

Read to Care

An Investigation into
Quality of Life Benefits
of Shared Reading Groups
for People Living with Dementia



Preface

By Melvyn Bragg

Dementia must be an ancient affliction. The consequences of aging have always been with us. But recently the quantity of those living longer has soared. Illnesses which once marked only the few are now common. The most insidious of these in my view is Dementia. Dementia lies in waiting at the end of a long life, like a malign reward.

Research into its causes and the searches for treatment are underway but were late in starting. Moreover, they deal with the most sensitive and still virtually unknowable part of the mind – that area in which memory, consciousness and imagination come together. Or, for those with Dementia, often fail to come together.

It was, then, in my view, something like a stroke of genius which set up The Reader Organisation. The notion that a shared reading experience could have a positive effect on those suffering Dementia must have seemed an unlikely longshot. It is proving to be a success. Softly, softly, judging from the casebook histories that I have read or heard about, but surely surely. Some profound chord has been struck.

Perhaps it is the power of poetry and of storytelling. We are told that the way to engage the attention of a child is to say ‘Once upon a time ...’ and then let the story unfold. It seems to link with our innate curiosity about life from ‘what is that?’ to ‘what is over the hill?’ It also tells us about who we are. The remarkable and unknown faculty of imagination allows a story to enter into us so that we live it. We are absorbed by the hero, the heroine, the villain and the narrative... And poetry, because of its rhythmic base, lulls into another world like the blowing of the wind or the crash of the waves on the shore.

I have read with admiration the examples of teachers who have patiently spent many sessions with the same group of four or five people.

And there is patience too in the group. So touchingly eager to find coherence, to join up the scattered essentials of their minds: to understand the world again.

There was one example which struck me forcefully. This was the feedback from a project worker who brought Wordsworth’s poem ‘Daffodils’ into her group. Over a period of 63

days/sessions, an hour or so at a time, and with much the same group, she describes in moving detail the influence of that poem. Reading aloud when others are there to listen, the sense of being in a unified community, has been the privilege of Poets for millennia. And it works. The words – common to all, unite minds and the shared stimulus appears to have an uplifting group effect. Eventually. At the moment we’re on the lower slopes and it is no wonder that time has to be taken.

But as those sessions went on people who barely grasped the poem began to know it and in one or two cases memorise it. The content – especially the ‘dancing’ of the daffodils triggered a rich range of comment. The poet himself emerged clearly from his work to some readers. The ‘inner eye’ an obstacle to many people, was hurdled effortlessly by a couple of readers. The development of this group is an inspirational story in itself; hesitant, uneven, tentative, wonderful. My own connection here is that in my novel *Grace and Mary* daffodils play a significant role. The novel is about two women, one of whom has Dementia. Her character is based on my mother who had Dementia for the last 5 years (90–95) of her life. I read to her. We talked about the deeper past; the 1940s which both of us could remember almost equally, rather than the preceding day which was always lost to her.

One day she recited the whole of ‘Daffodils’ – ‘We learned it at school’ she said. It was the National School which she left at 14. On other days we went daffodil hunting and her uninhibited delight in these golden dancing trumpets was heart-breaking but also quite marvellous in the intensity of her grasp on the moment. The world outside the mind’s confusion was being seen and acutely for what it was.

Singing, which used to be the way that Poets delivered their work, was something else we did together. I stumbled on its value when I discovered one day that she could remember more verses of Loch Lomond than I could. From then on we sang whenever we could. It seems to me that the melody that carries the words strikes an even deeper instinct in us than words alone. There’s a book called *The Singing Neanderthals* which traces speech back to the sound of singing.

But words have long been the way we now talk about the world to each other. Reading aloud, it has been proved by the Reader Organisation, is a key method of arresting and restoring that disintegration of the mind which is part of Alzheimers. For many people this will be a life saver.



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Introduction

The Reader Organisation (TRO)

is a Liverpool-based national charity and social enterprise that promotes the benefits of reading and engaging with literature for everyone, regardless of their circumstances. TRO has been delivering shared reading groups for people living with dementia since 2006 and there is a growing body of anecdotal evidence which shows how their shared reading programme has acted as a positive intervention in relation to the health and wellbeing of people living with dementia.

A recent evaluation of this programme supported by the Headley Trust, 'A Literature-Based Intervention for Older People Living with Dementia' (2012), showed marked improvements in agitation levels, mood levels and concentration levels for participants, as well as improved social interaction.

The Intervention

In the Shared Reading model, all reading material is read aloud in the session itself, and open-ended discussion is encouraged by the project worker. Group members participate voluntarily as they wish and interact in relation to what is happening in the text itself (in terms of themes, description, language) and what may be happening within themselves as individuals (in terms of reflections about personal experiences, feelings and thoughts). A trained project worker from TRO runs the sessions with a member of the care staff in attendance.

The four reading group leaders on the project are Katie Clark, Grace Farrington, Emma Gibbons and Charlotte Weber.

The basic structure of the Shared Reading model, used in libraries, prisons, GP drop-in centres etc, is sufficiently flexible to be adapted for different settings and for the needs of different client groups. The standard model involves a running time of an hour and a half, with short stories or whole novels being read aloud over a course of weeks or sometimes months, and with each session concluding with a poem to promote further reflection on the story read in the session. However, when reading with people living with dementia, the model is adapted in order to make the reading experience more easily accessible and meaningful, and to overcome obstacles common to people with dementia (such as poor concentration, loss of short-term memory, difficulty in following conversation and in communication, and confusion and disorientation). The following changes were made for this project:



Choice of Reading Material: Short Poems

Poems work particularly well in shared reading groups for people living with dementia, especially at the level of personal emotion and autobiographical memory. The language of poetry is often more compressed and immediately striking than that found in extended narrative prose, thus constituting what in neuropsychology is called an 'engram', a representation of a whole experience analogous to one's own, thereby encoding a memory trace. Rhyme and rhythm in the formal structures of the genre help to stimulate and maintain concentration. Poems can be reproduced on a single page, making it less likely that group members lose their place. People in the shared reading groups are often of the generation when poetry was learned by heart in schools, and it is often the case that group members with even the most severe levels of dementia are able to recite poems that they learned at school word-perfect.

Presentation of Reading Material

The project workers will generally read in a louder voice than they might usually deploy and also take more time in describing what has happened in the poem before moving on to discussion, in order to make the experience as live and as palpable to the group members present as possible. A copy of the poem is given to each participant: he or she may listen, or both listen and read, as preferred.

Conduct of Session

The project worker has to think very carefully about the use of questions to generate discussion, ensuring that there is no discomfort involved in any lack of immediate understanding. Questions which ask group members to draw on their memories are also handled with care. Although the literature read aloud and discussed often stimulates memories and encourages people to share personal experiences from their past, the reading intervention is not a reminiscence project. Group members are encouraged to enjoy the literature as an experience in the present moment as much as a medium for reflecting on past experiences, and the reading material selected therefore has to be able to stand alone as a moment in itself so that members are free to enjoy it however they choose.

Duration of Session

The sessions are shorter than the standard hour and a half and last no longer than an hour.

The Project

TRO was commissioned by NHS North West to undertake a follow-up study of the effects of shared reading in Care Homes, developing out of the report 'A Literature-Based Intervention for Older People Living with Dementia' commissioned by the Headley Trust (hereafter 'the Headley Report').

The primary aim of this project was further to investigate by both quantitative and qualitative methods the impact that engaging in a shared reading group activity (poetry group sessions) had on participants, involving

- Additional practical experimentation into, and further evaluation of, the mental processes involved in the shared reading activity, with particular relation to memory, emotion, awareness and individuation
- Use of case studies not just as verifying exemplification but for purposes of analysis and speculation for further research in what Rhiannon Corcoran (Professor of Psychology, University of Liverpool) describing the work of TRO calls 'psychology in action'
- Correlation of case studies with interviews of resident focus groups, staff, and (as recommended in the Headley Report) participants' relations
- Statistical analysis measuring not only the behavioural symptoms of dementia (as in the Headley Report) but (as that report recommended) quality of life, each month for six months
- Exploration of consideration of costs, cost-savings or consequences, and value for money in establishing shared reading groups in Care Homes

Four Care Homes on Wirral participated in the study. Two were randomly assigned to the reading-waiting group, two to the waiting-reading group:

- In the 'reading-waiting' groups the residents participated in poetry groups for three months and then were followed for a further three months after the intervention was over to identify if the impact of the reading group could be sustained once the activity had finished.
- In the 'waiting-reading' groups baseline measures were taken at commencement and then continued monthly for 3 months in order to identify any observable change from the start of the reading-group activity in month 4 and following.

	frequency	month 1	month 2	month 3	month 4	month 5	month 6
care home 1	weekly/3 times a week	N/A	waiting	waiting	reading	reading	reading
care home 2	daily	waiting	waiting	waiting	reading	reading	reading
care home 3	weekly	reading	reading	reading	waiting	waiting	waiting
care home 4	daily	reading	reading	reading	waiting	waiting	waiting

Table 1: Reading group allocation and study design

Care Home 1 was recruited a month later than the remaining care homes due to unforeseen circumstances. However, as participants were in the waiting condition, this meant that the baseline data for this care home was collected at month 1 and every month thereafter. Reading groups were started as timetabled above.

The 3-days-a-week group was created halfway through the project in order to make preliminary investigation into cost/benefit in comparison with weekly and daily groups. Further research is necessary here.

The Care Homes selected residents to attend the poetry groups quite carefully, generally choosing people with mild to moderate dementia who were not perceived as being ‘awkward’ or ‘difficult’. Residents with disruptive and/or violent tendencies were not felt to be suitable attenders, nor were people who might become worried, agitated or distressed in group situations. Those who would not sit down for a reasonable period of time were also not selected. Some people were chosen because they were known to have enjoyed reading (e.g. a former teacher), and others because they could still engage with other people and have an opinion. Ultimately, however, the decision to attend or not was made by the residents themselves.

Group sizes varied between about 6 and 10 participants, with some fluctuations over time. A Group with a core of about 6 to 7 regular attenders was generally perceived as working well. It was noted that the group dynamics altered as the participants changed. If the group was too large it was harder for the Project Worker to involve everyone in the discussion. However, in at least one Care Home, sessions were ‘open’, and people could come and go as they wished. Evaluation was carried out across 40 participants.

The TRO project workers were not made aware of any details of the condition of residents: people were treated according to the experience of the encounter, without prior knowledge. A care worker was to be in attendance throughout sessions to provide support, have experience of the project, and ensure welfare provision.

This report was compiled by CRILS. Dr Janine Carroll, University of Chester and Professor Peter Kinderman, Head of Institute of Psychology, Health and Society, University of Liverpool assembled statistical data and conducted interviews with staff, residents and relatives. The Liverpool Reviews and Implementation Group (LRiG) conducted further interviews with staff and carried out work in relation to evaluation of cost and value in consultation with TRO. Professor Philip Davis of CRILS conducted interviews with TRO project workers in relation to case-note diaries (also made available to Dr Carroll) and the formation of case studies.



Life Within the Care Home – Joan

Project worker G writes:

Joan came into the lounge as we were reading Robert Frost's 'A Time to Talk'. She commented on how long it has taken her to settle in to life in the home and to allow other people to see her and to get to know her. She had been a resident at the home for about a year by this point, but as the weeks went on it was evident that she would often stay out of the way in her room upstairs, and only came to the group occasionally.

That first time she talked of how she had realised that she had to make herself available in order for it to get any easier for her being in this communal environment. The poem by Robert Frost reads:

When a friend calls to me from the road
And slows his horse to a meaning walk,
I don't stand still and look around
On all the hills I haven't hoed,
And shout from where I am, What is it?
No, not as there is a time to talk.
I thrust my hoe in the mellow ground,
Blade-end up and five feet tall,
And plod: I go up to the stone wall
For a friendly visit.

The activities co-ordinator would often pass on copies of the poems that we read in the group to Joan, whose husband had a particular love of poetry, and paid regular visits, often taking Joan out for the day. On one occasion the activities co-ordinator suggested that I take the poems up to Joan's room myself, and read them with her. One of these was 'Thunderstorms' by William Henry Davies:

My mind has thunderstorms,
That brood for heavy hours:
Until they rain me words;
My thoughts are drooping flowers

And sulking, silent birds.
Yet come, dark thunderstorms,
And brood your heavy hours;
For when you rain me words,
My thoughts are dancing flowers
And joyful singing birds.

