listening to one another;
- Accepting that people are different from each other and behave differently.

Practical coping strategies

Other specific learning during the groups included sessions on relaxation techniques, and planning and preparing for end of life issues, such as going into hospital, which helped ease participants' anxieties and gave them a greater sense of control over their lives.

> *Relaxation was so useful. We had a lady come in to teach us relaxation and breathing techniques, I found that very useful. (Participant#3)*
>
> *Going into hospital with a picture board with your name on it with what you like and what you want to be called as and what your favourite food is. That was excellent that was a good idea. (Participant#3)*

Impact of social activities in the group

The most frequently reported positive aspect of the groups was meeting and interacting with others who shared a similar experience. Participants spoke about how much they enjoyed going to the group each week and how supported they felt by one another.

> *Oh yeah, I get along with the group. Cause it helps you know and you're not lonely and you listen to them and it's very nice. It's nice being talked to. (Participant#4)*

> *It [the group] livens you up. (Participant#6)*

Another extremely positive aspect mentioned by participants was that session activities reflected things that were of interest and had meaning to them.

> *I thoroughly enjoyed the film we had it was to do with the Old Kent road and life in the 1900s it's called say it with flowers. Hannah was brought up on the Old Kent road and she was singing away with gusto and she really enjoyed it. (Pariticpant#3)*

> *[facilitator] would always ask what you would like to happen in the group; all that was put down by us. (Participant#12)*

All participants spoke highly about the personality and approach of the facilitator which was integral to creating a safe space for participants to share their ideas and experiences.

> *We all took to her. She was very nice. She was very pleasant and if we didn't go down she would come up after us. (Participant#6)*

At T3 (three months after the departure of the facilitator) interviews explored whether participants were doing anything different now than a year ago, before the groups were set up. Similar to feedback given at T2, participants spoke of socialising more, both inside and outside the housing scheme. They also considered other group members as friends which they had not done prior to the groups. A few also spoke about becoming more involved in activities in the housing scheme, such as attending the arts and crafts or bingo sessions and mixing more with other tenants.

> *I remember the most the talking and the friends I've made. As it is going now, it's lovely. I want that to continue it keeps us all together. (Participant#9)*

> *I talk to people out in the street [more] (…) we have a good laugh in the group, the social activities [are the most memorable]. (Participant#8)*

3.3.8 Sustainability: after the departure of the facilitator

Currently, two of the three groups continue to run. Group A runs with the help of a volunteer from the SLAM Recovery Enablers Programme and a tenant in the housing scheme who participated in the group but does not have dementia. Group C continues to run with the help of a Housing 21 staff member and another volunteer from the Recovery Enablers Programme. Group B ran for one session after the departure of the facilitator but ceased to continue because there was no one who could take on the active role of a facilitator. Given the high level of cognitive impairment and physical mobility issues in tenants in housing scheme B, we would anticipate that greater support from housing provider staff or from an external voluntary organisation is required to ensure the running of the group can continue.

3.3.9 Perceptions of care staff and family members

The perceptions and feedback from family members (N=5) and care staff (N=1) of participants were included in order to capture some of the changes witnessed in the day-to-day lives of group members. Family members felt the purpose of the groups was to stimulate people with dementia, bring those with a similar experience together and felt it would improve and sustain their memory. They reported their loved ones becoming more outspoken, outgoing and that they had a greater sense of self-confidence as a result of coming along to the group. One family member mentioned that the size and intimacy of the group provided space for her aunt to have a voice.

> *She's been more outgoing, when she first started she was very insular, because it is a smaller group, she seems to relate with those people, and she talks to us about the group, she always says the Cindy's name (the facilitator) and tries to say what she has done in the group. (Niece)*
>
> *He enjoys going. It's good to go because I think he sees other people that are the same as him. He has more confidence in himself now. (Wife)*

Family members felt it was important for them to be included in the groups as much as possible as it helped them relate to their loved one with dementia and gave them strategies for how to communicate better with them.

> *In my aunt's case, she can't say much, but if you ask her questions she can answer with one or two words, if you leave it up to her to speak [she wouldn't be able to do that]. Sometimes I wasn't able to make all the sessions, but I spoke to [group facilitator] on the phone and found out what it was all about and then I could ask my aunt further in depth questions, so that was very good. (Niece)*

One care staff member noticed a marked change in one of participants following their participation in the groups.

> *She used to be so lonely, but since doing the group, a month from when the group started I see a real change in her. She [usually] just sits down there and doesn't talk to me. And after the group she started talking, she wouldn't stop. This memory group must be helping her because she never talks. And that day she was having a conversation. She had hearing problems but it was like she could all of a sudden hear, but it was actually her memory loss that was drowning her hearing.*

3.3.10 Researcher's observations

Observations from the researcher also captured positive changes in participants following participation in the groups. One difference noted was in the memory recall of one participant from their individual interview and their group interview. During the individual interview, the participant struggled to find their words; however, during the group they could spontaneously answer questions. On their own this individual would take a very long time to respond to questions even with prompting, they would lose their train of thought or disappear in thought in contrast to during the group where they were able to remain present in conversation and make their own contributions.

Changes observed in another participant were noted over the course of the evaluation during the administration of questionnaires. At T2 and T3, the participant was much chattier, expressed a sense of humour, and spontaneously initiated conversation and responses more than at T1 when questions posed required prompting. It was also noted by the researcher that for participants who did not have many visitors, being involved in the evaluation process was a form of social contact for them; it provided a space for them to talk about their experiences.

3.4 Conclusions

The evaluation showed some positive findings regarding the impact of the groups on the participants. Their mean wellbeing scores improved over the course of the groups, even if the change was not statistically significant.

Positive changes were seen on participants' perceived social support over time, with participants recalling more names of people living in the schemes, particularly names of other group members. Participants were more cognizant and had improved memory recall. Findings on participants' expectations of feeling more supported and less lonely showed that, on average, participants felt they benefitted more than they expected. This is in line findings from the Alzheimer's Society's recent report *Dementia 2013* which found that peer support groups provide a space for people with dementia to come into contact with others who have a similar experience which helps to alleviate and reduce loneliness.

The qualitative interviews at six and nine months showed positive results: participants had learnt approaches and strategies to manage their memory, improve communication abilities and manage their lives better. The greatest impact of the groups was reported around the social interactions members had with one another and the shared experiences that took place during the group, with many participants considering one another as friends following participation. In *Dementia 2013* the importance of having social activities that were of interest to people with dementia was emphasized, noting that too often there are a lack of opportunities within activities on offer in these schemes, where tenants can have discussions and engage with one another.

