



## Doing it for ourselves: Self-help groups for people with dementia living in extra care housing schemes

This case study showcases findings from the Mental Health Foundation's on-going evaluation of three peer support groups for people in the early stages of dementia living in extra care housing schemes. It highlights the groups as a promising approach for reducing social isolation, increasing social networks and improving wellbeing for participants.

The groups were run in three Housing 21 extra care housing schemes in London. Residents in these schemes live in assisted living housing developments which allow for independent living while also providing appropriate levels of care. These schemes provide support tailored to individual needs and are supported by care staff. Each extra care housing scheme consists of between 35 to 40 self-contained one and two bedroom flats.

Housing 21 are committed to developing services for their tenants and the local community. The delivery of peer support groups for people living with dementia or for those who are concerned about their memory is invaluable, not only for Housing 21 schemes, but for all extra care and sheltered housing schemes across the country.

The project is an on-going partnership between the Mental Health Foundation and Housing 21, and is funded by the Joseph Rowntree Foundation.

Written for the Housing Learning & Improvement Network by  
**Lauren Chakkalackal**, Mental Health Foundation

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## **Background to the group**

The peer support groups brought together residents in extra care housing schemes who have dementia or suspected dementia, with the aim that through more pro-active interventions members would learn to support themselves and one another through the difficulties of living with dementia.

Group members learned practical coping strategies and skills to increase independent living skills; in particular, to deal with memory loss, to improve wellbeing and also plan for the future. The positive, peer support approach of the groups enabled group members to make plans to retain their control and enjoyment of life.

Each group ran once a week for six months and was led by an experienced facilitator. After six months the intention was for the groups to become self-sustaining or sustained through local support. There was a different focus or activity at each weekly meeting; for example, group members might practice a skill such as creative writing, ways of remembering time, places and people, problem solving, and healthy living to help keep their minds active.

Occasionally, visitors were invited into meetings to share ideas and information with the group. Visiting guests have included a creative writer, a member of staff from the memory clinic attached to the community mental health team, and a physiotherapist who taught relaxation techniques.

The starting dates of the three groups were staggered so that potential learning from the first group could be implemented in the development of the second and third groups.

The first peer support group started in September 2012 and in March 2013 the group was handed over by the facilitator to two volunteers, one of whom is a tenant in the housing scheme.

## **What are the expected benefits of the groups?**

The aim of the group was to improve people's understanding of memory loss and dementia and enable them to share and learn simple, practical coping strategies to deal with memory loss. There was also a strong focus on social interactions among participants, which sought to help to reduce loneliness, increase social support, and in turn improve residents' wellbeing.

The evaluation of the peer support groups examined the following:

1. The impact of the groups on mental wellbeing of participants (people with dementia or suspected dementia) as well as family members and carers
2. The impact of the groups on independent living skills of participants (for people with dementia or suspected dementia)
3. Whether people participating in the groups are able to live with the same level of care and support
4. Sustainability of the group after the departure of the facilitator at six months

## **How we went about conducting the evaluation**

The evaluation was based on a mixed methods design; both quantitative and qualitative data were collected from participants. Quantitative data were collected at three time points: before the group began, baseline (T1), at 6 months (T2) and at 9 months (T3). Qualitative data were collected only at T2 and T3.

Five measures were used to collect quantitative data on participants' physical functioning, social relationships, wellbeing, expectations of the group and orientation in time. These included:

1. Lawton-Brody International Activities of Daily Living Scale (IADL; Lawton & Brody, 1969) to assess practical coping skills associated with independent living.
2. A social relationships questionnaire developed by the evaluation team which explores the level of social support and social networks of participants.
3. The Short Warwick-Edinburgh mental wellbeing scale (sWEMWBS; Stewart-Brown et al 2009) to assess mental wellbeing.
4. A participant expectations questionnaire developed by the 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 assessed by asking them: the current time, the day of the week, today's date and the season of the year.

Qualitative data were collected in the form of brief interviews with participants at 6 months (T2) for all three groups and at nine months for groups one and two (T3). Focus groups were carried out at 6 months with group 1 and 3. It was not possible to carry out a focus group with group 2 due to attrition in the group and severe memory impairment.

### **What do the early findings from the evaluation indicate?**

The results are based on findings from participants from all three groups who had completed both baseline (T1) and 6 months (T2) data. Evidence from the wellbeing scale (sWEMWBS) and from individual interviews and focus groups (groups 1 and 3) showed that participants really enjoyed the group and that it enhanced their overall wellbeing. Participants' reported enjoying the different activities each week, getting to know one another and the warm approach of the Group Facilitator.

*"I just hope it continues, like the musician, the man who played the guitar he was wonderful, I brought my little grandson, everyone loved that, one lady brought her dog"*  
(Participant #7)

*"I've had the best time of my life [here]"* (Participant #24)

*"Cindy [Group Facilitator] was our saviour"* (Participant #22)

*"It's a good thing people in the home should get together. It's been a good thing for group members. Oh yes! Oh yes!"* (Family member who attended Group 3)

*"...seeing different faces, different people, learning different things, we learn from each other."* (Participant # 19)

In agreement with participants' comments, the average wellbeing score on the sWEMWBS (n=14) increased from 21 at baseline to 23 at 6 months. Scores on the sWEMWBS range from 7 and 35 with higher scores indicating greater positive mental health.