Joan commented that she didn't think much of this poem. In fact she quite often seemed inclined to be disappointed with the poems: her favourite, which she often referred back to, seemed to have been 'A Sunday Night at Home, 1946', a local poem that describes the scene as a family gather around the fire. However I did ask Joan if she ever felt that her mind has thunderstorms, as this poem puts it. She then gave a vivid description of how it feels to her when she tries to go downstairs into the main lounge, and the noise suddenly hits her as she enters that space. She repeated the same comment when the activities co-ordinator came back into the room to meet us. It was not exactly a complaint; it seemed rather to enable Joan momentarily to re-imagine her own situation.



Qualitative Analysis

1 Interviews: Staff Feedback

Interviews with key members of staff were conducted at the start and end of the intervention period. Questions were devised by the study team and were designed to cover the key areas that have previously been identified when running groups in other projects.

PRIOR TO INTERVENTION

The primary expectation of the reading group was that it would be simply a 'nice experience' for residents [staff member, CH2] who it was hoped would 'enjoy it as a reading group activity' [staff member, CH2]. After that, the most ambitious aspiration was that it might stimulate residents to 'take on board what is being spoken about and interact' [staff member, CH1]. One staff member reported that it did not matter 'whether it is the poetry or an organised event that is stimulating the residents' [staff member, CH2]: what counted was any effect of stimulation. Another concern of the group was that the activity 'practically fits in with the care home' [staff member, CH3] environment.

Individual staff identified more specific categories of generic benefit to be looked for, which the research team as used as an initially helpful structural model for evaluation:

1) Cognitive benefits for individuals

Staff hoped that the reading group would 'influence the residents' cognitive ability' [staff member, CH4] by 'bringing back memories' [staff member, CH2] and being 'stimulating' [staff member, CH2]. It was hoped that the groups would influence the 'residents' concentration' [staff member, CH1] by increasing the 'length of time until residents stop taking

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in the information' [staff member, CH1]. Other staff members wanted the residents to 'look forward to it' [staff member, CH4] and for people to 'enjoy it' [staff member, CH3].

2) Social benefits in being in a group

One staff member wanted to see how residents coped in a small group and whether the 'intimacy of a group' [staff member, CH1] could have a positive influence on the residents.

'To see how residents cope in a small group setting and what benefits the group can bring (e.g. friendships, improving learning capacity etc).' [staff member, CH1]

It was hoped that the reading group would help residents 'form relationships with each other' [staff member, CH2].

3) Staff benefits

It would be 'rewarding to see residents taking part in a group' [staff member, CH1]. The same staff member discussed how she thought it may help staff 'interact afterwards with residents about the group and what they've read' [staff member, CH1].

One staff member thought the activity would 'help junior staff as well as the residents' [staff member, CH4].

Key factors

The *environment* was reported to be an important factor in making the group successful. A 'good environment' [staff member, CH4] that was quiet and 'well set out' [staff member, CH1] was considered essential to the groups' success. 'If it is not quiet, it will cause distraction and affect the residents' concentration' [staff member, CH1].

Another factor was the *project worker* facilitating the groups:

'The project worker needs to have a good rapport with the residents and be introduced to them individually so that trust can be built' [staff member, CH1]

Staff felt that the project worker needed to 'use poems that allow them [the residents] to reminisce' [staff member, CH3] and to 'go at the residents' own speed and not force/ rush their speech and opinions' [staff member, CH1]. The project worker also needed to encourage residents to 'read aloud themselves in the group' [staff member, CH4].

However, staff acknowledged that although these skills were required in the project worker, staff themselves needed to be 'willing to bring the group together' [staff member, CH2] and to ensure the residents were 'on hand for the start' [staff member, CH1] of the group. For example, if the project worker ensured the 'content is relevant to residents' [staff member, CH3] then it was the role of the staff to 'encourage some of the residents to come to the poetry session' [staff member, CH2]. This reciprocal relationship was considered necessary to the success of the group; staff attending the group itself might also contribute to its success.

Challenges

There was concern as to the residents' behaviour due to the nature of their illness. It was acknowledged that residents could sometimes be 'challenging as they can be unaware of the boundaries' associated with group discussions [staff member, CH4], depending on the

Qualitative Analysis

severity of their dementia. Some staff felt that there would be ‘more challenges for the TRO project worker than for us’ [staff member, CH2] and that project workers would also have to be able to manage any ‘distress reactions’ [staff member, CH4]. However, staff being present in the group would help monitor this and support the project worker during the session.

Attendance at the group was another issue, being dependent on staff availability to help residents to the group as well as on residents’ desire to attend.

Group Membership

Staff ‘asked residents who haven’t done it before’ [staff member, CH3] and tried to get a ‘mixed bag of people’ [staff member, CH1]. One of the staff members reported that they selected people ‘by how far their dementia is and what their concentration span is like at the moment’ [staff member, CH1]. The concentration span of the resident was considered to be an important factor: those who ‘needed stimulation and need to be active’ [staff member, CH4] were often considered most suited for the group. Residents were always asked if they wanted to join the group and given the choice as to whether or not they attended the sessions. It was important to staff that ‘everybody should be given the opportunity’ [staff member, CH1] and allowed to take part if they wanted to.

AFTER THE INTERVENTION

Reports were highly positive:

‘The sessions were a godsend and we want more of them.’ (CH4)

‘The sessions were an eye-opener. I never thought poetry would work, but it did.’ (CH4)

1) Cognitive Benefits

First of all, it was an ‘interesting activity to do’ [staff member, CH3]. Equally, the experience seemed to make participants ‘relaxed and more content’ [staff member, CH2].

One staff member reflected on the comment made to her by a family member who said that the resident now ‘talks a lot more’ as a result of attending the reading group. Although it is not possible to be certain that this is indeed the case, the staff member reported that residents would ‘carry on a conversation that happened in the morning [in the reading group] in the afternoon’ [staff member, CH4].

The majority of staff members interviewed commented on how some residents were ‘reading out loud more’ [staff member, CH2] while others ‘kept some of the poems [which] have been mounted and put on their walls’ [staff member, CH4]. A possible reason why some residents increased their commitment to reading aloud was their attendance at a *daily* group.

CASE STUDY 2 (p. 18)

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Staff from one Care Home observed that residents who were usually very quiet and ‘can’t normally be understood or string a sentence together’ could get involved in the discussion and ‘even become quite chatty’. Staff also noticed that residents who normally only had short attention spans (of about 5–10 minutes maximum) would often remain engaged throughout an hour’s session. Thus, although the poetry sessions were initially perceived as being most appropriate and effective for residents with certain characteristics and behaviour patterns, in practice they could also be suitable for a wider range of people.

People with dementia need their senses stimulated, and it was felt that plain prose was not, and would not be, as effective as poetry. Staff commented that the residents liked the sounds and rhythms of the poems, some of which they seemed to remember from their schooldays. Songs and singing could have a similar effect on group attenders. A particular word or phrase in a poem (e.g. ‘jocund’ in Wordsworth’s ‘Daffodils’) often ‘triggered’ memories and discussions). Sessions could generate memories and reminiscences for those attending; staff in one Care Home commented that a session on the effect of wartime evacuation in childhood had been particularly successful in terms of displacement, change and countryside memories. It was suggested that Poetry Groups should complement rather replace other activities such as singing groups.

CASE STUDY 3 (p. 20)

One staff member reflected that the group ‘triggered different memories with different poems’ [staff member, CH1] suggesting that the variety of reading material was influential in generating different effects in the residents. Another staff member similarly reflected that the material used in the group by the project worker was good in making residents think differently about a poem.

‘[It] triggers them to think differently. Certain lines trigger them which then forms a discussion. The trigger is good’ [staff member, CH2]

CASE STUDY 4 (p. 21)

2) Social Benefits

Staff reflected that the activity was successful because people were ‘part of a group and had an enjoyable chat’ [staff member, CH4]. One of the major benefits staff perceived came from the reading groups was the interaction residents had with each other. When the groups were going to happen, one staff member commented that residents ‘ask each other if they are coming’ [staff member, CH1] to the group. Residents were perceived to ‘refer to it [the group]’ [staff member, CH2] and were ‘talking more and more in conversations’ [staff member, CH2]. Another benefit was the group itself, which ‘brought a laugh’ [staff member, CH1] and provided an empathic environment for the members. The small group size allowed people to have ‘their turn to speak’ [staff member, CH4].

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One manager, whose Care Home had separate units for male and female residents, said that the poetry groups provided an opportunity for men and women to meet and mix, whereas most other group activities in the Care Home were often only attended by female residents.

CASE STUDY 5 (p. 24)

3) Staff Benefits

The impact on the residents has also had a positive impact on the staff, with one staff member reporting that 'more confidence in the residents has influenced the staff-resident relationship' [staff member, CH2]. Staff were also perceived to be more willing to make sure residents attended the groups, with a staff member reflecting that 'staff not involved have got the residents up in time for the morning group' [staff member, CH1].

CASE STUDIES 3, 6 (pp.20, 25)

There were also unanticipated benefits and issues

4) Benefits to Relatives

Staff also reflected that the reading groups appeared to have a positive effect on the residents' relatives, with one suggesting that the group 'brought families closer together as it's a common denominator' [staff member, CH1]. Overall, being part of a study investigating dementia was perceived to be a positive experience for all those directly or indirectly involved.

CASE STUDY 7 (p. 32); RELATIVES' INTERVIEWS (p.28)

5) Influence on Other Residents

Staff reflected on the influence the group had on other residents who may not have attended the group sessions. The groups appeared to positively influence the residents' communication as it 'opened up different topics of conversation' [staff member, CH1] and there was 'more communication over lunch but it comes from the residents going to the group' [staff member, CH2]. The group itself seemed to have a 'positive impact on wider social relations' [staff member, CH1] and some residents who 'sit off from the group now attend' [staff member, CH4]. One staff member reflected that residents would 'come in and out from time to time or wander in and see it as a pleasant thing' [staff member, CH4] suggesting that residents who were not attending the group were interested in it as an activity and may have seen it as a 'chance to chat' [staff member, CH4].

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6) Weekly and daily comparison

The residents 'all enjoyed it' [staff member, CH3] and for those attending the group on a daily basis, the residents 'got into a routine that's now become common place' [staff member, CH4]. Staff reflected that 'some of the residents are more interactive' [staff member, CH1]. 'One resident will say it is the poetry group' [staff member, CH2] suggesting that the daily attendance at a reading group was having a re-enforced influence, including an increase in residents' own reading aloud.

One staff member suggested: 'because it's daily, they recalled words they probably knew already' [staff member, CH2].

However, it was not just the daily groups that found residents became more interactive with one staff member in the weekly group reporting that 'when I get the poetry cards out, Resident I will say that's just like the poetry lady' [staff member, CH3].



Key factors

The importance of the project worker

The fact that the project worker was external to the care home was seen as a positive factor in that it kept the residents interested in the poems being discussed.

‘They reader being the same person and external so the residents are not thinking of doing something else’ [staff member, CH2]

The personality of the project worker was seen as being crucial to the group interaction. The project worker needed to be able to engage the group members in contributing their thoughts and ideas to the discussion. One staff member suggested that ‘if there was no engagement [by project worker], then can’t captivate them so no point’ [staff member, CH1]. Furthermore, another commented that ‘because of the age of the residents, they did poetry at school so it is right for their generation’ [staff member, CH2]. But the same staff member reflected that sometimes at school ‘they had to learn poetry out of fear’ [staff member, CH2]. The project worker then had to be able to encourage the residents to offer their ideas without being afraid to do so.

Staff reported that through training and experience, the Reader Organisation was paramount in helping establish and run the groups: the project workers had expertise both in managing groups and in drawing personal experience out of carefully chosen poems. One staff member commented that it was ‘good to have an outsider coming in to do the activity as staff do not have the time or experience’ [staff member, CH3] while another said that the ‘approach is good. The Reader Organisation explained everything and met with the home beforehand. They were helpful and the literature I was given was just right’ [staff member, CH2].

Environment

The interviews suggested that the choice of venue should be made by the group. Some groups liked sitting on comfortable chairs in a lounge, whereas others chose to sit in the dining room, around a table, on which they could put their copies of the poems and their cups of tea/coffee (which they felt gave the sessions ‘a sense of occasion’). It was important that attenders could sit in close proximity so they could hear the Project Worker and each other.

One staff member commented that having a ‘cross-section of residents’ [staff member, CH4] was essential and it was important to ‘keep the groups small and log information so you can see if it is having an effect’ [staff member, CH4]. The length of time for each group session was seen as good as ‘an hour is long enough’ [staff member, CH3], however the same staff member reflected that ‘doing it in the morning would be good’ [staff member, CH3] rather than having the group run in the afternoon.