Family members, care staff and the researcher also reported positive changes in communicative abilities of participants following participation in the groups. The increased social contact through the peer support group livened participants, they were more cheerful than they had been without the groups, would laugh more, initiate conversation and new memories and new conversation points would emerge. This is similar to changes found among people with dementia living alone who were having regular visits from volunteer befrienders (Alzheimer's Society, 2013).

There was some deterioration in the independent living skills of participants over time as measured on the IADL. It is possible though that participation in the groups slowed this deterioration in physical functioning. One explanation for this decline may be due to the high level of physical frailty and disability amongst participants in the groups, making it unlikely independent practical coping skills could be improved. This is in line with findings from a recent internal report from Housing 21 (Stewart & Keough, 2014), which found a high proportion of tenants in these schemes with medium to high dependency needs. This is further supported by findings from the English Longitudinal Study of Ageing (Zaninotto & Steptoe, 2012) which found the prevalence in both men and women reporting one or more limitations in IADLs increased with age. Among those 80 years and older, nearly one third (32%) of men and almost one half of women (46%) report one or more limitations on the IADLs.

Mixed results were seen on how orientated in time participants were, with the majority of participants recalling time of day (85%) at T1, more than at the two later time points. This may be explained partly by the loss of participants (i.e. due to death, hospitalisation, moved away) over the course of the evaluation, as well as the high numbers of participants using an aid to do so. At T3, three months after the departure of the group facilitator, more participants could recall the date (25%) than at T2 (15%).

On the whole, the evaluation showed that peer support groups are valuable to people with dementia living in extra care housing. They offer community engagement through the sharing of information based around the shared commonality of experience. The groups provide opportunities to participate in activities that are of interest to people with dementia. In addition, it is possible to make the groups sustainable, with the appropriate support. As an output of the project, the facilitator has produced a practitioners' guide to help setting up and running similar groups.

4 Process evaluation

4.1 Aims

The aim of the process evaluation was to gather information and learning about the process of setting up and running peer support groups to facilitate self-help for people living with dementia and memory loss within sheltered and extra care housing. The evaluation focused on understanding expectations, success factors, and challenges, and learning about sustainability and the potential replicability of this project. It is hoped that this will help other organisations wanting to set up similar groups.

4.2 Methodology

The evaluation involved collection and analysis of information from a variety of people involved in the project. This includes:

1. A baseline of information, collected using semi-structured telephone interviews, to identify initial expectations collected at the beginning of the project from:
    - Members of staff at Housing 21 where the self-help groups were being set up,
    - External stakeholders (members of the advisory group of the project)
    - Mental Health Foundation project staff (project lead and the group facilitator)
2. End of group interviews (six months after the initial interviews) to identify success factors, challenges and pitfalls, sustainability and future concerns from members of staff at each location
3. Feedback from group members and other participants in the self-help groups, via a group discussion facilitated by a researcher from the Mental Health Foundation
4. Reflections of the group facilitator
5. Document analysis of project plans, organisational agreements, minutes of the project evaluation advisory group

Structure of the process evaluation report

Section 4.3.1 of this report discusses findings from the baseline interviews and document analysis. The focus is on expectations from the project overall and the themes discussed identify potential benefits and challenges, understanding of the concepts of peer support and self-help, and practical aspects of setting up peer support groups including identifying participants. Section 4.3.2 presents findings from end of group discussions with participants of the groups, interviews with staff and volunteers who were involved in the groups and reflections of the facilitator who set up and ran the groups. Section 4.4 discusses key learning from the evaluation.

4.3 Results

4.3.1 Expectations before groups started

In order to collect views about the potential benefits and challenges of setting up and running peer support groups to facilitate self-help coping strategies for people living with dementia and memory loss, baseline interviews were conducted with the various stakeholders of the project. These included semi-structured telephone interviews with external stakeholders who were part of the advisory group (n = 3), project staff at Mental Health Foundation (n = 2) and staff members at Housing 21 (n = 9) where the three peer support groups were facilitated. Relevant points drawn from an analysis of the minutes of the advisory group meetings are also incorporated in this discussion.

Overall, there was a better understanding of the concepts of peer support and self-help and the possible benefits arising from self-help groups for those living with dementia and memory problems among those involved in setting up the project. Those who had more involvement in setting up the project and running it (group facilitator, MHF and Housing 21 managerial staff who were involved in the project conception) had more to say about the potential benefits of the project while frontline staff (healthcare and personal assistants) seemed less clear about the goal and benefits. The potential benefits and challenges identified spanned the personal, familial, social and practical. These are discussed below.

Theme 1: Meeting people with similar experiences

A peer support group could potentially bring together people with different experiences and at different stages of dementia and memory loss. The possibility of sharing these different experiences can be beneficial in many ways, including finding out more about the condition, learning coping mechanisms and ways of living, finding out about available support and so on.

> *"…people are in different stages of dementia and I guess the benefit would be different depending on people's cognition and abilities, but I guess potentially people derive enormous mutual support from knowing that other people have similar problems and hearing other people's experiences and strategies for coping." (Advisory group member)*

Reciprocity and mutuality are some of the fundamental values of peer support as a community based support structure, which was addressed several times by the interviewees; the hope was that this project would set the stage for testing out how these can work in potentially beneficial ways for people living with dementia.

> *"…what people want is friendship, we all have different dementias and we are all in the same boat, but we could all talk about it and we could all laugh about it and that's what you need, you need something where you can have people around you with similar needs, and you can talk to them and they can talk to you and the partners can talk to each other, and it works wonders." (Advisory group member)*

The potential that a peer support group has in reducing isolation and getting people engaged was also seen as a key benefit. The onset of dementia can be a confusing time and this confusion may lead to feelings of depression and sadness which result in many people isolating themselves. The basic tenets of peer support open up the potential for a space to address some of these feelings and re-establish social connections.

> *"A lot of people that I've sort of worked with in the early stages can tend to isolate themselves or be very embarrassed. Dementia can still be a very taboo subject, so to actually come together in a group and actually all admit that you do have memory problems and to be able to discuss that out in the open. Also to have people from the building that you live in as well, it can sort of build up links so that … you've actually got the confidence to come out and speak to other people that you realise are possibly going through the same as you are." (Housing 21 staff member)*

> *"…people would get to know each other, support each other. People could form friendships, that people would feel valued, that people would be able to offer each other ideas on managing, and that there would be a sense of humour and fun and enjoyment within the group as well." (MHF staff member)*

Theme 2: Supporting families

Being diagnosed with dementia can potentially change a person's sense of self and identity and also affect family dynamics and relationships. There was a feeling that families were often not receiving the information or support they would need to cope with these changes and to look after their relatives well. Peer support groups which involve family members could potentially be a life-saving support structure.