Regarding physical functioning, the majority of participants (n=12) saw a decrease over time, between baseline and 6 months, indicating that the groups did not prevent decline in deterioration of physical functioning. The average IADL score (n=13) at baseline was 3 and at 6 months was 2.

Group participants were selected by the Group Facilitator based on their cognitive and physical functioning. It was found that many tenants in the extra care housing schemes presented with greater levels of physical support needs than expected, which is reflected in the demographic of the self-help groups and is one explanation why independent living skills did not improve over time. It is also possible that the decline in physical functioning was slower than it would have been without the group, though a comparison with normative data is necessary to investigate this relationship further.

Perceived social support measured by the social relationships questionnaire increased between baseline and 6 months, with participants reporting other group members as friends.

*“...it (the group) was something different; [in the beginning] we didn’t know one another’s names, now I do get to know everyone.” (Participant #22)*

Participants’ expectations with regards to the impact of the group on feeling supported or feeling less lonely were either met or exceeded at 6 months, e.g. members felt they received more support from other members and that the group helped with feeling less lonely than they originally thought at baseline. Mixed results were seen, however, on the impact of the group on understanding of memory loss and on the outcome of doing more things. It is likely that participants were unable to do new activities due to their level of disability rather than a lack of interest.

Qualitative feedback at 6 months from participants revealed that some participants had learnt new approaches and strategies to manage their memory and a few were continuing to employ these techniques in their daily life.

*“I learned more through association, to remember, something like the telephone, if you want to remember numbers like the PIN number you make a number up on the telephone keyboard, like an L shape on the left or right...” (Participant #7)*

*“I’m remembering things more now because I’m thinking more about it...what I’m doing at the time...” (Participant #8)*

All group members spoke about enjoying various social aspects of the group and this should be considered an integral component of the groups when considering their sustainability.

## **Emerging lessons**

There is a very high level of physical and mental frailty in tenants living in extra care housing schemes. Sometimes, care staff can be overstretched and manage to only address the physical care needs of residents; their psychological needs, especially those relating to loneliness and isolation, are often not addressed. It appears that a number of people living in these schemes may have probable dementia but are ‘undiagnosed.’ These individuals may go unnoticed by staff who are unfamiliar with recognising the signs of dementia. Consequently, people may not get the required support they need. As a result, there is a need for timely diagnosis in order to maximise support available in the community, e.g. memory clinics. People living with dementia should be involved in activities and their community; just because they have a diagnosis does not mean they cannot learn and still contribute to the community.

When it comes to activities in these schemes, bingo seems to be the only activity on offer. Landlords should be thinking about offering more diverse activities which reflect tenants’ interests and their needs, such as loneliness and isolation. Interventions like the self-help group address the psychological, social and emotional needs of the residents.

## What comes next and when will the full results be available?

Data collection finished for all three groups in November 2013. The final report will be completed by the end of April 2014.

Based on the success of the different activities used by the facilitator, a resource pack is currently being made that will be available to assist others to run similar groups. Based on the very positive feedback from participants and the initial results from the evaluation, the Mental Health Foundation is seeking funding to build on this pilot project and develop more groups across the country. We look forward to sharing our findings with members of the Housing Learning and Improvement Network.

For information about the Mental Health Foundation's project and further developments, visit: [www.mentalhealth.org.uk/our-work/research/dementia-self-help/?view=Standard](http://www.mentalhealth.org.uk/our-work/research/dementia-self-help/?view=Standard)

## Further reading

For other useful resources from the Housing Learning and Improvement Network on reducing social isolation, increasing social networks and improving wellbeing for participants, visit:

- Walker N (2013), *Housing, dementia and the maintenance of independence*. Housing LIN
- Garwood S (2011), *Extra care housing and dementia commissioning checklist*. National Dementia Strategy Implementation Group (updated 2011)
- Kneale D (2013), *What role for extra care housing in a socially isolated landscape?* Housing LIN
- Blood I & Pannell J (2012), *Building mutual support and social capital in retirement communities*. Housing LIN
- Callaghan L (2010), *A directory for promoting social wellbeing in Extra Care housing and other settings*. Housing LIN
- Evans S & Vallely S (2008), *Social Well-Being in Extra Care Housing*. Housing LIN

## Note

The views expressed in this paper are those of the author and not necessarily those of the Housing Learning and Improvement Network.

## About the Housing LIN

Previously responsible for managing the Department of Health's Extra Care Housing Fund, the Housing Learning and Improvement Network (LIN) is the leading 'learning lab' for a growing network of housing, health and social care professionals in England involved in planning, commissioning, designing, funding, building and managing housing, care and support services for older people and vulnerable adults with long term conditions, including dementia.

The Housing LIN is a member of the Dementia Action Alliance. For further information on this and about the Housing LIN's comprehensive list of online resources at 'In Focus: Innovations in Housing and Dementia', and opportunities for shared learning and service improvement, including site visits and network meetings in your region, visit:

[www.housinglin.org.uk/HousingandDementia](http://www.housinglin.org.uk/HousingandDementia)

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Housing Learning & Improvement Network,  
c/o EAC, 3rd Floor, 89 Albert Embankment  
London SE1 7TP  
Tel: 020 7820 8077  
Email: [info@housinglin.org.uk](mailto:info@housinglin.org.uk)  
Web: [www.housinglin.org.uk](http://www.housinglin.org.uk)  
Twitter: @HousingLIN