Challenges

Practical challenges included ‘making sure residents are taken to the group as some are not sure where it is’ [staff member, CH2] and ‘making sure staff knew who had to be got up’ [staff member, CH1] were two challenges faced by the staff members themselves. The challenges faced by the project worker included some ‘residents dominating the session through repetition of speech’ [staff member, CH4] and ‘distractions taking away from the poetry’ [staff member, CH4]. However, overall staff felt that there was no real negative impact of the groups and the challenges were more of a practical nature for the care home staff. Providing the timing and placement of the group activity was well-managed, the only potential barriers to attendance perceived by staff was if the resident was ill or had a hospital appointment scheduled for the time of the group. One staff member however reflected that for one resident who chose not to continue attending, ‘It was just the end of the run’. Other group members could also influence whether or not a resident chose to attend the group but overall, most residents attended the groups on a fairly regular basis.



Reading Aloud – Edith, Polly and Pat, the little, the lost and the shared

Project workers G and E from their case diaries:

Edith usually needed both permission and encouragement to read aloud, and it was important therefore that there was someone there to remember how good a reader she was. She had been in the group from the very first session. In week 2 she asked me, several times, ‘Will anyone listen?’ when I suggested that she read.

LITTLE THINGS

Edith found real delight in the poems and was sometimes able to remember that the poetry sessions had been taking place. It tended to take quite a significant shift for her to get into the poems each time though, and sometimes this state of heightened attention would not last longer than a couple of the poems, after which she tired and her speech became slower. It seemed to require an almost physical exertion for her to involve herself in the reading (breathing; sitting up in the chair; attending to the words on the page and following these with her eyes/finger) and she would take long pauses both in responding to questions and in the reading aloud. (When Edith’s daughters were present in the group, their presence helped to buoy her up so that her energy levels in those sessions were slightly different.) She slowly read aloud ‘The Great Lover’ by Rupert Brooke. The excerpt gives a list, in 18 lines of verse, of things that are included under the poet’s opening statement: ‘These I have loved’. The first four lines read:

White plates and cups, clean-gleaming,
Ringed with blue lines; and feathery, faery dust;
Wet roofs, beneath the lamp-light; the strong crust
Of friendly bread; and many-tasting food

Edith looked at me afterwards and said, again with a sort of delight: ‘You don’t realise that these ordinary things are actually *treasures*’. This speaks to the very specific individuality of what is recalled, its value in being recalled, and the ostensible smallness nonetheless being of large value when now retrieved and concentrated upon, often with delight.

* * *

Polly sometimes struggled to focus on the words on the page but would often comment on the difference that it made when she heard a poem read well. In the first week I noticed that Polly was mouthing the words whilst Doris, a confident reader, read out loud. Polly seemed to be able to follow the poem much more accurately as she listened to Doris’s voice; when Polly had read herself it had got more jumbled, with bits that she added in. On another occasion Polly responded to certain lines as others were reading the poems, and would comment in sudden little phrases: ‘Oh isn’t that lovely!’

Polly kept her eyes on me as I read through the poem ‘It was long ago’ by Eleanor Farjeon (a longish poem that continues over the page).

I’ll tell you, shall I, something I remember?
Something that still means a great deal to me.
It was long ago...

I asked her a question a bit later and she seemed slightly startled, as if she had been thinking. She then said: ‘Do you know what I think. When you’re young, why do you grow up?’ This felt like a very good question to be asking: perhaps somewhat in the spirit of a child, but from an adult’s perspective.

The losses in dementia are often like the gains in development when, in the child, they come and go because not yet firmly established as acquired skills.

Polly started to speak towards the end of the session of several childhood memories. She spoke of her father, who I had not heard her mention before. He had had a stroke when she was still only young, and Polly said that she couldn’t understand, as a child, why he couldn’t speak. She said there were times when she did not know where he was; she seemed to imply that it felt as if he was not there. The first poem that we had read in this session had been about a boy who cannot see: ‘I asked the little boy who cannot see / “And what is colour like?”’. ‘You read it as if it was true’, she said afterwards. I felt that some of Polly’s thoughts here had begun with this sense of trying to compensate for – or understand the effect of – a disability or absence.

* * *

SHARED THINGS

Pat exhibited more severe symptoms of dementia than the rest of her group. At first when she tried to read aloud, she would start reading from the bottom of the poem, or start again at some odd place, unable to follow line by line. By the second month of these daily groups, however, she could read aloud as normal from top to bottom. In this she was encouraged by Monica who could not read aloud on account of her chronic breathlessness, following a stroke. As Pat read Monica would finish off some of the lines along with her.

Poetry and Song

Project worker G writes from her notes:

One day, as an experiment in variation, I brought in several poems by the same writer, Emily Brontë, instead of bringing poems that were linked more thematically. The poem that we talked about most was ‘Love and Friendship’. It asks the question ‘which will bloom most constantly?’ and so we talked a bit about things that last or might even go on forever. There was a woman in the far corner of the room who was not reading with us and who has not been in the poetry groups before. But after I had read the poem a final time she suddenly started to sing, in a very loud voice, a verse of what sounded like a love song. I had not heard her make much of a sound before. The activities co-ordinator was quite taken aback and thought the poetry must have triggered something for her.

Triggering, Stimulating and Translating

One word characteristically used by both care staff and project workers to describe the immediacy of effect of the poetry was the verb ‘trigger’. What was triggered was often deeply, even hiddenly individual as well as specific.

Here is project worker K’s example, concerning Ivy:

We were reading war poetry and as I read John McCrae’s ‘In Flanders Fields’ Ivy shifted in her seat, and I could tell before I finished the poem that she wanted to speak.

We are the Dead. Short days ago
We lived, felt dawn, saw sunset glow,
Loved and were loved, and now we lie
In Flanders fields.

At the end I looked at her

If ye break faith with us who die
We shall not sleep, though poppies grow
In Flanders fields.

and she said, without any prompting, ‘That was lovely that, my Dad went away in the war and people used to say to him “But what about your family?” and he would say “Family are one thing but so are your mates”’. She was clearly very proud of her father and remembered him in great detail. Much of her memory of him seemed connected with the war in which he served, the idea of missing him, and revering him when he returned home.

One memory in particular, translated through the poetry, brought tears to her eyes as she shared it with the group:

‘I remember once I walked in on my Father as he was changing his shirt ready to go out with Mother. He shouted ‘Don’t come in, I’ll be down in a minute’, but it was too late, I had seen his side and there

was a great hole there. I ran down the stairs to Mother crying and said 'What happened to Dad? Did he fall down the stairs? And she said, 'No love, that is a war wound'. I remember I was so upset.'

Her emotion at recalling the story of the wound demonstrated why, even though it took place when she was very young, this was an event which shaped her and has stayed with her over the years. I asked her if she was okay, if she was happy to continue reading the poems and she replied 'Oh yes, I like them.' When we read next 'Now to be still and rest, while the heart remembers' by P.H.B. Lyon, she smiled and nodded and was keen to point out, 'We celebrate every year, we never forget.'

Reminiscence therapy often works by offering participants a material stimulus, frequently an object designed to keep spirits up. But I believe it is the *clarity* of the memories that spontaneously comes from the less material object called poetry which is unusual – giving something of the feeling of the original life, no matter whether it was a pleasant feeling (conventionally called 'positive') or a painful one (usually thought of as 'negative'). In poetry's version of 'lest we forget', so-called negative emotions of sadness are given expression in a way that does not allow simple dissociation of the positive emotions (e.g. of love) contained within them.

In another session we were reading Thomas Hood's poem 'I remember, I remember':

I remember, I remember,
The house where I was born,
The little window where the sun
Came peeping in at morn;
He never came a wink too soon,
Nor brought too long a day,
But now, I often wish the night
Had borne my breath away!

I remember, I remember,
The roses, red and white,
The vi'lets, and the lily-cups,
Those flowers made of light!

And a resident, John, suddenly said, 'They called it The Roses, and we drove them up with cameras to see it'. Often people come out with something abrupt, like that. Sometimes they seem to be looking for a very specific, tangible word or name, and when they do find it isn't always right, but it is descriptive and is like their version of poetry. Here it was 'The Red Roses' that John kept repeating. John's daughter was sitting in on the group and she realised it was, by rhyme, the Red Noses, rocks in New Brighton.

CONCLUSION

(i) Some care staff have recommended the use of pictures in these sessions. But it is not so much the visual that has an effect here as the *translation into* the visual in the mind of the participant: 'The roses, red and white', the colours and the rhymes lighting up the brain. Perhaps by working through linguistic pathways, visual memories seem to be triggered more powerfully – more deeply and more individualistically – by non-visual means. That route seems at once more personal and the translation more holistic. Something very *bright* is brought into the mind. That would be a hypothesis for future research, comparing the use of pictures in two media.

(ii) Future research might compare reminiscence therapy with shared group reading where arguably the latter, working via poetic language, is more personally surprising and complex in the transcendence of the distinction between simply positive and simply negative emotions.

(iii) Participants have felt stretched by the poetry, and project workers felt they had (cautiously) to take the risk of seeking extra concentration on the language of the poem, often through repeated re-readings, in order to help produce a beneficial emotional stimulus and challenge. One resident said, 'It is more than interesting. It gets inside your head and makes you think.' Another told me, again, 'It makes you think and brings pictures to your head.' The power of poetry is gently delivered and non-coercive but, as the residents say, it does *make you think*.



Reading Aloud, the Social and Synchronicity

Project worker G writes:

Ken came for the first session, and walked out towards the end, but the activities co-ordinator noted at the time that he had done well to stay that long. He was then in hospital and when he came back he did not come down out of his room for some time, apart from initially when he came into the group for a few minutes. He began to reappear about a month later, and in his first session back in the group, he read all of the poems out loud.

Ken has a beautifully slow, sonorous tone when reading aloud. He would often pick up a poem and begin reading as if to himself but in a still quietly audible voice. He sometimes did this regardless of whether the rest of the room was quiet or whether anyone was likely to be listening in to him, whereas other group members, particularly those who were hard of hearing, would tend to look around for an indication of when to begin. But Ken seemed to really feel the poetry as he read: giving emphasis to the turns and inflections of the verse, its lifts and falls, not only with his voice, but in his facial expressions too. I often felt quite captivated by his performance of it.

My impression had been that Ken is often quite isolated. He seems to find it difficult to apprehend what is said to him in the context of conversation, and often does not seem to know how to respond when asked a question. In week 7 however there was one session in which Martin was sat next to Ken, and I noted how well they were working together. Martin had commented after Ken's reading of one of the poems: 'spot on, that', and was sharing Ken's own enjoyment of particular bits of the poem as Ken read.

In week 11 we were reading some poems about birds. At one point both Ken and Dora ended up reading the poem aloud at the same time. But Dora, who is deaf in one ear, probably could not hear Ken reading. When Ken realised what was happening he carried on but brought his voice into time with Dora's reading. I found this attentiveness rather beautiful, particularly given that there were occasions when Ken would seem to get locked into reading the poems on a loop, moving from one to the next, which made it difficult to carry on any other discussion or reading within the group without appearing to ignore him.

Residents often read aloud together, even when they might not read separately, as a way of getting in touch with each other via the poem (see also [Case Study 2](#) above, 'Shared things').

Care staff, 'Something', Memory

Linguistic analysis of participants' comments recorded in project workers diaries reveals a significant, repeated use of 'something', to indicate an unnamed but felt presence.

Project worker C writes:

We were reading Wordsworth's classic and much-used poem 'Daffodils'. 'Did you like it, Joan?' asked the activities co-ordinator, to which Joan responded, very audibly – 'Yeah. There's *something* about it, I can't explain.' This felt like a moment of progress, even though or especially because it was about not being able to explain and also being able to say that. Poetry of course is good at creating that effect for any of us, whatever our supposed mental ability or disability: poetry is, as it were, content with making something become present though not fully explicable. After the group, the activities co-ordinator told me that she had never heard Joan able to string so many words together, let alone read aloud words from a page, and in the right order. Staff at the care home have since told me that Joan has a framed copy of 'The Daffodils' up on the wall in her room.