> *"There will be a time when you can't or won't be able to use them [peer support group] but it will be there for your wife, your husband and your sons and daughters and family members because they still need help. Peer support does not just help the person with dementia; it helps the persons living with it: the family." (Advisory group member)*

There is a possibility that memory loss or dementia can engender role changes within family structures, for example, between partners, and these can be very difficult to deal with. But such issues, it was felt, did not get sufficient attention normally and self-help and peer support groups were seen as potential contexts where these shifts in responsibility and power that affect family dynamics could be better understood and ways to cope explored.

The involvement of family members or those caring for people living with dementia and memory loss in the setting up of this project (mainly through their role as advisory group members) was identified as a positive and productive practice.

> *"…we have had one meeting of that group which has raised a lot of questions and challenges to myself and to the facilitator about how the groups should work and that has been really useful in terms of developing the details and thinking through how the groups will work so the advisory group have been more than a sounding board in terms of developing the project and that has been really great." (MHF staff member)*

Theme 3: Specific impact on memory loss and remembering

The memory loss attached to dementia can be a frightening experience for many people and the support needs people have in coping with this may not always be picked up within the context of general domiciliary care.

> *"While they're living in extra care, they can, well I think anyone can be overlooked when they first have a diagnosis or they're worried about their memory. It's really that it affects people when they've got worries about their dementia or they're sort of early stage diagnosis which is a big part which I think is missed out." (Housing 21 staff member)*

> *"The problems associated particularly with memory difficulties are increased anxiety, increased depression, increased worry about forgetting things, frustration with themselves. All those things, if they're not catered for, in a person centred approach, can lead to, um, depression and agitation and aggressive behaviour and behavioural problems." (MHF staff member)*

Self-help groups where people at different stages of memory loss come together could potentially be a learning and support space for them to deal with the emotional impact of it, learn new techniques for remembering and recall, share memories from the past and focus on this aspect of dementia without feeling embarrassed or anxious.

> *"When one has memory problems one loses ones' sense of identity and orientation so it's quite frightening. [Peer support] groups can offer both practical and emotional support, masses." (Advisory group member)*

> *"Losing good memories. That is a difficult thing. It will be good to learn from others and hopefully from the facilitators also what can be done. They have things like memory boxes and reminiscence exercises now, don't they, which everyone can do together…" (Housing 21 staff member)*

Theme 4: Wellbeing and sense of self

Within a sheltered housing context, there is a possibility that the specific needs of people with dementia or memory problems are not picked up or supported as they should. Specifically set up groups can address this gap and promote better engagement and interaction, thereby improving not only the ability to remember, recall and learn practical ways of coping, but also improving a sense of self and self-esteem.

> *"…people with dementia still have a life. It's a different life but they still have a life and they can be somewhere doing something, learning something. … I know they do art and they do exhibitions, and I think this is a big benefit to people because they think, people are looking at me and taking notice of what I am doing, and that I can do things." (Advisory group member)*

That social isolation can be a specific problem connected to dementia and memory loss in the community was underlined by the interviewees, but this was a problem not only in the community but also within housing settings. Self-help groups could function as a context for reducing social isolation, increasing coping skills and maintaining wellbeing and a good quality of life for as long as possible. The possible social benefits of peer support and self-help was emphasised:

> *"Peer support has enormous social benefits. We know that maintaining good social relationships and developing new friendships, laughing, sharing the difficulties and challenges of having dementia can all be very beneficial, so if they can result in an individual coming away from a group after a session feeling better about themselves because they can offload their frustrations or talk about what they are worried about in terms of having dementia or have a laugh about becoming forgetful…" (MHF staff member)*

Theme 5: Staff expectations

Interviews with frontline staff (healthcare and personal assistants) showed that they had slightly different expectations from the project. None of the frontline staff interviewed in the three locations had any previous experience of facilitating peer support or self-help groups or specifically of working with people to increase coping skills for living with memory loss. In some cases, 'peer support' was not a concept that they were familiar with and the groups were understood to be the same as other 'activity' groups. Nevertheless, the potential benefits of having groups where people with similar experiences of dementia and memory loss could share those experiences and learn from each other were acknowledged. There was also an expectation that staff would be involved in a way that would teach them how to facilitate peer support groups and work more closely with people with dementia.

> *"Well, we are involved in personal care. When I meet a new client, sometimes, they'd have behaviours that I don't know how to deal with. It [the self-help groups] would give us more experience and help us deal with these. … There are benefits on both sides. Care staff will know how to help clients with memory issues and the clients will know that they have someone to listen." (Housing 21 staff member)*

Indeed, some of them had understood from the initial information they had that there would be an element of training involved.

> *"I think basically we are care staff and we will have more benefit, probably will know more, be trained, and know more what we can do, how I can help them." (Housing 21 staff member)*

There was also a concern that without direction, the groups could become just another social group. At the baseline stage, frontline staff seemed to have little information about the project as a whole and its specific aims and objectives; the expectation was that they would gain the knowledge of how to facilitate and sustain self-help groups either by working with the facilitator or by receiving specific training.

Theme 6: Challenges in setting up and sustaining peer support groups in extra-care housing settings

A key challenge noted in advisory group minutes and in the interviews with stakeholders and MHF staff is how best to identify participants who will benefit from the peer support groups. The facilitator did not have access to medical backgrounds or histories of potential participants and not all those who were identified as suitable by the housing provider had memory problems[1]. At the

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[1] Recorded in minutes of the advisory group, dated 11th September, 2012.

baseline stage, the suggestion was that criteria for inclusion should be worked out before setting up the groups and that a formal screening tool for recognising early signs of dementia would be useful for assessing individual suitability.

There was concern was around the sustainability of such groups over a period of time. One issue highlighted was around the progressive nature of dementia and whether the participants will have the necessary support to continue running the group after the facilitator running the group as part of this project withdraws.

> *"… expecting a group of people with dementia independently to keep a group going is a high expectation or perhaps an unrealistic expectation though not necessarily so. There clearly needs to be some thought and work done by the group with the facilitator to think through a) do we want to keep this group going after the facilitator withdraws and b) how we are going to do that. What resources are there available within the housing scheme or perhaps more widely in the community to enable them to continue going." (MHF staff member)*

> *"I think that the hope is that people will continue to attend and maybe people will volunteer to continue with some of the co-ordination but … I actually think and my experience with these sorts of things is that without a facilitator things can wither on the vine frankly…" (Advisory group member)*

Frontline staff also felt that there will be a need for someone to be in charge of facilitating the groups after the project appointed facilitator withdrew. Staff members were generally keen to see the groups continue but expressed the need for special training (which, as discussed above, they hoped to receive during the project's life) and dedicated roles rather than as an ad hoc part of their daily duties.

