

Together

An Innovation Fund Project delivered by Enrichment for the Elderly



Introduction

Age Better in Sheffield is a partnership of organisations working to reduce loneliness and social isolation amongst people over 50 and to help them to live fulfilling lives. It is funded by the National Lottery Community Fund and is one of 14 Ageing Better pilot areas across England working to explore what works in reducing loneliness and isolation. Age Better in Sheffield services are commissioned to focus on four target wards (Burngreave, Woodhouse, Firth Park and Beauchief and Greenhill) with a high percentage of the older population at risk of loneliness and isolation, as well as a number of hotspot areas across the city where there are particularly high numbers of people in groups at higher risk of loneliness and isolation (carers, people experiencing poor physical or mental health, people experiencing financial hardship and people from black and minority ethnic (BAME) backgrounds).

In 2017, eight pilot projects were commissioned through an Innovation Fund to explore new ideas for tackling loneliness and isolation. After an initial seed funding round in which organisations were supported to refine their proposals through codesign and design thinking tools with potential participants, five projects were commissioned to deliver their service over a year.

This report provides an overview of the Together project which was delivered by Enrichment for the Elderly, including the outcomes achieved and the lessons learned.

Methodology

This report has been compiled following an interview with the director of Enrichment for the Elderly. It also draws on feedback and on views expressed by participants and care home staff in a <u>video of the Together project</u> which can be found on the Age Better in Sheffield website.

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Context

Going into care is a major change for older people and their families, and people living in residential care homes are increasingly recognised as being at high risk of loneliness. Families often find it difficult to know what to talk about or how to get the best out of their visits, often meaning that visits become less frequent, increasing loneliness and isolation and poor wellbeing for both the person living in residential care and their family.

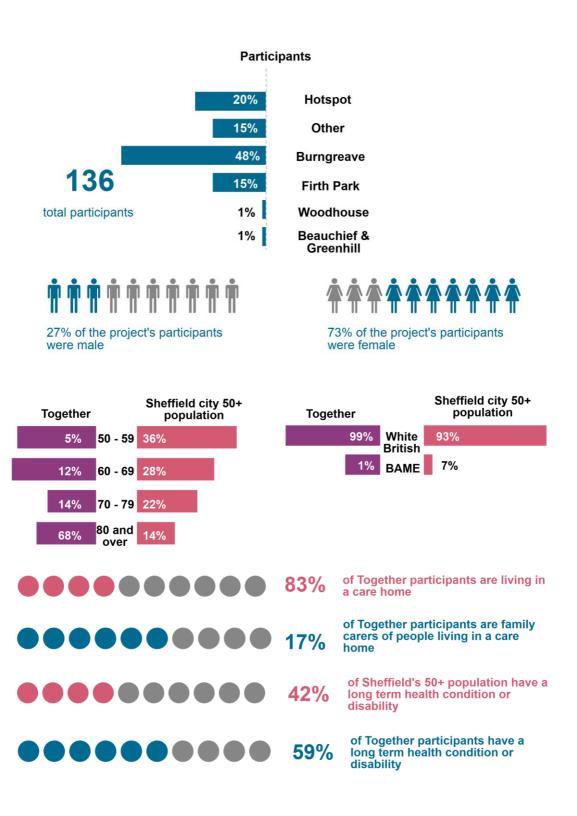
The Project

Together by Enrichment for the Elderly worked with people living in four care homes in Sheffield, their families and care home staff to help improve the social contact between families and their relatives living in care homes. The care homes cover three of the four wards and one hotspot area and were chosen when they responded after Enrichment for the Elderly invited attendees from Sheffield's Care Home Managers' Network to express an interest.

Enrichment for the Elderly worked with family members and the person living in the care setting to understand their experiences, concerns and aspirations about their relationship. The initial proposal was for monthly workshops which people could attend in a group setting. During the seed funding coproduction stage it became clear that this approach was not what families wanted: there was a wide variation in the times and frequencies that family members visited, so finding times that would be suitable for all those who might benefit was difficult, and the aspirations and preferences of families differed. As a result, each family received a bespoke service tailored to their circumstances, with advice and support, a 'go-between' to mediate with care home employees where necessary and one to one and group activities organised around their interests. Group activities would be arranged around the preferences and timetable of one family, with other residents and families invited to take part.

Enrichment for the Elderly also worked with and provided support to care home employees by encouraging them to think about new activities and to understand how they can support their residents' and families' relationships.

Who we worked with



Four care homes in different parts of Sheffield took part in the project:

- Twelve Trees (a care home in Nether Edge providing residential and day care, including care for people living with dementia; based in Nether Edge including a broadly affluent demographic).
- Rosebank (a care home providing care for people living with dementia; based in Burngreave, one of the Age Better in Sheffield target wards and a deprived area of Sheffield)
- North Hill (dementia care home; based in Firth Park, one of the Age Better in Sheffield target wards and a deprived area of Sheffield).
- Pexton Grange (a care home for people living with dementia and patients requiring intermediary care meaning they were too well to be in hospital but not well enough to go home; based in Burngreave, one of the Age Better in Sheffield target wards and a deprived area of Sheffield).