During the session Joan also responded well to the poem 'Your Dresses' by Carol Ann Duffy: I worked through each stanza, each separate 'dress', of the poem and picked out words or phrases with my finger, asking her questions as we went. She seemed to really enjoy looking at the words in this way, and responded either verbally by saying, 'Yes, very nice', or by gesturing as if she was trying on a dress in a window. Joan also began to pick parts of the poem to read on her own, and seemed to be trying to say something about it – that she did like it, but seemed frustrated that she couldn't wear the dresses, or get inside it in some way. At the end of the session we read 'Everything Touches' by Roger McGough, to which she listened intently with a big smile on her face. I could tell she liked the poem, but also that some of it made her quite emotional. She said 'I'm frightened' at one point, but when I asked her what of, she changed again and seemed to be smiling and happy, reading the last three stanzas of it aloud on her own. On our way out of the room the staff member who had been in the session commented to me, 'It is amazing – there is definitely *something* still there, and the poems really seem to bring it out.'

CONCLUSION

What seems important here is that though memory and awakened consciousness seem to come and go for people living with dementia, 'something' still remains behind as a fragile trace of the whole, for re-activation at another time (see stimulus 'triggering' [Case Study 4](#) above).

It may not matter as much as we may think, or relatives anxiously fear, that conscious awareness is not steadily retained over a duration – though relatives often feel that they have lost their beloved almost entirely to the extent that the resident has lost his or her memory. Nonetheless, what remains at stake in terms of what we call 'memory' on such small breakthrough occasions as these shown above is less the continued conscious retention of personal experience than the ability to access it again however fleetingly. It is as though at such moments the *person* is being re-called (in the sense of having a parent back for a while) as much as recalling. That fragile access and return restore faith, in carers and relatives, that 'something' is still there – the unique person, their life – albeit just for the present, as long as it lasts. That repeated present of partial recall, that temporarily revived benefit, is what is patiently to be valued, for what it is rather than for what it does not continue to be. This is arguably often easier for care staff to accept than close relatives, though, equally, relatives are much moved to find their loved person still there again.

The deep, long-lasting things in memory (including basic emotions of happiness, sadness, fear etc. vital in evolutionary terms for survival and fitness) are regarded by psychologists as the last things that go in the context of deterioration. The reading group intervention acts as an emotional linguistic stimulus for the temporary but recurrent recovery of such core autobiographical experience and identity in a person.



2

Interviews:

Relative Feedback

One of the new initiatives in this study was to obtain feedback from the close visitors or relatives of the residents – including those encouraged also to take part in the reading group. Responses fell into three categories: ‘little’, ‘some’, and ‘big’ difference.

1) One relative felt that there had been ‘*little difference*’ from how the resident usually was and what she was like after attending the reading group but this was attributed to the resident’s condition. Even though this particular resident did not ‘have ability to concentrate or understand’ [V1, CH2], the relative reported that engaging with the group did have an influence on other residents. ‘I have noticed several group members being involved verbally and others smiling and the group as a whole being calmer’ [V1, CH2]

2) Relatives who reported ‘*some difference*’ in their family’s residents, commented on:

Reading aloud.

One relative reported that the resident ‘likes actually reading aloud but does not remember much’ [V2, CH4]. On the other hand, some relatives commented that the poems seemed to bring memories relating to school experience to the forefront. ‘[The resident] talked about school and books such as ‘the Waterbaby’s book’ which was her favourite and she enjoyed at school, so it’s a good memory to bring to the front’ [R1, CH1]. Another reflected ‘how much she [the resident] enjoys reading and poetry . . . and [talked] about her reading at school’ [R2, CH1].

Behaviour, emotions and awareness.

Relatives were conscious of how much the residents enjoyed the group and they appreciated this as ‘anything that helps is great’ [R1, CH1]. The group also appeared to raise interest and alertness in some residents which was seen as a positive step.

‘[The resident] appears to be showing positive awareness of her visitors since the readings and for the first time in many months has used my name’ [R3, CH1]

This increased awareness was coupled with an increase in engagement with activities in general, and one relative commented on how the resident ‘carries a book on seeds and bulbs and she engages with this to talk about Grandad’s allotment’ [R2, CH1].

One relative commented how ‘[the resident] is very elated about how well she’s doing when we tell her how good she is’ [R2, CH1], while another reflected how ‘[the resident] has, post reading group, displayed more emotions and appears to be able to take in what is going on more readily. She laughs more often’ [R3, CH1].

Another relative, though doubtful as to the amount of information the resident retained, commented on how ‘he always participates’ [R1, CH4] and that ‘he spoke more than usual immediately after the poetry session [R1, CH4].

CASE STUDY 6 (p. 25)

3) Those relatives who felt that there was a *big difference* in the residents also focused in particular on:

The behaviour and awareness of the resident

One relative reflected that there was a marked increase in non-verbal behaviour. ‘[The resident] seems to be making eye contact more and is very animated’ [R2, CH4].

Furthermore, the same relative commented that the resident’s ‘whole demeanour was noticeable. She seemed content and not agitated’ [R2, CH4]. Alongside this, another relative reported that her family member was ‘more alert and had a greater awareness of conversation and what is going on around us’ [R3, CH4]. Overall, the increased awareness shown by these residents was observed by the relatives who found that they ‘seem uplifted’ [R3, CH4] and that in general, there was a ‘relaxing and calming atmosphere’ [R2, CH4]. A marked difference appeared to be manifested in the residents’ mannerisms, mood and general behaviour.

4) Four relatives were interviewed in more detail as they had actually *attended the group*. The purpose here was to identify their impressions of the group and the impact it had on them as well as on the residents.

CASE STUDY 7 (p. 32)

Communication

Communication applies at different levels. One relative reported that she ‘read to her [the resident] when she can’t communicate’ [R6, CH1], whilst another reported ‘that [the resident] was more vocal and could hear the poems and was responding to certain words’ [R4, CH1].

The ‘different subjects make them talk about themselves’ [R5, CH1] and the ‘different theme each week makes them [the residents] more vocal as it triggered off memories’ [R4, CH1]. The relatives noticed that while they were in the group, the residents were ‘all talking to each other’ [R4, CH1], and those residents who tended to walk around ‘usually started saying things that made more sense and noted that it was strange to sit and be quiet’ [R3, CH1].



Qualitative Analysis

Another relative reported, with pleasure:

‘[The reading group] stimulated her and there was more meaningful interaction which got her thinking about things’ [R5, CHI]

Group Community Environment

Being away from other residents was seen as a positive step in facilitating a good group discussion as it was nice to have some quiet time. This quiet atmosphere of the group helped establish a ‘shared common ground’ [R4, CHI] which limited interruptions. When thinking about the impact the reading group has on the resident, one relative liked the fact that the group had a ‘relaxed atmosphere bringing memories and conversation through the use of poetry’ [R6, CHI].

The social aspect of the group was felt to be generated by the project worker who had to be able to ‘get people engaged’ [R4, CHI]. Furthermore, the project worker had to be able to put the residents at ease to ensure they were ‘not intimidated. Not embarrassed if they [the residents] don’t remember’ [R6, CHI].

Benefit to Relatives themselves

The groups helped relatives to communicate better with their resident and retain the relationship. When asked to give any other comments they felt were important in terms of the reading groups, the relatives reported it had had an impact on them as well as on the residents. Relatives who were participants felt the groups supported them by enabling them to meet other people from other families also going through similar experiences to themselves, offering a support network. One relative reflected how she felt it was good for family members to attend as it gave them something to look forward to and something to discuss with the relative.

‘Good for family. Sometimes they come but don’t know what to say so it is an excuse for relatives to join in’ [R4, CHI].

Another relative reported that it has ‘done me good... makes me feel a bit more normal’ [R3, CHI]. The support of other relatives who attended the group contributed to her enthusiasm for the activity and her sense of it as a valuable activity in bringing people together.

CASE STUDY 8 (p. 34)

Relatives felt that for moments they had loved ones back. In order to appreciate this even its short duration, it is necessary to alter expectations and perceptions as to both what is possible and what still to be valued (perhaps all the more), in the experience of dementia.

Relatives' Role

Project worker K encouraged the presence of relatives in the reading groups, considering it more natural that they should be participants rather than merely observers. Here a daughter accompanies Cathy to the group.

We read E. E. Cummings' 'Maggie and Milly and Molly and May':

maggie and milly and molly and may
went down to the beach (to play one day)

and maggie discovered a shell that sang
so sweetly she couldn't remember her troubles, and

milly befriended a stranded star
whose rays five languid fingers were;

and molly was chased by a horrible thing
which raced sideways while blowing bubbles: and

may came home with a smooth round stone
as small as a world and as large as alone.

For whatever we lose (like a you or a me)
it's always ourselves we find in the sea

After the third of the short stanzas Cathy very quietly said the single word 'Bathroom'. We thought she must want the lavatory. But her daughter said, "Millie befriended a stranded star/whose rays five languid fingers are". . . I remember that in our bathroom at home Mum had a collection of shells and a starfish mounted on the wall.' If her daughter had not been present, I could not have taken anything from Cathy's contribution because I did not have this shared history and mental image of the starfish mounted on the wall. It would have sounded like nonsense, a word plucked from random. But that one word 'bathroom', as compressed as any language of poetry, contained in it a history

not otherwise to be unfolded. As Cathy's daughter said to me, 'That wouldn't mean anything to anyone else, but I knew what she was thinking about'. As a consequence, she was able to interpret for her mother the real memory behind the word, the connection made between the poem and Cathy's own home and life, as though the daughter were a mental part of Cathy herself now for whom the mother herself seemed grateful. 'Whatever we lose . . .'

In later sessions Cathy seemed much more lively as we read the poems, often smiling and participating by nodding in response to comments from group members, or laughing. Once we read the poem 'The Evacuee' which reminded Cathy's daughter of the film 'Goodnight Mr Tom' and her own father who looked like the actor. She shared a story about him and Cathy laughed and nodded. It was a lovely moment between the two of them. The sessions seemed increasingly to succeed in rousing Cathy from sleepiness and her daughter told me, 'Mum is much more engaged when reading the poems. She is more talkative and she seems to remember names afterwards. The other day she remembered my partner's name and spoke his name herself for the first time in months after a session.'

CONCLUSION

This is a significant indicator of what may remain trapped hidden within residents through linguistic breakdown even after the stimulus has unlocked personal memory. The close relative in this case acts interpretatively as an extended mind and voice for the person living with dementia, for which the resident herself seemed grateful in a renewal of the link between mother and daughter.

Relatives' Participation – Further examples

Project worker G wrote of Herbert:

Herbert, who attended seven of the sessions, tended to feel that he wasn't any good at reading, and unfortunately this feeling sometimes seemed to be reinforced during his wife's visits, as she wanted him to do well in front of the group and would get frustrated with his quiet, stumbling voice

Also of Jane at a very advanced stage of dementia:

Though Jane did not have the capacity ongoingly for coherent speech, she would make verbal sounds which were akin to speech in response to stimulation. I think for this reason the activities co-ordinator had been keen to include her on the list of members of the group. On one occasion, at the end of a visit and just before the group, her daughter asked if I had some spare copies of poems that she could read on her own to her mother, so the following week I provided her with a copy of all the poems we had been reading in the group thus far, as the only way I had of helping or including her.

Projector worker K on Iris:

One week when I turned up, Iris was struggling with her throat and finding it difficult to read aloud, but she still made an effort at reading all the poems herself. Her two daughters had begun coming along to the sessions with her. This week we were reading poems about music. We read 'A Lost Chord' by Adelaide Anne Proctor:

Seated one day at the Organ,
I was weary and ill at ease,
And my fingers wandered idly
Over the noisy keys.

Iris had been sitting at the table over an untouched plate of lunch. She was quiet and seemed more unresponsive than usual. But after reading this she began talking quietly about an accordion and told me, 'I was so good that I got a review the following week and everyone started clapping as I played.' I couldn't understand exactly what she was telling me., but then her daughters told us that she had been an accomplished accordion player and had performed at The Floral Pavillion. They laughed and joked with her as she recalled how well received her performance had been. It was lovely to see Ivy smiling and enjoying the words of the poems despite feeling unwell.

But I struck one chord of music,
Like the sound of a great Amen.
It flooded the crimson twilight
Like the close of an angel's Psalm,
And it lay on my fevered spirit
With a touch of infinite calm.

She liked the idea of a chord of music changing your mood, 'lifting you' as she put it.

Project Worker K On Carolyn:

Carolyn cannot speak but her eyes move, When we were reading Thomas Hood's 'I remember', her daughter Pauline was telling us about the family living in South Africa, and her mother's eyes lit up. Relatives act as interpreters not only for the project worker leading the group but as mouthpieces or extended minds for the person herself. Pauline still comes in now to the group after Carolyn has died.