> *"We would have to get more care staff involved…" (Housing 21 staff member)*

> *"In [another location] they have brought in someone from the outside to run this. We may also need that or someone here trained up and freed up to run the groups." (Housing 21 staff member)*

The issue of staff training was also discussed by the advisory group. As noted earlier, none of the frontline staff interviewed had previous experience of working with people living with dementia or memory loss. It was felt that staff needed training in identifying signs of dementia and that training should be more than knowledge-based, incorporating also 'carer behaviour' to help provide person-centred care[2].

4.3.2 End of group feedback

Peer support groups were run in three locations for six months, at the end of which feedback was collected from those involved.

Feedback from those who attended the group was collected via a group discussion facilitated by the MHF researcher (n = 12) in two of the three locations. At the third location, this was not possible as the level of cognitive impairment was high among the participants and the group was no longer running.

Staff feedback through semi-structured telephone interviews (n = 9) were collected in all three locations. The initial plan was to re-interview the staff members who

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[2] Noted in advisory group minutes, dated 11th September 2012.

were interviewed at the baseline data collection stage. However, this was not always possible as some staff had moved away or left the organisation. In some cases, the healthcare assistants who were interviewed at the baseline stage were re-interviewed, but they had had no involvement in the project since. However, it was felt that they would be able to shed light on the general changes, if any, that the self-help groups had brought about in the way the house was run and in how the members benefitted.

Feedback from those involved in facilitating the groups was collected via a reflective diary maintained by the project facilitator and interviews with two volunteers who helped co-facilitate the groups in two locations.

Although there was a separate outcomes evaluation, it was important to capture a sense of what was achieved as part of the process evaluation, as what the groups achieved or faced as challenges are intertwined with the process of setting up the groups and how they were run. Similarities with the findings from the outcomes evaluation are highlighted where relevant in the discussion below.

At the time of writing this report, peer support groups are continuing to run in two of the three locations, facilitated by volunteers. These groups are expected to run until end of September 2014.

Positive aspects and benefits from the groups

Overall, staff and facilitators felt that the peer support groups had brought in several benefits for people living with dementia and memory loss, for the staff involved, for family members and friends, and for the housing organisation as a whole. Participant feedback showed that there was a high level of satisfaction both in terms of personal benefits from the sessions and in terms of the facilitators' interactions with the group. This has been highlighted in the outcomes evaluation as well. It was difficult to say how much actual difference the group sessions made on people's ability to learn ways of coping with memory loss, but there seemed to be an overall emphasis on the supportive nature of the group, a sense of sharing and getting to know each other more and an increase in social interaction.

Increase in social interaction and well-being

Group members said that they had joined the group to learn more about dementia, to "relieve boredom" and to have more opportunities for learning from others with similar experiences.

> *"I joined because I've been recovering from a stroke, and I needed to understand why I was behaving…, and the problems, and my thinking processes, that's why I joined. And I have found it very … I only came and started from November. So I have found it very, very useful. And I have learnt a lot." (Group 1 participant)*
>
> *"I joined the group because I like to meet people, people that sort of suffering what I'm suffering with, and what others have suffered with. And we all seem to get along very, very well." (Group 1 participant)*
>
> *"Loneliness, there was nothing going on at the time…" (Group 2 participant)*

In all these aspects, they expressed satisfaction with what they had gained from the group. This is explored more fully in the outcomes evaluation.

The groups had helped in ensuring that the people who attended them had better social interaction within the housing facility, and there was an overall improvement in some of the participants attending the group and changes in the way they interacted outside of the groups.

> *"They can speak to each other, listen and encourage each other, and they are not stuck in the flat all the time. They can come down and have a chat and a cup of tea, I think this is very important." (Housing 21 staff member)*

> *"I have certainly seen a change in people's self-esteem, I have seen people who have come out of their shell, some of the quieter members of the group become more involved, so it encourages confidence and a sense of community and friendship, and a mini society within the housing group, and people really enjoy it, so it had multi benefits to those who have attended the group." (Housing 21 staff member)*

In some situations, what was valued most was the opportunity to come together and share experiences, memories, and generally interact with each other, rather than focusing specifically on self-help strategies as such.

> *"Group often doesn't go as planned, sometimes doesn't seem self-help more a focus on wellbeing and an opportunity to express themselves and be heard." (Facilitator)*

Coping with memory loss

As with the outcomes evaluation, the groups helped with learning to cope with memory loss. Learning elements mentioned by group members included gaining more information about dementia and how memory worked and how certain techniques could help in coping with memory loss.

> *"Well I think you start thinking … if you've got to remember something, somebody asks you something, you start association with what they're asking and what you do remember. And come up with the answer kinda thing." (Group 1 participant)*

> *"I've learnt from the group why my memory does certain things... We had a very interesting week when we had a balloon, didn't we, with bits of brain [drawn] on it. That was quite interesting. Which bit does what – which was quite good. I found that very interesting." (Group 1 participant)*

Specific mention was made about the exercises that helped to learn new ways and strategies put in place for remembering things.

> *"We play the ball game to help us remember other peoples' names and our own."[3] (Group 2 participant)*

Some people indicated that they were continuing to practice some of the techniques they learned in the group.

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[3] At the beginning of each group, a ball is passed around. Each member throws the ball to another person sitting in the circle. In the first round, everyone says their own name before throwing the ball to the next person and in the second round people say the name of the person to whom they are passing the ball.

> *"I try and do games and exercises that keep me much more mentally alert. Because I did go through a stage where I had to write myself Post-It notes and stick them on things because I couldn't quite remember what was what. But I seem to have moved on from that." (Group 1 participant)*

One member, however, did indicate that she did not feel more in control of her memory issues, while another member who does not have dementia or memory loss said that attending the group had helped her learn more about dementia and how to live and learn with each other.

The focus on memory and the range and level of activities had generated more interest even among those who normally were reluctant to attend other activity groups.

> *"The people always talk about how helpful the group is and what they do in there, the people always talk to me… They had been given some albums with the staff pictures and names in there and other residents' pictures in them. There was this man who didn't know my name and now he can remember my name and say it, now he can identify who is coming to his flat." (Housing 21 staff member)*

> *"I have noticed the high level of attendance at the group, if it was a normal activity like a sing along to the CD, I noticed that not all of them would come out of their flats, and it helps them and their memory too." (Housing 21 staff member)*

The feedback, overall, showed that the facilitator had been successful in bringing in some changes to the physical environment of the housing facility which has helped people and supported personal strategies learned. Key among these were installations of clocks around the facility and display of floor plans on each floor. In one location, the running of regular sessions had resulted in the creation of a more homely atmosphere in the meeting room which, the participants said, was being used quite regularly to meet up with each other and socialise, even after the self-help group sessions were over.