Participants were almost all of white British ethnicity. People with BAME heritage are very much under-represented in residential care settings¹ so this is not unexpected.

Family members were mostly adult children of the residents, with a small number of intimate partners. Families had different circumstances with some living in Sheffield and some living further afield.

A high proportion of residents lived with dementia which was sometimes diagnosed and sometimes undiagnosed but present.

Key learning points

- Past history affects the quality of visits to care home residents: The
 phrase 'person' rather than 'loved one' or similar is used because
 through the work it was clear that for some families, relationships were
 very difficult and love might not be present or might be complex. For
 example, one family member disclosed that visiting was difficult
 because of abuse that had taken part in the past.
- Men (both family members and residents) were less likely to be interested in being involved in the programme and also less willing to complete paperwork or questionnaires: This may be partially explained by demographics (Enrichment for the Elderly suggests that approximately 70% of care home residents were women, and that men are more likely to move into a care home following a 'best interest' decision made by another person whereas women often enter voluntarily and earlier in life), but reducing the administrative burden may make it easier for men living in or visiting residential care settings to engage with projects aimed at reducing loneliness and isolation.

¹ Banks et al (2006) Changes in Communal Provision for Adult Social Care 1991-2001. York: Joseph Rowntree Foundation.

Initial engagement

Care homes were engaged via a citywide Care Home Managers' meeting. An open invitation was issued and four homes expressed interest. It is noted that all four care homes are likely to be examples of relatively forward thinking and proactive care homes.

Families became involved in the project through a range of routes. Some were identified and introduced by care home employees who recognised that a family would benefit from support to help them connect with their person; some saw posters or fliers and approached Enrichment for the Elderly; while others saw activities that were being carried out, or Enrichment for the Elderly staff present in the home and asked to become involved. Residents themselves also engaged with activities and told their relatives about them which also led to families becoming involved.

Key learning points

Paperwork is offputting: Administration was a barrier to engaging people in the project so the project engaged people first and introduced the paperwork further into the project.

Don't plan too far ahead: Plans and support packages were developed incrementally because residents were often towards the end of their lives and unfortunately the situation could change very quickly.

Delivery

Key learning points

The changes brought about by dementia can be difficult to deal with emotionally: Dementia affects people profoundly. Family members can find it difficult to know how to hold conversations or spend time with a relative with dementia, and visiting can be emotionally very difficult. Visitors can struggle with a resident cuddling a doll or not looking after their appearance – it can be hard to visit when their relative has changed a lot, for example if they don't respond to the visitor or behave aggressively.

"I do find it difficult sometimes, you never know what you are going to get. It can be upsetting."

(Andrea, family member)

For intimate partners, the relationship is changed fundamentally when one person enters residential care: This is particularly the case when this is due to dementia. Support around sexual relationships can be valuable to help

partners and care homes to understand how to support couples to maintain a sexual relationship, including when and how this is appropriate. Enrichment for the Elderly encouraged care homes to invite the partner in to discuss the issue which resulted in a more positive relationship and open dialogue.

For some relatives, time is genuinely the biggest challenge Many relatives live very busy lives, caring for children as well as parents, and working at the same time. It can be difficult to fit visiting in with everything else, especially for those who live further away from their person.

Family relationships are not always easy even before someone needs residential care: Care home staff should recognise that relationships often have complications that they are not aware of which can make visiting particularly challenging.

Different packages of support would be valuable at different points: During the first three months of someone living in a home, they and their family members are settling in to a new life and learning how to relate to each other in a very different environment. End of life is another key point when people would benefit from support: people often do not know how to talk about death and support could help people to have a closer relationship at the end which, can in turn, help with bereavement. After someone has died, people often feel rushed to clear their person's room.

Each care home and family is different and personalised approaches are important to allow people to engage.

Visitors to care homes have very different timetables, so care homes hoping to involve family members should hold activities at different times: Some (particularly older and retired visitors) visited frequently and at regular times, some visited less frequently (especially those who lived further away – a number of families in the most affluent areas lived outside of Sheffield and sometimes not in the country so visited less frequently but for more intense periods while they were available) and some lived locally but had unpredictable lives and often heavy demands from work and family which meant visits could be unpredictable. Younger relatives were more likely to visit in the evening, older relatives more likely to visit in the day.