CONCLUSION

There is a case for creating a training programme for sympathetic relatives to be the volunteer deliverers of reading groups in order to sustain the intervention nationally without prohibitive cost. Relatives may remain committed to such a project not only after but because of the death of their loved one. The case of Herbert indicates one aspect of the need for caution here where the presence of relatives may act as an inhibition, and it may be that they would be of best service working with groups that did not contain their own relations.



Qualitative Analysis

3

Interviews:

Resident Feedback

Focus groups with some of the residents who participated in the reading group revealed interesting insights into the activity. There were no differences between residents who had participated in a daily group and residents who had participated in a weekly group in terms of their sense of the nature of the benefits they felt the reading group gave them.

Enjoyment

Overall, residents reported enjoying the group which as described by one participant as 'lovely' [R2, CH4].

Some of the residents kept the poems that were discussed in their groups and they felt that the reader 'gave us loads' [R1, CH4].

One participant reflected that even though 'I can't see very well, I like to listen' [R1, CH1] showing how residents did not necessarily feel the need to read the poems while the project worker was reading but would still actively listen to what was being said.

This was re-iterated when residents were asked if they thought it mattered if a poem was difficult to understand. One resident said that it was good to 'recite it back' [R1, CH3] while another said they had 'no difficulty so far' [R2, CH1]. Overall, residents felt that not understanding a poem was acceptable and did not prevent them from listening. 'Sometimes I don't understand things but it's ok' [R1, CH2].

Participants all reported enjoying the groups and were positive in their attitude towards the activity.

Overall, residents felt that the reading group made them feel good and 'relaxed' [R1, CH1].

Memory, Emotion and Imagination

Across all four care homes, residents agreed that the poems helped them to remember things from the past. One mentioned that it was 'good to remember' [R3, CH1] while another reflected 'I could remember poems about flowers' [R2, CH4]. Furthermore, one resident said how she 'did it at school' [R2, CH1] suggesting that memories relating to poetry in school were being recalled. Generally, residents thought the number of poems brought by the project worker 'were enough' [R1, CH4] and that the variety made one resident feel like she was going 'round the world' [R1,

Qualitative Analysis

CH4]. Another resident who attended a daily group reported that she had ‘been inspired to write’ [R3, CH4] while another reported on ‘never having read so many poems before’ [R2, CH4].

CASE STUDY 9 (p 40)

The Project Worker

The residents liked the fact that the project worker was not someone who worked in the care home. One resident said that it was ‘good when [the project worker] speaks to us individually’ [R2, CH4]. The majority of residents thought the project worker for their groups was ‘very good’ [R1, CH1] and reported that it was ‘good to see someone new’ [R3, CH4]. The main positive point raised by the residents was the ability of the project worker to include everyone in the discussion and not exclude anybody. ‘[The project worker] seems happy doing it and don’t leave anyone out’ [R1, CH4]

CASE STUDY 10 (p 43)

Duration and Regularity

When asked about whether they would like the group to be shorter or longer in duration and more or less often, mixed reports were obtained from the residents. Some wanted the groups to be ‘more often’ [R1, CH1] yet another resident in the same care home felt that having a daily group would be ‘too strong’, ‘every third week’ would be sufficient [R2, CH1]. In another care home that had the group on a daily basis, one resident wanted it to ‘carry on [and have] longer ones with more questions’ [R4, CH4].

Communication and Community

One resident reflected that ‘it’s about communication’ [R1, CH2]. Most reflected that the reading group ‘gives [the conversation] context’ [R1, CH2] while some reported it helped their focus that they could ‘relate to [the poems]’ [R2, CH4].

CASE STUDY 11 (p. 45)

Another resident reflected that the activity was good though ‘not so keen on a group, but it depends on the size’ [R2, CH1]. The reading groups appeared to provide the residents with the feeling of being part of a community from which they benefited. ‘It was a laugh and a community’ [R3, CH1].

Qualitative Analysis

Observations from Commission for Social Care Inspection visit

One Care Home (4) had had its annual Commission for Social Care Inspection (CSCI), an unannounced inspection, at the same time as one of the (there daily) reading sessions was being held: it was largely successful. The Professional Visitor, an ‘expert-by-experience’ who lived with his wife in a Care Home in Cheshire, attended one of the sessions and was so ‘spellbound’ that he was keen to share the idea and for the reading groups to be introduced at the Care Home where he lived. The final report specifically reflected the contribution of the reading group, the only activity on the day of inspection, in mitigation of some deficiencies in care, treatment and support in other areas of provision and overall deemed minor: ‘We observed an activity with some of the people who were attending a poetry class and we found that people enjoyed this.’



Residents, Memories and emotions

Project worker G writes of the difficulties of making connections via conversation, and the problems of isolation. At the same times she notes the deep need for human connection. Reading aloud gives the residents something to which to connect.

'I was keen to let individuals know I was listening to their reading aloud of the poem in order to make that first link, whatever it was – between me and the resident, the resident and the poem, one resident and another. The signs of shared enjoyment seem emotionally more important to me at times than what actually gets said.'

Most of the instances in my account point to one particular poem that a person has been reading. I tended to bring three or four poems each time. Sometimes at the end we would ask people which had been their favourite. This was partly a question of rounding off the session. But it was also about wanting to be able to leave the residents with something, and to see if some connection had been made.'

MARTIN

To begin with Martin had not stayed with the poems for very long at all, and would fold up the piece of paper and put it in his pocket after the poem had been read out for the first time. A breakthrough came when Martin was clearly moved by a poem by Elizabeth Barrett Browning, 'Beloved thou hast brought me many flowers', commenting on how much 'substance' it had. He then went through and read over several parts of it again. The staff member present commented afterwards that at this point 'Something really struck a nerve'. Martin wiped away a tear as he spoke further about the poem. It was not always clear where this emotion was coming from or what it related to. There was also a poem 'Walking Away' by Cecil Day-Lewis in our session on evacuation: Martin kept repeating the lines on the child, 'That hesitant figure eddying away/Like a winged seed loosened from its parent stem', and continued, 'That was me.'

HEATHER

I first became aware of Heather as we were reading 'Outside the Baker's' by Heather Farish. She was sat to the left and slightly behind me (I had to slot in my stool wherever I could be seen by most people). She started reading the poem, but on reaching the fourth little stanza she made a loud outburst or cry: it is difficult to describe because it sounded as though she was getting upset, but I also thought at the time she was actually reacting to what she found to be an unexpected comfort in the poem:

She thinks how for every thousand
there is one like this:
Your turn at the head of the queue

I was slightly concerned about Heather after this, as she carried on talking quietly to herself throughout the rest of the session. Something had obviously been sparked, but I didn't know if this was actually helpful to her. In the following session I had brought a poem by Christina Rossetti (beginning 'We met, hand to hand'). It is a poem which is about both a meeting and a parting, but it also closes with the suggestion of a future meeting. Heather quickly became upset however during the second stanza ('We loosed hand from hand, / We parted face from face') which she said reminded her of her son. She clearly needed consoling at this point and when the activities co-ordinator moved to sit next to her, Heather spoke of how alone she felt.

The activities co-ordinator told me after a subsequent session that Heather had said that the poems upset her, and so staff thought it best to leave off giving the poems to her. I also noticed that in the following weeks Heather looked quite different, as if she had been treated with a sedative or tranquilliser, or with treatment accompanied by such effects.

There were two further sessions in which Heather participated, wholly unexpectedly. The first was on Remembrance Day; I had brought a few war-themed poems but had tried to find writing which was not directly dealing with the damaging effects of war. During the session Heather had been looking around to see who was speaking (she was also quite deaf). Towards the end she suddenly started reading out the last poem that we had read, 'The Evacuee' by R. S. Thomas. She had a strong voice (and a lovely thick Scottish accent) and read to the end of the poem. Her reading surprised both The staff member and I. She did the same in another session, reading the final poem ('The Single Mind' by Sybil Birch) in the same manner.

BETTY

Betty said initially that poetry did not interest her much. I sat next to her a few times to read a poem with her individually. She was willing for me to try this out with her, but still did not find it particularly engaging. A couple of weeks on we read 'Things men have made' by D. H. Lawrence:

Things men have made with wakened hands, and put soft life into
are awake through years with transferred touch, and go on glowing
for long years.
And for this reason, some old things are lovely
warm still with the life of forgotten men who made them.

Betty laughed in the midst of reading this, as she came to the phrase ‘old things are lovely’. She looked around the room as if addressing everyone at this point. When she had finished reading I asked her about this. ‘We need to underline that bit,’ she said.

During the Remembrance Day session I again went over to sit by Betty. The lounge was quite a large space, and if there were people interspersed through the room who were asleep or not participating it became difficult to gather the others together as a group. Betty was thoughtful in response to the Robert Frost poem ‘Not to Keep’, about a soldier who returns home injured, but not sufficiently to be spared going back to the front. Betty commented that her grandmother had lost two sons in the war: ‘They went away and never came back. I sometimes wish I’d asked her more about it. I was only a teenager at the time – 12 or so.’ Betty then looked again at the lines of the poem and said: ‘She must have felt a lot’. I was quite struck by how Betty was using the poem here to think about someone who was not herself, but also by the way in which she was now doing the imaginative thinking that she had been unable to do at a younger age.

CONCLUSION

As in Case Study 4, what is important is being able to site group participants in a place of emotion and memory created by the poem, whatever the feelings are. These spontaneous responses have to do with what the project worker does not know and cannot control for. It seems right, though, that we cannot know the full meaning of what is happening as it happens; there is respect in that for what remains properly mysterious, deeply private, and personally human. People were allowed to drop in and out of the group and, similarly, within the group itself there were unpredictable individual moments of switching on and off. The effect was not simply progressive as we might prefer to think. The switching on could happen at any stage, as the language of particular poems or phrases triggered something at different times for different people. This is related to a similar conclusion about fleeting memory in Case Study 6: it is the moments of visible and precious life that matter, not how much we know about what is going on within them or how long they last and remain conscious.

The Project Worker

As project worker C reports,

It was not just about memories, but about being present and helping to make the people present to themselves. If we look too generally at a poem, it turns into a theme or a cliché and is a re-telling of old stories. We did not want to under-rate the capacity of the residents to respond to the sheer force of the words by reading less carefully than we would be groups in other settings. We tried to reach for new things by focusing on the language and going deeper down.

Project worker G also compared her sense of the role of the facilitator with the interventions offered by an enthusiastic care worker who attended the group:

There was a particular kind of conversation which the staff meaning, with the best of intentions, would try to instigate on the back of the poems, by asking such questions as ‘do you think anyone has a problem-free life?’ etc. I remember the staff member posing it as a general question, addressing the group, and then asking people individually what they thought. It was an attempt to get a sort of consensus, a group feeling. Although this might prompt people to say something, or to express an opinion, the conversation in such instances was not based on a real sense of emotional connection. These questions were different from those which a TRO project worker asks in groups (particularly older people’s groups) to get conversation going: ‘Do you remember such or such, or do you like this bit . . .?’ I think actually the questions came from the staff member’s very decent attempt to share a thought or to make a point from her own life-experience. But the sense of real connection seemed lacking because, though meaningful and well-intentioned, it was also generalised, and it seemed difficult for people to give much of an answer beyond agreeing or disagreeing.

On the other hand this same staff member also told some anecdotes that struck me as being useful in the context of talking about the poem. For example, after we had read ‘I asked the little boy who cannot see’ the staff member recounted a couple of quite poignant memories, firstly of a blind person with whom she had worked in a previous job, and secondly of a blind neighbour whom she had played a joke on as a child. After the first of these anecdotes, she had said that you cannot discount a person even if it appears that they cannot do

something. You have to go the extra mile to see what that person can achieve with your help. The session carried on. What I thought was interesting was that after the last poem ('A slash of Blue', Emily Dickinson), the staff member said 'if you close your eyes and imagine the sky, that's what it would look like isn't it'. I thought this was a great comment of hers. It went beyond the point-making, the more moralistic thinking, but it also seemed to use those earlier thoughts which the conversation about blindness had facilitated.

When I say moralistic – I am also thinking of a couple of other occasions when the staff member talked about a homeless man to whom she had given money in exchange for a painting but later found that she had been deceived by his account of himself. Again I felt that when a story like this is told, a certain response is expected afterwards, and such expectation, though understandable, is not right for this context.

These are issues to do with the need for further training in what is necessarily a skilled function.