Benefits for staff

Although not all staff interviewed had been involved directly in the facilitation and running of the groups, the overall view was that the groups were beneficial for staff too. They felt that there was better understanding and awareness of dementia and memory loss and how to work with people needing support for this.

> *"I am the only staff who took part in it, and I get to understand them more, understand about dementia more it has taught me more how to interact with people with dementia. It was quite enjoyable, especially reminiscing because I have learned so much about the past in England what I didn't know." (Housing 21 staff member)*

The benefits also included learning new activities which they could use in their work with other clients too

> *"[Staff] only occasionally come but I think, they probably see the same things day in and day out and it might help them to try and mix things up a bit maybe and adopt some of our strategies to their care work just to make things more interesting so yeah, I definitely think the staff can benefit as well." (Volunteer)*

One person interviewed felt that the groups helped in creating a sense of community within the housing project.

> *"I think just giving the residents activities to do, and getting the clients out of their rooms and interacting with each other is very much valued by Housing 21, and I think we are creating a sense of community." (Volunteer)*

An unexpected outcome seems to have been that the groups freed up time for staff to attend to the other clients while clients with dementia or memory loss were engaged in the groups.

> *"Sometimes [the group] was at times we do other activities like tea time. Most of the tenants would be participating in the group, so staff had more time to prepare for other activities, or to attend to other people who had no problems with memory. Normally people with memory problems need more attention and you need to engage them more. So the staff have that time off to give more attention to the other tenants." (Housing 21 staff member)*

Benefits for families

Family members or friends of the participants who attended the groups were not interviewed for the evaluation. However, staff members and volunteers interviewed were asked to comment on any potential benefits for families and friends that they perceived. The feeling was that the techniques used to assist in memory and remembering, especially the use of photo albums, are beneficial for families and friends in improving the quality of interactions with their loved ones.

> *"I think the families think it is benefiting, the people in the group, and so that is good for them because that makes them feel like they are having a better quality of life and, I think that the family members attend sometimes as well they can see what we are up to and they seem to enjoy it and they get involved and seem very supportive so it can only be a good thing for them as well." (Volunteer)*

> *"I think they know how much they enjoy the group, and I have spoken to close friends of some of the residents. I don't think I have met family yet, but I think they are aware because we take pictures of the groups and they put them up in their rooms, so I am pretty sure the families see them and we give out resources, and we are going to have this album system, where they can store their pictures from the different sessions but I think their families appreciate it and they definitely know the clients look forward to the group and I think they are happy about it." (Volunteer)*

Families also benefit from seeing people engaging more with the domiciliary community and having a better quality of life.

> *"The families have seen the advantages of being involved that it has been a therapeutic environment, a stimulating environment, within domiciliary care." (Housing 21 staff member)*

Concerns and challenges

Those who attended the groups indicated that they would like the sessions to continue, although the possible implications of facilitation and other practical aspects were not discussed by the participants. The facilitator's reflections highlighted some difficulties and challenges in setting up and running the groups, which were discussed with the advisory group and the project management team to find solutions. Staff members interviewed had two main concerns: one was to do with the way self-help was introduced into the locations, and the other was to do with the continuity and sustainability of the groups.

Challenges in setting up and running specific groups for people living with dementia within extra care housing

A key challenge faced by the facilitator, volunteers and some of the staff was the difficulty in setting up and properly running peer support groups that focus on people living with dementia and memory loss within extra care housing. The facilitator's diary discussed some challenges faced while setting up the groups and embedding them within the day to day functioning of the housing facility. It was difficult to set up and run such groups "as an outsider", and, understandably, there were conflicts with existing organisational cultures and practices, available resources and staff awareness and capacity.

> *"I feel like running this group here is like putting a table cloth on a three legged table and that there needs to be some foundation work that has to be put in place before anything to work long term namely staff attitude, morale, training, basic care and communication skills, understanding of culture and history." (Facilitator)*

Where there was more staff involvement, flexibility in work rotas and schedules and willingness to help, the progress of the group was smooth.

The experience of facilitating the groups showed that people who did not necessarily have memory problems or dementia living in these schemes also wanted to join the group. Inclusion of these members was based on several factors, whether people with dementia wanted to "open" up their group to other tenants in the schemes without dementia and whether the facilitator felt other tenants would not be a disruption to the running of the groups. Tackling social isolation and loneliness within extra care housing is a problem often encountered in these settings and the groups are a way of encouraging friendship and social interaction. This may have been one of the reasons why people without memory problems or dementia also wanted to attend. [4]

The facilitator's diary also noted that some people who could have benefitted from the groups chose not to attend while others had to stop attending along the way. The reasons for this included: being too withdrawn or anxious and not able to leave their flat, the need for one to one support rather than in a group context, feeling too agitated, being in denial of or not wanting to address memory problems, time of the group conflicting with another activity, and progressing cognitive impairment.

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[4] Noted in advisory group minutes, 21st March 2013.

Staff involvement

All staff members interviewed felt that the way the groups were introduced was somewhat ad hoc and that there was not enough thinking or planning about how to involve staff. Staff also felt that more thought should have gone into the additional time and involvement required in facilitating or co-facilitating the groups and how that would affect their daily rotas and responsibilities. Some staff members who were involved at the start could not continue being involved because of this.

> *"I think to make it run better would have been to allocate separate staff, individual time to be involved in the group long term. It was a little ad hoc because we have tight allocations here we have to see people at certain times and it was rather difficult to free up as many staff as I would have liked to attend the group and to take part." (Housing 21 staff member)*
>
> *"Again it is the time, we have to find time for one or two staff to be involved in it, or be part-time involved in it and this is something we have to look at in terms of allocations, and who they have to see. And in regards to rotas, to have someone consistently on as the same time as the group is running is difficult." (Housing 21 staff member)*

Sustainability of the groups

While staff and volunteers who were interviewed agreed that attending the groups had brought in real changes and benefits for the people who attended the groups, they also expressed concerns about the sustainability of the group after the facilitator and volunteers involved had moved on or were in the process of moving on. There was general agreement that there should be at least one, or ideally two, facilitators to ensure continuity of the groups. In some cases, there were people within the groups who would be able to facilitate the group, but the consensus was that the group required support from staff or volunteers on a regular basis.