Care homes or projects that are looking to involve family members should try to understand the culture of their communities: Broadly, the experience of this project was that visitors in the less affluent homes were more likely to engage in group activities and to see their role in visiting as being visiting their person and other residents – there was a more communal feel to social life in the home, whereas visitors to the more affluent home were more likely to visit their person and to visit them in their room and not engage with other residents.

A higher number of family members in the home with the most affluent demographic approached Enrichment for the Elderly, but they were then less likely to engage fully or get involved with activities: It is unclear why this was, but they benefited by receiving personalised action plans, and visit frequency increased for some visitors.

Care homes often have good intentions, but practically putting activities into place can be challenging: Lack of time or staffing levels and concerns over risk activities proposed by the project were often challenging for care homes but when these were managed they recognised the benefits.

"It's really difficult actually getting people out, arranging it all, paying for it but it makes such a difference for people to be able to get out and meet other people and just be in different surroundings."

(Jane, Activities Worker)

Care homes varied in their responses to introducing new ideas: Some homes were more rigid in their approach, for example being clear that their activity staff finished at 4p.m. and activities couldn't take place after, whereas others were more flexible and open to staff changing normal working hours to accommodate evening or weekend activities. Levels of risk aversion and approaches to Deprivation of Liberty Safeguards (DOLS) also varied between homes with some taking much more restrictive approaches than others.

Giving examples of how other homes addressed challenges could sometimes be helpful: There is some great practice taking place within care homes in Sheffield, for example techniques used in one home to make residents settle easily after an evening activity (giving them an evening drink and a biscuit, an activity that would more usually take place in their home than at a party) were used to encourage another home to try an evening activity.

The Sheffield Care Home Managers' meeting is a valuable way of sharing good practice and providing peer support and networking.

Usual practice is not evidence of demand: Sometimes care homes can presume that usual practice is evidence of what residents and their families actually want. For example, in some homes everybody is in bed at 6pm as there's nothing to do. This is then interpreted that that is what residents want – but if activities are offered in the evenings people enjoy them and appreciate being treated like an adult.

Collaborations with other organisations and charities can increase the range of activities available for residents and their families: Care homes often have tight profit margins and low budgets for activities for residents but there are charities and organisations that are keen to engage and provide activities within homes, for example Lost Chord which offers interactive musical entertainments.

Involving volunteers

There was little interest from participants in formal volunteering, but a number of family members carried out informal volunteering roles which benefited their person and other residents in the home, as well as care home employees. One family member cared for the garden at a home which allowed him to prolong the time spent visiting his person by giving him 'something to do' rather than just talking, which can become difficult. Another enjoyed taking their person out for walks and was encouraged to draw up maps of manageable walks from the home to be shared with other families.



"I do find it difficult sometimes, you never know what you're going to get. It can be upsetting. I have learnt to do reiki and haven't done it in a while but this afternoon was a great opportunity for me to do some for residents of the care homes you work with, staff and family. It's lovely to make a difference. So, when's the next one?"

(Andrea, Family member)

Exit and progression

Both shorter and longer term support have their benefits: As support was bespoke, some support was provided on an ongoing basis throughout the life of the project, whereas others had a defined period of support and an action plan to use at the end of the support period. It was felt that both approaches have their benefits depending on the family circumstances.

Men in particular may benefit from longer periods of support: Longer periods of support could help to build richer relationships and to build trust, with men in particular taking longer to develop a trust of the project and to fully engage.

Outcomes

Enrichment for the Elderly found it very difficult to work with family members and residents to complete evaluation paperwork, particularly due to residents of care homes lacking capacity, but a range of outcomes were observed by and reported to Enrichment for the Elderly or were reported in case studies and videos.

Family members

"Having a relative with dementia... you don't know what it's like until you've been there. The way you feel; you feel it's just you, but when you talk to someone else they say 'that's just the same as me... this is how I dealt with it...' It doesn't feel like I'm coming to see my mum now, it feels like we're all part of a big family."

(Anne, Family Member)

 Families who were in crisis or finding visits particularly hard benefited most: Enrichment for the Elderly felt that good outcomes were often obtained for people in crisis who were not visiting regularly or finding visits particularly difficult. For them it appeared to improve their relationships and visiting experiences. Some people at the other end of the scale, who already have good connection with their person through the project were able to use their own skills to upskill other people. However, the project struggled more to engage with people "in the middle" – people who are visiting their person regularly but just not getting much out of it.

- Some family members reported feeling more part of the family of the care home.
- Family members reported feeling like they are "coming to see the family" rather than just their person in the care home.
- Coming together for shared events meant that family members were able to develop a peer support network and some reported reduced isolation.
- Family members felt that they can visit their person and it will be a more enjoyable experience.
- Enrichment for the Elderly reported that people were more likely to use the resource trolley that is often available in care homes – more able to take part in doing something with their person.