Poetry offering a compressed hold on/ focus for minute attention

Project worker G notes:

Dora did seem to like a little poem that I had brought in by a contemporary poet, Raymond A. Foss. It is called 'Skipping to School':

Little hands holding mine
 skipping to school.
 All three of us
 Matching strides,
 and the all-important
 swinging of the arms
 down the sidewalk,
 downhill, skipping to school

We read the poem several times and several people, including the activities co-ordinator, spoke of the different kinds of memories that it evoked. Dora commented that it was amazing how the poem can bring back so many memories, in so few words. She then counted the number of words in the poem to prove her point

4

Interviews:

Project
Worker
Feedback

Apart from providing further information from the fourth party involved in the process, these interviews with the 4 TRO project workers, conducted by CRILS (Centre for Research into Reading, Literature and Society, University of Liverpool), contributed towards:

- (i) reflection on the case studies derived from diary notes, with a view to diagnosing the intellectual or policy implications of the narrative accounts
- (ii) recommendations for future research
- (iii) consideration of further practical experiments within group work

EXPERIMENTS

1. On Breakthroughs

Project worker E has extensive experience of delivering weekly groups in the care homes but in this project was involved in daily provision. She was clear as to the benefit of the increase in regularity – ‘People begin to behave as human beings to each other rather than residents passively institutionalised in a care home’ – but was concerned that many ‘results’ may never be recorded, for being apparently small and/or transiently ‘in the moment’.

One solution in future would be the live recording of groups, given ethical and individual approval.

But she also proposed that project workers should note the number of breakthrough moments in any one session by making an unobtrusive stroke of the pen at the point of occurrence. Breakthroughs would be previously defined and agreed as including in terms of behaviour: residents beginning to be willing and able to read aloud; paying more attention and offering more recognition to the poem, the project worker and/or each other; showing new interest and animation through body and/or verbal language. Project workers would then note the number of such occurrences in a session and as a result be able to quantify any perceived development over the course of the project.

Her own retrospective working estimate, resulting from consultation of notes made after each session and offered as a thought-experiment and hypothesis/guide for future testing, was as follows, across 60 daily sessions, marking crucial transition points in development:

At session 1: 1 breakthrough per session (first ten minutes of session often lost in preliminary attempts at organising attention, as often happens at beginning of weekly groups even after several previous sessions)

By session 25: 3 breakthroughs per session (half-way stage of increasing ease, in terms of group familiarity and increased practice in reading)

By session 45: 5 breakthroughs per session (developed stage of achieved community spirit and collaboration)

Obviously such findings would have to be cross-checked for impartiality etc against other evidence derived by other methods.

2. On Repetition: Triggers, Memory and the New

Project worker C took advantage of the regularity of the daily sessions to improvise and experiment in delivery of content. She decided to repeat the same poem from time to time, across different sessions.

What she found, remarkably, was that regardless of whether residents seemed to remember and recognise the poem or not (from previous sessions or from memories of school), they kept coming up with different thoughts at different times, new thoughts, new places in the poem, or different formulations of old thoughts, rather than merely repeat a default response.

This is her account:

In the early weeks of the reading groups at Care Home 4 I had been trying to avoid repetition of poems in sessions, partly out of a desire to create new conversations with residents by using new material, and partly in order to keep myself fresh. However, by around the half-way mark in the delivery I had noticed that we were getting through fewer poems in the sessions but having more conversation around them, despite the average group size now being smaller than at the start. I had also had a conversation with a colleague at The Reader Organisation about the benefits of using one to two poems in a session, rather than the 5–7 that can be standard practice in reading groups in such settings. I decided that I would consciously start trying to do this with the group.

I decided to begin the ‘experiment’ by bringing two poems that I had used previously in the group, and in other dementia care groups I have run, and which I knew had prompted good conversations and a great deal of enjoyment for residents. The two poems, sometimes taught and learnt at school, were ‘The lake Isle of Innisfree’ by W.B. Yeats, and ‘The Daffodils’ by William Wordsworth, and increasingly my focus was upon the Wordsworth. I think this was the right thing to try: resident K for example, in one session where I had brought new poems to read, commented that he felt confused because ‘it feels like we just get started on this one, about the flowers, and then we’re on to a different thing!’ He clearly felt that there was still much thinking and working out to be done around ‘The Daffodils’, even though by this point we were in the final few weeks of the reading group and had read the poem a number of times. The repeated slow readings did not actually result in repetitive discussion or in slow mental responses to which one might condescend.

Day 1

I started my very first session with ‘Daffodils’ because on previous occasions I had used the poem successfully in a dementia care home where I ran a weekly group. As I hoped, the poem did go down well in the new group, with several of the residents telling me that they recognised the poem. However, as was the case in most of the sessions in the first week of delivery, we did not really get ‘into’ the poem. We did not read the poem again until I decided to repeat it in session 35 (week 7).

Day 35

I wanted to get conversation concentrated a bit more tightly around the poem and its language. I told the group that I loved the descriptions of the daffodils ‘dancing’ in the poem – that it made me happy, but I wasn’t sure why. I pointed out that the word ‘dancing’ was repeated in each stanza of the poem, and asked what they thought about it. In response, J came out with a lovely description of how if you were standing in a field watching daffodils moving in the wind, they wouldn’t all go the same way – ‘some of them would be going this way, some that – so it would be like they were dancing’. M agreed with J and for a few seconds, we were all swaying in our seats as we thought about the motion of the flowers.

Day 37

I used the poem for a second time this week. M recognised it and the other members, though not explicitly making it clear to me whether they recognised the poem or not from day 35, were all smiling during the first reading of it, and clearly enjoyed it. K was initially very quiet in the discussions following readings, though he would continually look back down at the words on the page and seemed to be mouthing some of the lines to himself. After a second or third reading I directly asked him if he liked the poem, to encourage him to vocalise his response. He responded positively and I asked him if there was anything in particular he liked in it: ‘I just like the whole thing, the daffodils’. He then went on, however, to express that he felt the daffodils had their own particular character in the poem, saying ‘they’re funny, aren’t they. Dancing around. They’re like people.’ After some initial discussions about daffodils, the beauty of some of the descriptions, and several more readings of the poem aloud, it felt like we were able to go ‘deep’ into this poem for the first time. In using the poem previously in the group, I had tried to initiate a discussion around a part of the poem which I find very interesting, by asking group members to help me work them out – the lines come at the end of the poem, where the poet is back at home lying on his couch, and remembering the visions of the daffodils:

They flash upon that inward eye
Which is the bliss of solitude.

In both previous attempts, however, none of the residents was able, or willing, to volunteer a response to this line, and conversations moved on to more general topics. This time however, when I asked, ‘What do you think the *inward eye* is?’ M immediately said, ‘It’s imagination!’ I can’t say exactly what might have triggered this breakthrough, other than the general feeling the poem had created in the group that day, which was one of excitement, energetic conversation, and genuine exploration. It might have been the momentum of the previous conversations which enabled M to suddenly verbalise a thought which she may have already had about the lines. Following this, we had a good conversation about how imagination helps us to see things that aren’t necessarily there, or obvious.

It was towards the end of the session, however, that what felt like the biggest breakthrough that day took place. It was concerning J, a fairly regular attendee of the group, who was also by far the most advanced in terms of her dementia. J’s symptoms presented themselves in an inability to form coherent sentences, or often to even pronounce coherent words. Mainly, J’s communication came in the form of exaggerated facial expressions and other expressions such as blowing her tongue, waving her hands, and, as it were, babbling. During this session, the activities coordinator at the home was sitting next to J, and sharing her copy of the text with her. She was tracing her fingers along the lines of the poem, which allowed J to follow my reading. Suddenly as I was reading, I realised that J was reading aloud along with me. She was reading very slowly, and it was as if she was only reading the poem one-to-one with the activities co-ordinator, as she was a little way behind my reading but seemed not to notice or to mind. I didn’t want to interrupt the reading and draw attention to J, or stop so that she could catch up, as I thought this might interrupt her flow, and she seemed happy enough reading it this way. She read almost the whole poem through, losing the thread of it just short of the final stanza. The activities co-ordinator looked up at me, amazed, and then praised J very highly for the achievement. I did similarly, and pointed out how much of it she had read. The activities co-ordinator asked J if she had enjoyed the poem, to which she responded: ‘There’s something about it, I can’t explain’. To me, this identification of a vague, unverballed ‘something’ in the poem, signalled the depth of thought and feeling it had prompted in J, even if she wasn’t able to say more about it in the group. The activities co-ordinator spoke to me after the group, saying that she felt it was a real breakthrough for M, and commenting, ‘That’s the most she has ever strung together’.

Day 38

This was the third time this week I used the poem, and the group was larger today, attendance rising to 7 from 4 on the previous two days. During an early conversation, we were discussing the first lines of the poem and what it would feel like to ‘wander lonely as a cloud’, and N (a regular who had been present on days 1, 35 and 37) commented, ‘It’s a different type of thinking’. I asked her to elaborate, and she described something like getting in touch with a new or different kind of thought, which was like a cloud above you – or perhaps your previous way of thinking, your worries, being lifted like a cloud. She used lots of hand and facial gestures to try and get across what she wanted to say when the words weren’t quite there.

K also had a very interesting response to the poem in this session, and was able to say more about his thoughts and feelings towards it than he was on the previous day. We spoke for a while about what a shame it was that our countryside is getting destroyed and people stay within the cities so much. K then independently took our conversation back into the poem: ‘It’s like him here, *I wandered lonely as a cloud*.’ He then read out the whole first stanza, stopped and said, ‘I suppose you would wander lonely as a cloud, wouldn’t you? ’Cause you are walking around, and looking around you, and you’re sad that what you’re seeing might not be there much longer’. I thought this was a really powerful connection to make between the words of the poem, and the concerns he obviously felt himself.

Day 43

This was the core group of 4 again: N, K, P, M. Again, the poem got good responses from the group – although M was still the only member to show explicitly that she remembered the



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poem. In this session, I again drew attention to the lines in the final stanza of the poem, and this time N commented that the 'inward eye' is 'a thought that comes from inside, not from the eye', and about seeing in a 'new way'.

M, who in previous sessions has only ever expressed pleasure in hearing the poem and was delighted in being able to recite it from memory, today had a quieter and more troubled response to it. She said it made her feel sad, but then also acknowledged that on another day it would probably make her happy. She related it to a 'longing' for something, which was different from her simply pleasant feelings and responses in previous sessions. It seemed that through her feelings towards the poem she was approaching it from a new side, and developing new thoughts and understandings from it.

M worked for a long time as a teacher, and has a real passion for reading and poetry – despite the difficulty she has with her eyesight. Sometimes in the group, however, she tended to respond to poems in an over-simplified manner, almost 'telling' us what the poem meant, and then finding it harder to talk more about the poem and explain her feelings and interpretations. In later session such as this one, however, it felt like M was able to approach the poems in a different, more uncertain and intuitive way and express feelings that she couldn't account for. I believe this was progress for her.

K spoke about poems more generally at the end: 'They do make you feel emotion, these words. You can get all sorts of books out there now – adventure, mysteries or whatever. But it's a whole different ball game, this. They make you feel emotion – I get all choked-up! And you can get your emotion out – give it to a friend and they know what to do with it. Be a friend... I like it.'

Day 44

In this session, I had planned on using a couple of new poems that I hadn't read before with the group, but when I arrived at the home, it was obvious that things were in a state of turmoil. There was a new floor being laid-down in the ward, which had caused a lot of re-organisation in rooms, noise, and clutter. The staff were all very preoccupied, and the activities co-ordinator who normally brings the group together for the sessions was off sick. After eventually gathering some of the regular members of the group with other staff, I was able to get them settled in seats – but there was a palpable feeling of unease and confusion within the group. I made a last-minute decision to use 'The lake Isle of Innisfree' and 'The Daffodils', which I had brought along in my bag, as I thought that hearing familiar words and rhythms might help to soothe the atmosphere, and both of the poems have a rather more restful and calming tone than the poems I had planned to use.

After reading Yeats, the tone in the group had relaxed and the members had been able to connect with and speak about the poem well. We moved on to 'The Daffodils', and in this session both N and K were able to produce very interesting and thoughtful responses.