> *"Yes I do have concerns about how the group is going to sustain itself after I leave...– there is quite a varied ability within the group and there are a couple of them who stand out as potential facilitators ... and I hope they do but there is that concern that the group would disintegrate." (Volunteer)*
>
> *"Two facilitators are needed. It really is too much work for one person to do, particularly I am a volunteer and on a volunteer basis I think it is quite a lot of work to do and I think it will benefit everyone involved if there were two facilitators just to make things easier." (Volunteer)*

Based on the baseline data collected, there was some expectation that staff members would be trained in running self-help groups. Some felt that this was necessary for sustaining the groups and said that this should have been addressed right from the beginning.

> *"If the staff were involved from the beginning they could have done some of the activities on the weekends, and staff rotas needs to be taken into consideration to help people to train and learn how to facilitate the group." (Housing 21 staff member)*

> *"I think it would have been better if staff could have been involved but it is a shame it was once a week just at one time, so I couldn't attend, I really wanted to attend. I think it was a good idea so in the future if they should discuss with staff and management about times and rotas, and try and work it better, so staff can attend. It is a good opportunity for staff to attend so they can learn more and help to run the groups in the future too." (Housing 21 staff member)*

The groups continue to run in two of the three locations and are currently being facilitated by volunteer recovery enablers. This is expected to continue until September 2014. Plans for sustaining these groups after the volunteers leave, however, were not clear.

4.4 Conclusion and key lessons

The feedback at the end of the group shows that many of the expectations expressed at the baseline stage in terms of the potential benefits of self-help groups for people living with dementia and memory loss have been met. Key among these are increased socialisation opportunities, learning from each other and sharing experiences, and a general sense of wellbeing. Specific strategies for coping with memory loss were identified by participants. The staff and volunteers were also able to identify perceived benefits for staff, for families and friends and for the housing provider as a whole. This was due to the fact that the peer support groups increased awareness of dementia and memory loss within the housing environment as a whole and showed how everyone could support the needs of people with dementia better; for example, through changes in the physical environment such as increased signage in schemes or addition of clocks, which increased wellbeing.

Differences between groups

The evaluation showed that there were some differences between the three locations which had implications on the way the groups progressed. The key differences were:

- The level of involvement of staff and managers and awareness of the project and its goals
- Organisational structure and work culture with varying levels of available resources, staff time, one to one and personalised care,
- Staff attitudes towards people with memory loss
- The extent of memory loss and capacity of participants: for example, in one group the participants were more physically able but mentally frailer when compared to the other groups. In another group, early assessment showed that there were unidentified mental health support needs
- Existing level of activities, staff support and interaction
- Involvement of families and friends: for example, in one location, there were a large number of tenants who were homeless before they came there and had no family

As a result of these differences, the ease of running groups differed from scheme to scheme. For instance, content and focus of the groups varied to accommodate the specific needs of the participants attending each group. Where housing staff were more involved, had flexibility in work rotas and schedules and were more willing to help, groups ran more smoothly. The larger structural issues – culture of the organisation, resources available, staff capacity, capability and awareness etc. – were more difficult to address. Specific recommendations for housing providers, staff and facilitators are laid out under the recommendations section of this report.

Sustainability of the groups

The emerging picture is that of staff working in a highly task-oriented and less flexible environment, with several changes in shifts and rotas. Unless specific commitments and their resource implications, in terms of staff time, are addressed beforehand, it seems unlikely that staff would be able to be involved in any meaningful way.

In two locations, volunteers were involved in co-facilitating the groups and in both these places the groups are currently continuing to run. Appointing a volunteer or a paid facilitator would be one option to ensure sustainability. But if the support is to come from existing staff, more attention needs to be paid to their capacity and capability.

The feedback also showed that there are potentially some members who, with appropriate support and guidance, would be able to continue facilitating the group. The evaluation was not able to identify any specific plans for this to happen.

5 Overall summary, limitations and lessons

Overall summary and reflections

Both the outcome and process evaluations agree on the positive findings of peer support groups on wellbeing for people with dementia, social support, and the learning of practical coping strategies. Mean wellbeing measured by the sWEMWBS increased from T1 (22) to T2 (23) following participation in the groups. Participants' perceived social support over the duration of the groups also improved, with many participants referring to group members as friends. Participants demonstrated greater awareness of group members and improved memory recall which can be attributed to the increased socialisation opportunities that the group provided. Qualitative feedback at T2 and T3 showed that participants had learnt practical coping strategies to manage their memory, improve communication, and overall manage their lives better.

From staff and stakeholder interviews the perceived benefits of the group extended beyond participants and were viewed as a benefit to staff, families, friends, other tenants living in the schemes, and for the housing provider as a whole. However, it was noted that the level of peoples' understanding and awareness of dementia and memory loss were low among these groups.

The findings show that sustaining peer support groups within extra care housing require a much more embedded approach, with dedicated staff time and resources and as a regular part of the activities within the house. More time needs to be spent to ensure that frontline staff understands the purpose and goals of setting up self-help groups and their potential hands-on involvement.

This evaluation also found that the level of understanding and awareness of dementia and memory loss and of the concepts of peer support and self-help were low among frontline staff. Training or capacity building may be necessary in order to support person-centred care.

There was some deterioration in the independent living skills of participants over time as rated by the IADL scale. However, the high level of physical frailty and impairment among group members meant that practical coping skills as assessed by the domains on the IADL were unlikely to improve.

The external evaluators' access to Housing 21 staff members and to the groups involved in the project was facilitated through the facilitator. In some cases, when they contacted staff members they were put in touch with, some staff refused to be interviewed saying that they had no involvement in the project. In other cases, it was difficult getting staff to commit to a mutually agreed time to conduct the interview. The impression we gained was that a) staff were extremely busy and had very little time to spare for being involved in this research, b) the facilitator's understanding of the level of involvement of a staff member was different from that of the staff at the locations, and c) the 'research' aspect of this work was not understood enough or committed to by the staff at each location. Consequently, there are gaps in the process evaluation, the most important of which is developing a case study based on one of the groups in order to provide a complete picture of setting up peer support groups for people living with dementia or memory loss.

It is worth noting that one of the three groups was ethnically very diverse. A gap in the information collected during the course of this evaluation was insights about the implications of ethnic and cultural diversity in setting up peer support groups in a multi-cultural context. In discussions about peer support in mental health, for example, the need for a 'peer' to be defined beyond a shared experience of mental distress and taking into consideration shared social and cultural backgrounds and experiences have been emphasised (Faulkner and Kalathil, 2012). Working productively with people on memory and recall may entail knowledge of historical and cultural memory that may not be shared (between tenants or between tenants and staff), making the issue of cultural knowledge and competencies paramount. There needs to be more investigations in understanding how cultural memory works in a context of difference and diversity and its implications for peer support groups for people with dementia and memory loss.