Residents

- Some residents reported or were observed enjoying having something to share with others and a reason for their family to visit.
- The care homes involved started to host more creative and ambitious events and activities, often including outside organisations, such as music recitals as well as smaller scale activities: events co-ordinators normally only have capacity for small, cheap events – bingo, cards, etc.
- The project arranged for people to go to more outside events which they enjoyed.

Care homes

- Care home workers reported valuing the support provided by Enrichment for the Elderly.
- Enrichment for the Elderly felt that care homes became better at sharing and celebrating people's life events, i.e. birthdays and anniversaries, which had the effect of making people feel cared for. It can often initially feel for a care home that it's too much to do this, but those in the project found that it doesn't take much effort or cost to provide a birthday card and cake or some balloons or bunting (bunting especially can be reused) and makes for a much warmer environment.
- There was progress toward the perception of managing risk. In one home a relative took his dad and his dad's friend to an event this would never normally have happened. Many homes are reluctant to allow family members out with their resident, let alone someone else, but benefits can be huge. Enrichment for Elderly supported by carrying out a risk assessment for this. It helped that the home trusted Enrichment for the Elderly who were running the event.
- Providing supportive challenge to the care homes made a difference.
 For example, if there was resistance to holding an evening event,

- asking why not and then offering solutions sometimes changed decisions and behaviour. Sharing best practice from other homes can make it easier for less willing care homes to innovate.
- However, care homes are very busy and pushed for resources, and it can be hard to engage. Enrichment for the Elderly recognised that it was important to build positive and trusted relationships and to try to change things slowly. Being persistent and encouraging gradual change are key.

"Care homes can be critical of the visitor who only comes for half an hour but don't understand how hard it has been for them to come and see their relative so changed and not know how to talk to them. They don't always realise how difficult it is when one sibling visits regularly and their relative just asks when another less engaged sibling will come and says that the other sibling was always their favourite."

Grace, Enrichment for the Elderly

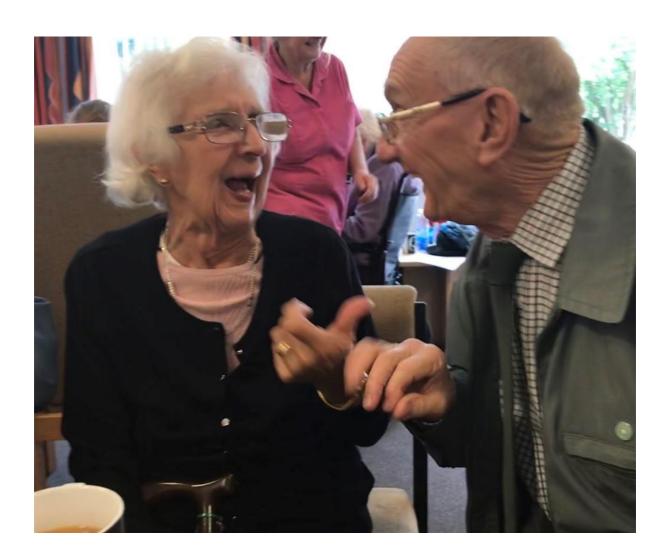
Conclusions

Although loneliness amongst people living in residential care is increasingly recognised as a problem, there is minimal support available for families of people living in residential care. Together demonstrated that there is demand for support for families of people in residential care, and that involving families in activities was appreciated by family members and by care homes.

Further recommendations

- Families would benefit from different interventions at different points in their journey: Support would be particularly valuable at points of transition:
 - when someone moves into permanent residential care (to reduce anxiety and build positive habits around visiting);
 - when someone is in intermediary care (to maintain links with the outside world); and
 - at the end of life (to support people to have a 'good death' and to help family members in their bereavement).

- Supporting the social and family lives of residents could benefit care homes as well as residents: There are a lot of negative perceptions about care homes and people often don't choose to live there, but good care homes can have benefits: they can be real benefit to people's social life and sometimes a care home is the best option for an individual and their family. We recommend that care homes should do more to support the social and family lives of their residents and their families, particularly those living with dementia, and to be clear in marketing material that this is a priority. Further advice is available in the information booklet for care homes, as well as an example of a handbook for family members.
- Age Better in Sheffield should further explore the ethics and practicalities of collecting evidence from people with dementia: Enrichment for the Elderly found it particularly difficult to engage with families and participants to collect data and evidence. This was particularly challenging for participants living with dementia. More work to explore the ethics and practicalities of collecting evidence from people living with dementia might make it easier to gain learning about the impact that Age Better in Sheffield has on these participants.



"I don't always know what to talk about or do when I visit. It was lovely to be pampered today and enjoy some time together. Then Brian came in, can you believe it! He lives at the sheltered housing the event was at, but used to live across the road from me! Small world. I wish you had been here sooner. It's been great to catch up and have a laugh together. This wouldn't have happened without the Together project, so thank you."