N had read the poem aloud in the group previously, and always enjoyed doing so, reading it with great emphasis and eloquence. This time, after reading the poem aloud she independently linked the 'inward eye' to 'something that God has given us, in the mind – what brings us here, not just one, but all of us (she waved her hand around the table) – as a whole? It's so that we can see all around, like we can travel all around the country' (she gestured in a

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wide circle). I asked her if this was like being connected to other people in some way, and she said – ‘Yes, we see all around – we can all see and feel one another’. This seemed like a big development, but one which built upon her previous, quite spiritual and holistic, responses to the poem. K again linked the poem to his love for nature and sadness at it being destroyed, but this time through a new memory that he had not spoken about before. He spoke about a small lake on the Wirral where he took his children – ‘They want to put something more interesting there now – but what could be more interesting than water and ducks and kids playing?’

Day 56

K said of ‘Daffodils’, some time after we had turned from it to look at another poem, that it brought ‘the outside in’.

Day 57

When K arrived at the group the next day he had his copy of ‘The Daffodils’ from the previous group folded in his top pocket. He took it out when he sat down at the table, and unfolded it and began to read it silently to himself. I suggested that we could all read it as a group, as I had some copies with me – which seemed to please him. We read it in the group, and K picked up on the lines ‘continuous as the stars that shine/ and twinkle on the Milky Way’. He started speaking about his interest in astronomy, mentioning the cosmos, black holes and infinity, and we spoke about how unknowable space is, how it goes beyond our thoughts and ideas about it.

Day 63

The penultimate reading session at the home. Another great moment with J, as she read the whole first verse through on her own, very well, without prompting. The activities co-ordinator at the home told me that she has the poem up on the wall in her room, and she took the copy of it with her from the group today. K also has the poem up on the wall in his room, as does M. M was reciting the poem from memory along with me the whole time. After the first reading, J was the first to speak – her speech was very difficult to understand and many of the words were incomprehensible but I made out ‘wander lonely as a cloud’ in her utterance, and I asked her if she liked that line. She frowned at me and laughed and nodded her head, and then began speaking and gesticulating again in a confused manner. I asked the rest of the group what they thought of that line. M said she wouldn’t like to be like that, because you need company when you’re on a walk. We spoke about benefits of having someone to share things with for a little while. Then I pointed out the daffodils, that are ‘jocund company’ in the poem – and M said, ‘oh yes, jocund company – something to keep you happy and smiling and in good spirits’. N said, ‘they are happy, the flowers’ – we spoke about why flowers make us feel good – N said, ‘it’s the colour’, M, ‘the smell’. N said ‘they make you feel homely, like you’ve come home’.

K read aloud the first couple of verses from the poem, very quietly and slowly, without being asked – and he kept saying ‘yeah’ every now and then. I asked him if he liked the words in the poem and he said, ‘Oh yeah, very nice’ – he then started remembering going out for walks in North Wales with his children and wife – the mountains and hills. He also said of the person in the poem, ‘It seems like he’s trying to get away from some troubles.’ I asked him what he meant by this, and he said, ‘Like, it’s all got a bit much, and he’s not talking to people, so he’s just gone out – and he’s with the daffodils and he “floats on high over vales and hills” – he



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needed to go out.’ I said that was a really interesting point, and asked if sometimes it can help you deal with problems or difficulties if you go outside into the country. He nodded and said, ‘Yes’.

Summary

Although M was the only member of the group who ever explicitly said that she remembered the poem, in later sessions other residents would show that it was familiar to them in other ways, for example, K bringing the poem to a group in his pocket. N’s frequent readings of the poem aloud also grew in confidence as she became more familiar with it, and towards the end would be able to speak some lines or parts of verses whilst looking at the group, rather than at the page. Normally, when she finished reading I would immediately ask her a fairly direct question about it, or a line in the final stanza – as she could become disconnected from what she had read if much time passed between reading and question. In session 44, however, she was able to do this for herself – immediately drawing attention to ‘the inward eye’ after her reading and producing a powerful and eloquent series of ideas around it. N was a devoutly religious person but poetry enabled her to combine her feelings about religion and about ordinary life as well. She could talk to others of deep ideas coming out of her religion which she would not have the opportunity to talk about in everyday life in the Home. Her thinking also made M go to deeper places.

Sometimes, the conversations were simply variations on a theme: for example, the general conversations about why flowers make you happy, walking outside in the country, and the dancing of the daffodils, were all common topics which got repeated throughout sessions. Sometimes, however, these topics also led to what seemed like new or different ideas for group members: for example, J’s ‘discovery’ on day 35 of the image of flowers moving in different directions as they blow in the wind, and in session 38 K’s thoughts about why walking in the countryside might lead to feelings of ‘loneliness’.

Conversations around the poem never felt repetitive or formulaic, even when we were discussing similar themes to a previous session. Perhaps this is because even when I recognised responses that individual members were having to the poem, they would express them in different ways: for example, N’s enjoyment of the images of the flowers led her to describing the feeling they gave her in different sessions as ‘dainty’, ‘homely’ ‘comely’ and ‘feminine’.

Group members’ responses to the poem could also change in what seemed like quite significant ways, for example M’s wistful remarks in session 43. The poem suddenly was no longer just about a pleasurable experience and happy things, but also an expression of a sense of desire for something that was perhaps not attainable. Similarly, in variation of K’s repeated response to the poem as love of nature, his thought in session 63 about what had led the speaker to be out in this landscape and why he was ‘lonely’ before he arrived. Or N’s different formulations across different session as to the deep meaning of ‘the inward eye’. Of course, these different responses could be a reflection of how the resident was feeling on that day: if they had just received a visit from a relative, for instance, and were now missing them, the poem could come to hold a sense of regret; or if they were feeling ill or confused themselves, this might be reflected in their responses. I never knew these extra details to residents’ lives in the home, although sometimes I could tell if their moods were lower, of course. But whatever the cause for it, it always felt as though the residents were talking about

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this wide spectrum of feeling within a safe and supportive environment. Also, by repeated readings of the poem and conversations with other residents – looking at the elements both of ‘loneliness’ and of ‘pleasure’ – the poem nearly always produced an uplifted, or at least a more peaceful or reflective mood than had previously existed.

Conclusion

Whether residents seemed to forget ‘Daffodils’ or not, they regularly offered new or different thoughts and formulations with regard to the same poem. Whatever the failures of conventional memory (working memory, procedural memory implicit in the performance of task, semantic memory of general knowledge, short-term or long-term recall), the residents kept associating the poetry with core parts of their personal selves retrieved through careful and repeated attention to the poem’s language. It seems important not to under-rate what residents are capable of, in a context of safety and regularity which itself can provide through shared reading stimulating opportunities for something more than default responses or repeated phrases and stories in a continuous loop.

As in Case Studies 6 and 7, what is vital is not complete auto-noetic consciousness (the full and steady awareness of being aware – as simply, for example, in the consciousness of having read the poem before), but the sudden episodic awareness itself, transient and yet capable of being re-activated often through emotion more than memory itself. What is more, such small awakenings are activated and re-activated newly and freshly through the poetic stimulus, especially when available repeatedly on a regular basis.



Quantitative Analysis

1

Dr Janine Carroll,
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The aim of this project was to investigate the impact engaging in a reading group activity had on residents living with dementia. Four care homes took part and two were randomly assigned to the reading-waiting group (3 months reading followed by 3 months no reading) while the other two were assigned to the waiting-reading group (3 months no reading followed by 3 months reading).

Sample

Care Home 1 was recruited a month later than the remaining care homes due to unforeseen circumstances. However, as participants were in the waiting condition, this meant that the baseline data for this care home could be collected at month 1 and every month thereafter. For Care Home 1, the number of residents in the weekly group at the start of the project was 8 and at the end 7 (1 resident died during the project). For Care Home 2, 10 residents began the reading group but 9 were still participating at the end: 1 resident decided to leave the group three months into the project. For Care Home 3, 10 residents started the group and remained in the project until month 6. For Care Home 4, 8 people started the project with 2 residents joining the group in month 3. At the end, 7 of the original 8 were still in the project (alongside the 2 residents who joined after baseline). Any resident who joined the project after baseline was not included in the full analysis.

This is, in statistical terms, a small sample. In addition, best practice in qualitative analysis would recommend statistical controls for the 'clustering' effect – participants in this study cannot be regarded as fully statistically independent, as their experiences were held on a group basis. Consequently any quantitative analysis should be regarded as tentative at this stage, without a more substantial cluster-randomised controlled trial.

Quantitative Analysis

Measures

The project involved measuring behavioural symptoms and the residents' quality of life every month for 6 months.

- The DEMQOL-Proxy (Smith, Lamping, Banerjee, Harwood, Foley, Smith... & Knapp, 2005) measures the quality of life of the person living with dementia and focuses on asking primary carers/relatives information on the person's feelings, memory and everyday life. They are required to answer in the way they think the person would probably respond and consider many aspects of the person's life (e.g. their emotions, how they feel about forgetting things, concerns about finances, cleanliness, being able to help others etc). All information was collected from care-home staff at baseline prior to the start of month 1 and then every month thereafter.
- Information on behavioural symptoms was collected by the Neuropsychiatric Inventory Questionnaire (NPI-Q; Kaufer, Cummings, Ketchel, Smith, MacMillan, Shelly, Lopez & DeKosky, 2000). The NPI-Q is a measure of whether symptoms are present in the individual living with dementia and how severe and distressing these symptoms of dementia appear to be for the individual. The measure can be completed by the person living with dementia or their relatives/carers. For the current project, only the severity of the symptom was focused on as the quality of life measure considered the emotional aspect of living with dementia.

Hypothesis

The main aim was to investigate whether there was improvement in behavioural symptoms and/or quality of life for participants in the reading groups.

Graph: The DEMQOL-Proxy Data



Results

1. DEMQOL-Proxy Data

Because of the limitations of the data mentioned earlier, the possible impact of the reading intervention was explored using a repeated measures analysis of variance, comparing DEMQUOL-Proxy scores in the two conditions (waiting then reading (n=12) versus reading then waiting (n=19)).

This revealed a significant group x time interaction ($F(1,29) = 14.588, p < .001$). Examination of the group means indicated that the participants in the 'waiting then reading' group recorded scores on the DEMQOL-Proxy that rose from a mean of 102.9 (SD = 11.7) to 114.9 (SD = 3.0), whereas the DEMQOL-Proxy scores in the 'reading then waiting' group remained steady; with a mean score of 114.3 (SD = 2.4) in the 'reading' period and 115.8 (SD = 2.7) in the subsequent 'waiting period'. When compared with the waiting condition, the beneficial effects of the reading group in respect of quality of life can be seen once the group begins and appear to be maintained once the activity finishes. These results suggest that engaging in a literature-based activity may significantly benefit those residents living with dementia. This is further supported by the qualitative comments and analysis.

Although these results are encouraging, the small sample size very much limits the generalisability of the results, and therefore they should be interpreted cautiously. The increases noted above cannot be statistically significant in terms of sample size and critical mass, until further tested by Randomised Control Trials. This current report acts as a further preliminary indicator of the need for a large-scale RCT on the effectiveness of shared reading-aloud.

2. NPI-Q Data

Scores on the NPI-Q were extremely low for all participants (with the vast majority of people scoring zero – i.e. reporting no distressing behavioural symptoms for the duration of the study). These data were therefore not analysed further.

References

- Kaufer, D. I., Cummings, J. L., Ketchel, P., Smith, V., MacMillan, A., Shelly, T., Lopez, O. L., & DeKosky, S. T. (2000). Validation of the NPI-Q, a brief clinical form of the neuropsychiatric inventory. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 12(2), 233–239
- Smith, S. C., Lamping, D. L., Banerjee, D., Harwood, R., Foley, B., Smith, P., Cook, J. C., Murray, J., Prince, M., Levin, E., Mann, A., & Knapp, M. (2005). Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technology Assessment*, 9(10), 1–93

2

Liverpool Reviews and Implementation Group on cost and value

The Liverpool Reviews and Implementation Group (LRiG) was asked to explore the costs and cost savings associated with TRO shared reading groups in the four Care Homes located in Wirral. Behavioural symptom data and quality of life data were collected by the University of Chester and are reported above. LRiG's main aim was to investigate the economic effect of setting up and delivering the poetry sessions in Care Homes by considering whether the groups had any impact upon costs incurred by the Care Homes. Access to this information, alongside qualitative and quantitative data about the outcomes and other benefits of the reading groups, could help Care Homes to determine if such reading groups offer value for money and should continue to be run.