Another concern raised was about recruiting the right participants for the group, in the sense of achieving a balance of people at different stages of dementia and memory problems, ensuring that the people attending the group are those who can benefit from it and not feel alienated etc. A question to address in replicating this work is whether participation should be restricted to those with clear support needs for dementia and memory loss. The evaluation shows that there are potential benefits for those who do not have memory loss problems, especially in terms of reducing social isolation and increasing wellbeing through friendships and social networks.

While the involvement of those without dementia or memory loss may not adhere to a strict definition of 'peer support', keeping the criteria for inclusion flexible and involving the participants in making decisions about the nature and content of the group seem to have contributed to the success of the groups. Another argument for keeping the inclusion criteria flexible is that some people may develop dementia while at the housing scheme or during group attendance (Garward 2005). Attendance at such groups may slow down memory loss and/or maintain social functioning for longer, especially if occurring at early stages of dementia.

Several challenging issues arose from the staff and stakeholder interviews which emphasized the difficulties with running the groups, this included: the demographic of tenants living in the schemes, limited staff capacity to become involved in the groups, and the overall organisational structure and culture of specific schemes.

It is clear from the findings that sustainability of these groups requires a more embedded approach with housing providers taking on more responsibility to support activities which promote supportive relationships (Croucher and Bevan, 2012), which interventions like the peer support groups provide.

Recommendations

On the basis of the findings from the outcomes and process evaluation, a number of recommendations can be made for a variety of stakeholders (e.g. housing providers, carers, group facilitators, staff, research and policy etc.). The recommendations for the two distinct evaluations have been combined and are presented below.

For group facilitators

The peer-support elements of the groups worked very well for participants and it was one of the greatest strengths of the groups. However facilitation by group members posed challenges. It is possible to make the groups sustainable, though support is likely needed by a trained facilitator particularly when working with people with dementia who have deteriorating cognitive conditions as well as those who have significant physical impairment and disability. We would also suggest that group facilitators would benefit from using a semi-structured approach to the groups with regards to the themes of each session allowing for participants to voice topics which are of interest to them as the group is running (See summary of contents of resource pack in Appendix F). We would also suggest that facilitators and group members have an agreed plan in place if a member becomes too impaired to continue participating.

Future groups would also benefit from keeping inclusion criteria flexible, as there are a number of benefits for those who do not have memory problems participating in the groups, such as reducing social isolation, increasing wellbeing and reducing stigma in the housing community. Facilitators should also give consideration to the cultural and ethnic diversity of residents, staff and themselves in order to make groups accessible and to understand what skills and techniques may be needed to address memory and recall in relation to historical and cultural memory that may not be shared between participants and staff/facilitators. Cultural beliefs can serve as barriers to help seeking, and may prevent participation (Seabrooke and Milne, 2004). Future groups need to be sensitive to the needs and beliefs of a variety of cultures and ethnicities and would benefit to work in partnership with organisations from these communities.

For carers

Few carers or loved ones were able to participate in the groups; however the few that did found that the groups helped them understand their relative with dementia better and they also learnt strategies for communicating with their loved one. While it may be difficult for family members who live far away or work during group times to attend, regular conversations with the group facilitator to hear what was discussed and learnt during the group increases family members' conversation topics with their relative with dementia as well as reinforcing learning from the group. Staff also felt carers and family members benefit from seeing their loved ones engage more with the housing community and seeing them have a better quality of life in the housing scheme. Appendix F provides the contents of a resource pack with activities and games, some of which can be useful for professional or home carers for improving communication and /or memory of persons with dementia they are caring for (e.g. songs, memory games etc.).

For housing providers

A more embedded approach of peer support groups in housing schemes is needed if the groups are to become sustainable. Groups should be viewed as part of the life of the scheme rather than as an external activity coming into these schemes. There needs to be a shift in the work culture from a primary focus only on maintaining residents' independence to one which maintains residents' connectedness That is, we need to support an organisational culture and environment which focuses on community engagement and meaningful activity and supporting relationships. An individual's ability to be able to live with more independence does not protect them from social isolation and loneliness. Cultural and ethnic diversity within extra care housing settings, between staff, carers and residents needs to be considered in provision of care and when promoting community engagement, meaningful activities and supporting relationships.

For housing staff

Whilst housing staff are interested and want to be more involved in activities like the peer support groups, they currently are not able to do more than the practical tasks of their job. Thus care for social, emotional and psychological needs of residents fall by the wayside. Staff also reported a lack of confidence in doing tasks related to these types of needs. Frontline staff and housing staff need training in understanding how peer support groups work and how activities like these can enhance residents' lives. They should be motivated and supported by management to be more involved in activities such as the peer support groups. Staff is vital to sustaining groups like these in the scheme, where a range of disabilities and impairments requires certain levels of support.

For other residents

Future peer support groups for people with dementia in extra care housing schemes should consider inclusion of other residents who do not have dementia or memory problems as the project also sparked interest from other residents in the wider housing community. Doing this would begin to tackle stigma associated with having dementia. In addition, a mixed group may attract individuals who do not want to categorise themselves as having dementia or a memory problem.

For research and policy

There is still far too little research available on the effectiveness of peer support models in the UK, and peer support for people with dementia. Based on the positive findings of our groups, future research activities are needed in this area. In addition, further exploration around cultural sensitivity and diversity is needed, particularly when participants, housing staff and facilitators may not share the same historical and cultural background.

For commissioners

In our present financially constrained times, the social and financial value of employing peer-support and self-help approaches in housing schemes should encourage commissioners and housing providers to support these approaches. While thinking about replicating this work in other locations, it would be useful to conduct a needs assessment study to understand the level of current knowledge and awareness among staff and address any gaps through awareness raising or specific training courses.

Future Work

Following the success of this project, the Mental Health Foundation hope to expand and run more groups in extra care schemes across London. The groups will be more inclusive and include tenants in schemes who may not have dementia but may be lonely and socially isolated, as this appeared to be the most commonly reported issue for the majority of tenants.

Appendix G provides the approximate costing of running one group for six months following the current pilot study. Because these were pilot projects, we chose to employ someone with more experience, on a higher salary to be the group facilitator. The approximate running cost of one new group for 6 months, using the resource pack created during this project and with trained activity coordinator acting as facilitator should be £3,364.54 excluding room hire. Please note that there may be also some additional costs depending on local circumstances e.g. travel and any other costs associated with supporting group participants' attendance (see Appendix G).