Conventional economic evaluations in health care often use cost-benefit analysis, cost- effectiveness analysis or cost-utility analysis to enable decision-makers to compare the costs and outcomes of an intervention with the baseline situation. Cost-benefit analysis considers the costs valued in money and compares these with the outcomes, which are also valued in money. Cost-effectiveness analysis compares costs in money with a single primary outcome. Cost-utility analysis is a specific form of cost-effectiveness analysis in which outcomes are measured in terms of quality-adjusted life years (QALYs) gained. These 'conventional' approaches are not appropriate for all evaluations, especially where is not a single primary clinical outcome. Many potential outcomes and benefits cannot readily be assigned monetary values. J. Coast (Is economic evaluation in touch with society's health values? *British Journal of Medicine* 2004; 329:1233–36) suggests that cost-consequences analysis, which identifies and considers the costs of not undertaking a particular intervention (and thus identifies the likely cost savings associated with the intervention) as well as the costs of delivering it, would often be a better approach as it is easier to understand and may lead to more informed decision making.

With regard to this study, there are several ways in which shared reading groups could affect costs. For example, there are the direct costs associated with the person leading the sessions (e.g. their time and the reading materials) and the costs associated with any additional Care Home staff

attending the sessions. Attendance at the sessions may result in reduced agitation, depression or sleeping problems. These improvements may lead to reduced medication levels resulting in indirect cost savings. These are examples of tangible costs that can be identified, measured and valued.

Table 1: Summary of potential costs, cost consequences and other benefits of poetry sessions

Costs of delivering intervention (tangible):	
FOR THE CARE HOME	<p>Direct cost of external Session Leader (e.g. professional from TRO or volunteer)</p> <p>Direct cost of materials for sessions (e.g. photocopying copies of poems)</p> <p>Direct cost of employing additional care staff to accompany residents attending poetry sessions (or to provide cover with other residents whilst regular staff attend poetry sessions with residents)</p>
Potential cost savings (tangible):	
FOR THE CARE HOME	Need fewer care staff because residents less anxious, agitated and/or aggressive
FOR THE NHS (VIA CARE HOME)	Residents require less medication as more relaxed, less agitated/aggressive and sleep better
Other potential benefits (intangible):	
FOR THE RESIDENTS ATTENDING THE SESSIONS	Attending an enjoyable, stimulating activity that improves residents' sense of well-being and quality of life
FOR THE RESIDENTS' FAMILY/VISITORS	Identify memories and reminiscences to share
FOR THE CARE HOME STAFF	Learn more about their residents' former lives and activities which can lead to increased respect and improved communication

Information relating to costs and cost consequences (and thus cost savings) was collected via semi-structured interviews undertaken by two LRiG researchers in discussion with relevant staff from each of the four Care Homes. The interviews started by trying to explore the costs and cost consequences associated with the Poetry Groups, and then focused on the staff views on the delivery and the effects of the sessions. Findings are summarised in Table 2.

Table 2: Costs, cost consequences and other benefits of poetry groups Identified by interviews with Care Home staff

Costs of delivering intervention (tangible):		
FOR THE CARE HOME	<p>Direct cost of external Session Leader (e.g. professional or volunteer from TRO)</p> <p>Direct cost of materials for sessions (e.g. photocopying copies of poems)</p> <p>Direct cost of employing additional care staff to accompany residents attending poetry sessions (or to provide cover with other residents whilst regular staff attend poetry sessions with residents)</p>	<p>Sessions were provided free of charge during pilot, but would need to be paid for subsequently (£5000 per annum for a once-weekly session)</p> <p>These were covered during pilot and, if not subsequently covered by cost of a Session Leader, are likely to be very low [Researchers' estimate: max £1 per session]</p> <ul style="list-style-type: none">No additional staff requirements were identified during the pilot – accompanying residents to sessions was one of their regular activities-related tasksPoetry Groups neither increased nor decreased pressures on staff
Potential cost savings (tangible):		
FOR THE CARE HOME	<p>Need fewer care staff because residents less anxious, agitated and/or aggressive</p>	<p>Most of the residents attending sessions were not especially prone to anxiety, agitation and/or aggression, but even if these behaviours were reduced by attending the poetry sessions, it would not have had any impact on the number of Care Home staff required to be on duty at any time</p>
FOR THE NHS (VIA CARE HOME)	<p>Residents require less medication as more relaxed, less agitated/aggressive and sleep better</p>	<p>Most Care Homes try to minimise the amount of medication needed by their residents, and those attending the poetry sessions were generally on no, or on low levels, of medication. Staff felt that the poetry sessions would be very unlikely to affect attending residents' medication requirements (in either the short- or long-term)</p>

Other potential benefits (intangible):		
FOR THE RESIDENTS ATTENDING THE SESSIONS	<p>Attending an enjoyable, stimulating activity that improves residents' sense of well-being and quality of life</p>	<ul style="list-style-type: none">The sessions improved residents' well-being and quality of life (this was generally perceived as the main outcome)The Poetry Groups were an enjoyable social activity that brought back memories and encouraged talking and conversation and interaction between residents (both during and after the sessions)Residents often seemed “<i>more settled and content</i>” after a sessionResidents also became more confident and responsive and engaged more with other activitiesOne manager thought that some residents seemed to sleep better after attending the sessions (but did not know if the sessions had an effect on people's appetites)
FOR THE RESIDENTS' FAMILY/VISITORS	<p>Identify memories and reminiscences to share</p>	<ul style="list-style-type: none">Family and others who regularly visited the Care Home often noted that their relative/friend seemed to really enjoy the sessions and was more talkative and ‘engaged’ afterwardsThe sessions could provide them with something to talk about togetherSometimes they attended a session with their relative/friend, or delayed taking them out until after the end of the session

Quantitative Analysis

FOR THE RESIDENTS' FAMILY/VISITORS	Identify memories and reminiscences to share	<ul style="list-style-type: none"> Sometimes visitors learned new things about their relative/friend that they had not known before On some occasions the sessions helped a relative <i>"re-connect with a loved one who they had 'lost' to dementia"</i> Some visitors asked for copies of the poems so that they could read them together with their relative/friend
FOR THE CARE HOME STAFF	Learn more about their residents' former lives and activities	<ul style="list-style-type: none"> Staff felt that they got to know and understand the residents better through gaining insights into their lives and interests Such glimpses helped staff relate to the residents and facilitated bonding

Quantitative Analysis

Conclusions

Very little research has considered the costs and cost-effectiveness of group interventions such as reading and poetry groups for people with dementia living in Care Homes.

Interviews with Care Home managers and other staff indicated that the only direct, tangible cost to the Care Homes was the cost of an external facilitator; no cost consequences regarding staffing levels or reduced medication requirements were identified. The reading intervention will not extend the life of the residents, nor does it have impact upon one particular symptom as outcome; but improvements in quality of life are significant.

Many intangible benefits for residents, their families/visitors and staff were identified during the interviews. Groups were considered to have very positive effects on the wellbeing and quality of life of those attending, and staff at one Care Home felt that 'their value cannot be overstated'. The groups are popular and promote engagement and interaction between residents, who are encouraged to remember and reminisce. See above for quantifiable measures of benefit in terms of quality of life, helping to give further confirmatory evidence for otherwise intangible benefit registered in the qualitative analyses.

- These benefits are increased when an external facilitator runs the Poetry Group and when groups take place on a daily (rather than weekly) basis. The sessions were also appreciated by families/visitors, who were sometimes helped to reconnect with the person they had lost to dementia. Staff got to know and understand residents better through seeing glimpses of their former lives and interests. This potentially provided a maximally triple value per resident (resident, care worker, relative).
- Although the sessions were generally perceived as being most appropriate for residents with mild to moderate dementia with certain characteristics making them suitable for attending a group activity, they were also found to be beneficial to some other people. However, the activity has not been piloted with people with more severe dementia and/or disruptive tendencies, for whom it may not be as effective. This needs further testing.
- Decisions about the value for money of such groups will need to be taken by Care Homes based on their assessment of the needs of their residents. Given the cost of using professional readers in residence, TRO is able to cost what is required for it to launch a national training programme for volunteers (including care workers and relatives) in order to roll out the programme more widely: see 3 below.



3

Training costs provided by The Reader Organisation

READ TO CARE PROGRAMME

The benefits of shared reading can be rolled out on a substantially wider but affordable scale by training individuals to deliver the groups.

Trainees would include:

- Care-home workers seeking extra skills and career advancement
- Relatives of people living with dementia
- Community volunteers.
- The responsibility for the recruitment and management of relatives and community members would need to be held within each individual care home.

THE READER ORGANISATION SUGGESTS TWO SCALABLE TRAINING MODELS:

Suggested Scalable Model 1: Small Scale Care Providers, On-Site Scheme

Intensive Training by a Reader in Residence, 3 months in-house, during the course of the residence

This model would be purchased by either a single home or by a group of small care providers with the following options:

- a) Project worker who is present to provide 1 session a week (at annual cost of £5k) would train 1 person every 3 months, ensuring trainee's regular involvement in the weekly group: 4 people over 12 months, at an additional annual cost of 2k
- b) Project worker providing 3 sessions a week (£15k p.a.) training 12 people annually at an additional annual cost of £6k
- c) Project worker providing 5 sessions a week (£25k p.a.): training 20 people at an additional cost of £10k.

The additional training cost results in the establishment of new volunteer-training groups each of which costs £500 for the first year of delivery, or just over £43 per group participant.

Suggested Scalable Model 2: Large Scale Care Providers, Training Courses

Two-Day Training Programme, followed by Individual Visits

This model would be purchased by a large health and social care provider:

- a) One shared-reading trainer with specialist experience of the intervention for people living with dementia could deliver 10 training courses per annum for two days with 8 participants.
- b) Each trainee would be visited twice thereafter by a trainer for half a day (Quality Visits), within the year of the initial training, and once again (as Refresher Quality Visit) in the year of delivery thereafter.
- c) The creation of 80 trained staff per annum, working in pairs to deliver 1 group (6 participants) per week, creates 40 groups and serves a minimum of 240 group participants. Cost of trainer: 70k per annum. This works out at £1,750 per group or £291 per group-member for the first year.

Scaling up nationally could be considered through further calculation of costs involved in training staff from large health and social care organisations: these would be the multipliers that could lead to hundreds of trained staff members and thousands of group-participants.

Notes:

- In each model the training costs would be an initial investment in what becomes increasing low-cost unit delivery going forward after the first year of training, though it would be wise to include further Refresher Visits in yearly budgets.
- Trainees would have access to web-based resources from The Reader Organization and would be given an anthology of 150 poems to ensure sustained quality of material
- The models are not mutually exclusive, and each model is modifiable in light of further needs and development

Conclusions & Recommendations

- The shared reading group significantly improves the quality of life of people living with dementia
- This improvement may be a factor important to care homes in terms of the quality of provision, as registered by Inspection Visits
- The benefit is also of value to care-workers in renewed respect for the participants and to relatives in encouragement of remaining human possibilities
- Qualitative evidence suggests considerable advantage in increasing the regularity of sessions during the week
- Further research is needed into the relative efficacy of increased regularity of sessions
- In terms of cost, a potentially nation-wide training programme is both necessary and feasible for best use of volunteers and for sustainable national delivery of shared reading groups
- The nature of memory investigated in this report is neither short-term working memory nor autobiographical stories as recalled through reminiscence therapy: the use of memory in shared reading is to do with personal reawakening triggered by literature in significant emotional areas that bring participants back to life for the moment
- Further research into the nature of emotionally activated memory from deep human sources of self is necessary – not least in educating relatives' expectations of what can still be achieved in retrieval of the person, especially when triggered by literary stimulus.

Conclusions and Recommendations

- There is at its best a richly attentive presentness in the shared reading activity and a sense of activated newness or renewal in the experience.
- Participants were given not merely familiar and easy works but new and challenging ones, including poetry that involved sad and painful experiences as well as joyous and loving ones, and were often asked to look closely at the specific words and phrases.
- This befits the richness of adult experience and memory. It is important not to underestimate the capacity of the participants or attempt to protect them from the range of both general human experience and their own share of it.
- Further research into literature's transcendence of the negative/positive emotion division may serve to change public perception and policy agenda with regard to the uses of all kinds of experience
- TRO needs the opportunity to test its work on people suffering from more severe versions of dementia, including aggressive behavior
- Though quantifiable data is hard to extract, progress is being made with regard to measures of wellbeing and quality of life, especially when correlated with qualitative analysis
- In relation to quantifiable data Randomised Control Trials are now necessary in further testing the case for this intervention

*‘Isn’t it funny? We come in with nothing
and go out with all these thoughts.’*

Reading group member, living with dementia

‘I was spellbound’

Professional Visitor, expert by experience
reporting during Inspection Visit

‘Their value cannot be overstated’

Care home staff member on the shared-reading groups