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7 Appendices

Appendix A: LAWTON – BRODY – INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (IADL)

A. Ability to Use Telephone - ***Do you have a telephone?***

1. Do you know your own telephone number?
2. Operates telephone on own initiative-looks up and dials numbers, etc.
3. Dials a few well-known numbers
4. Answers telephone but does not dial
5. Does not use telephone at all
6. Does not have a telephone

B. Shopping - ***Do you do any shopping?***

1. Takes care of all shopping needs independently
2. Shops independently for small purchases
3. Do you make your own shopping list?
4. Needs to be accompanied on any shopping trip
5. Do others decide your shopping for you?
6. Completely unable to shop

C. Food Preparation

1. Can you prepare your own food independently?
2. Can you prepare ready meals or snacks for yourself e.g. sandwiches, breakfast, etc.?
3. Needs to have meals prepared and served
4. Can you prepare your own hot drink?

D. Housekeeping - ***Do you do any housework or chores?***

1. Maintains house alone or with occasional assistance (e.g. “heavy work domestic help”)
2. Performs light daily tasks such as dish washing, bed making
3. Performs light daily tasks but cannot maintain acceptable level of cleanliness
4. Needs help with all home maintenance tasks
5. Does not participate in any housekeeping tasks? Due to? - Physical disability?

E. Laundry - *Do you do your own laundry?*

1. Does personal laundry completely
2. Launders small items-rinses stockings, etc.
3. All laundry must be done by others

F. Mode of Transportation

1. Travels independently on public transportation or drives own car
2. Arranges own travel via taxi, but does not otherwise use public transportation
3. Travels on public transportation when accompanied by another
4. Travel limited to taxi or automobile with assistance of another
5. Does not travel at all

G. Responsibility for Own Medications

1. Is responsible for taking medication in correct dosages at correct time
2. Takes responsibility if medication is prepared in advance in separate dosage
3. Is not capable of dispensing own medication

H. Ability to Handle Finances - *How do you manage your finances?*

1. Manages financial matters independently (budgets, writes checks, pays rent, bills, goes to bank), collects and keeps track of income
2. Manages day-to-day purchases, but needs help with banking, major purchases, etc.
3. Someone else manages all financial matters

I. Ability to handle post - *Do you receive post?*

1. Do you check your own post?
2. Are you able to open and deal with it yourself?
3. Is not capable of handling own post? Due to? – Physical disability?

Appendix B: Social relationships questionnaire

1. If you are really worried about something do you have someone you can call/contact/ talk to?
    - A relative? A staff member? A friend? Anyone inside the home? Anyone outside the home?
2. How many people do you know living here? {can you name them?} Do you consider any of them to be your friends?
3. How many people in the home would you feel comfortable to speak to if something was bothering you?
4. Do you do an activity outside the home? Inside the home?
    - If yes, what and how often?

Appendix C: Below are some statements about feelings and thoughts.

Please mark on the line which best describes your experience recently

None of the time	Rarely	Some of the time	Often	All of the time

I’ve been feeling optimistic about the future

I’ve been feeling useful

I’ve been feeling relaxed

I’ve been dealing with problems well

I’ve been thinking clearly

I’ve been feeling close to other people

I’ve been able to make up my own mind about things

Appendix D: PARTICIPANT EXPECTATIONS

What do you hope you might gain from participating in the memory group? Please tell us what it means to you by marking each line with a tick ✓ nearest to your response

Supporting each other

Not much	Somewhat	A great deal

Feeling less lonely

No different than I do now	A bit less lonely	A lot less lonely

Understanding more about memory loss

Understanding no more than I do now	Understanding more than I do now	Understanding a great deal

Doing more things

No more than I do now	I do more than I used to	I do a lot more than I used to

Each item is rated on a three point Likert-type scale (e.g. for the item supporting each other, 1- not much, 2- somewhat, 3- a great deal).At 6 months (T2) questions were slightly modified to see if expectations had been met.

Your name:...

Group attended: ....

Appendix E: follow up schedules

6 month (T2) interview schedule

- What strategies/approaches have you learnt in the group that would help them to manage their memory or memory loss? *Ask them to specify*

- Were you given any equipment from Cindy?–(date clock, photo book of names, magnifier, calendar, hospital bag, preference sheets , information on planning for the future.. power of attorney) Do you use any of the new equipment? Has it made a difference in your day-to-day life? How?

- Have you started doing new things as a result of coming to the group? If so, what things have you started doing?

9 month (T3) interview schedule

- Are you doing anything differently since starting the group?

  Prompt: Think back to a year ago and now

- Have things changed over the last three months? (Since facilitator left)

  Prompts: socializing more, interacting with others in the home, started any new activities, feeling more content with themselves

- What do you remember MOST from the group?

- Do you use any memory strategies in your day-to-day life that you learnt in the group?

Appendix F: Summary of contents of resource pack

PARTONE – Introduction	Page
Aims of the project	6
Evidence on why self-help groups work	7
Who is the resource guide for?	8
What is a 'self-help' group?	9
What is facilitation and the role of the group facilitator?	10
What is dementia?	12
What is sheltered housing and extra care housing?	15
Working with a housing provider	17
How to involve and make use of your local community?	22
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Preparing the group environment	32
Planning the format/structure for the group	34
Setting ground rules	36
Forming a group identity	38
How to get the group to support each other	41
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Sustaining the group	44
Evaluation: Is the group working?	46
Inclusivity	47
When things go wrong	50
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What to do when someone is no longer suitable for the group	54
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17. What do we call our group?	76
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19. Colour bingo	78
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27. What's in a name? 87
28. Learning names 88
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30. Personalised word searches and crosswords 90
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32. Creative writing exercise 1 92
33. Creative writing exercise 2 94
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APPENDICES

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Appendix G: Approximate costs of running one dementia self-help group for six months

Costing factors	Running MHF pilot costs	Future running costs
Facilitator salary	£199 daily rate by 110 working days (4 days per week including the setting up, selection, preparation of materials and resource pack) = £21,890	£80 daily rate[1] by 27,5 days (1 day per week) = £2,200
Resource pack	£6,000 (including design, printing and launch by MHF)	n/a
Assistive technology	£243	£243
Communication equipment	£150.00	£150
Reminiscence resources	£ 255.67	£255.67
Sensory equipment	£60	£60
Training of staff facilitator/ volunteer	0	Depending on staff hourly rate
Refreshments	£150	£150
Evaluation costs	£9,168,67	£305.87
Total costs	£ 37,767.34	£ 3,364.54[2]

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[1] Based on average activity co-ordinator salary estimated as £10 per hour. The figure does not include the cost of staff support in terms of tenants' attendance.

[2] Management costs, staff travel or room costs were not included in the calculation.

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