

## Reminiscence in Dementia Care

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In this article, I sketch the history of an idea, placing it in its historical and geographical context. I trace the development of the project “Remembering Yesterday, Caring Today,” from 1997 when it was first funded by the European Union, through its UK development as the focus of research studies funded by the Medical Research Council and the Research Institute of the UK Department of Health, to its present state as the basis of a training and apprenticeship scheme. I show the impact on practice of various findings (positive and negative) to emerge from research studies and some resulting interesting moral and practical dilemmas which have exercised those of us who have been on this journey.

*Key Terms:* Reminiscence; Dementia; Creative Arts; Personhood; Randomized Controlled Trials

In this article I shall trace the evolution over a 20-year period of an idea. This idea has developed through practice and study across international and language barriers.

In the 1980s, the idea of using reminiscence in the context of dementia care would have sounded like a contradiction in terms. Inviting people whose memories were failing to recall their pasts would have been considered a recipe for failure and humiliation. Instead, efforts were being made, through reality orientation and other related interventions, to encourage people with various forms of dementia to live in the present, to face their own current reality, however bleak that might be, and not on any account to indulge in what would have been considered unhealthy nostalgia.

Care for people with dementia was then largely a matter of containment and warehousing (Kemp, 1999) and the limited efforts to alleviate dementia-related stress were concentrated on providing support and, later, support groups for carers. Awareness of the ever-increasing prevalence of dementia was only gradually dawning in developed countries and was barely acknowledged at all in the developing world, where other forms of illness were still claiming lives much earlier, so that the incidence of dementia was much lower. Governments were not making public policy statements concerning dementia, and families affected were mainly expected to cope on their own or,

when the going got too tough, to deposit their relatives in nursing homes where their safety would be assured and their physical needs met, hopefully by kind, if low-paid, staff.

During the 1980s and 90s, group reminiscence work and individual life history work (both emphasizing the value of the older person’s past experience, as well as their present reality) had been gaining acceptance and were being used in ever more varied contexts (Bornat, 1994; Kitwood, 1997). There was widespread growth in reminiscence projects run by community history groups, community arts teams, adult-education-based projects and, increasingly, by activities organizers in care homes, including those working with people with dementia (Tomkins, 1987). From the latter, some surprisingly positive results were emerging. Long-term memories seemed to remain intact well into the onset of dementia, and sharing those memories with others and thereby finding common ground was seen to improve spirits and raise self-esteem. Revisiting aspects of their own lives in the company of others, singing and talking together, appeared to shore up people’s sense of identity at a time of increased vulnerability, and enable them to engage at least for a while in pleasurable exchanges around remembered shared experience (Gibson, 2011; Osborn & Schweitzer, 1987).

During the 1980s, my own work had been to set up Age Exchange, a professional arts organization and charitable trust developing reminiscence theatre. This was a new idea in which plays were developed from the recorded memories of older people and performed back to the contributors, and to a much wider group of older people, to stimulate them to recall their own lives (Schweitzer 2007). Performances were in community and day centres, sheltered housing units and residential homes. Clients with dementia often showed a

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strong response to these productions, identifying with the stories and responding appropriately to the situations portrayed. Staff in the venues where we performed, seeing how the shows stimulated their clients, wished to learn to use reminiscence in their regular activities programmes, so we set up training and support programmes for them. I designed the Age Exchange Reminiscence Project, with support from social services advisers, in response to this expressed need. Project workers went through a two-week intensive training and were then employed in pairs to run reminiscence sessions in care settings. Over eight weekly sessions, we provided residents with a quality reminiscence activity and staff with a useful in-service training opportunity (Quinn, 1989). The project begun in 1986 ran for twenty years and led to a greatly increased recognition for the value of reminiscence groups (Osborn, 1993).

Throughout the 1990s, interest in reminiscence work was developing across Europe, engaging people from a range of backgrounds, such as arts, oral history, creative writing, biographical work, mental health, and social work. The European Commission was interested in supporting the creation of Europe-wide co-operative projects in social, cultural, and health fields. In 1992, I received funding to set up the European Reminiscence Network. Its tasks were and remain to support best practices in reminiscence across Europe, to undertake joint projects and to share results. Many of our programmes were arts-based: senior theatre festivals and inter-generational and inter-cultural reminiscence programmes (European Reminiscence Network, 1998). But a growing number of our members in different EU countries were now wanting to explore the use of reminiscence with people with dementia.

In 1997, the European Reminiscence Network secured EU funding to run a conference in London entitled “Widening Horizons in Dementia Care,” exploring the links between reminiscence and dementia. We called together experts from across Europe and beyond to share their experience in both fields with 250 delegates. At this conference, an EU statistician, Lars Rasmussen, spoke of the urgent need to address the issue of the exponential increase in dementia across Europe, and to respond to the needs of families who, now and increasingly in the future, would be bearing the brunt of the caring responsibility.

The European Reminiscence Network responded to this challenge by creating a new joint action-research project called “Remembering Yesterday, Caring Today” (RYCT) with advice and support from the International Alzheimers Society (Dr Nori Graham) and the Universities of Bradford (Errollyn Bruce) and Ulster (Professor Faith Gibson).

The RYCT project was funded by the Health Promotion Unit of the European Union and involved twelve partner countries in the following stages:

- partners in twelve countries underwent a shared training course, so that we were all starting from the

same place;

- partners took this course back to their own countries to train group leaders;
- together we devised an 18-week participatory reminiscence programme for people with dementia and their family carers, to explore their life stories together using creative reminiscence approaches;
- partners provided multi-sensory prompts to aid engagement and developed non-verbal, failure-free activities including art, drama, music and dance;
- partners offered on-going support and a reminiscence training element for the family carers who met separately on alternate weeks;
- partners participated in the on-going evaluation of the project;
- partners in all 12 countries tested the programme and shared results at regular meetings and at a final conference.

Although there were initial problems recruiting families in some countries, all partners reported the enthusiasm of those families who participated and the success of the project in re-igniting positive feelings between participating couples. They also reported increased self-confidence and capacity for social engagement on the part of people with dementia (Schweitzer, 2011).

At a conference hosted by the European Reminiscence Network in Vienna in 1998, we shared our very positive results (Bruce & Gibson, 1998). We also discussed making some alterations to the project, such as laying rather less emphasis on carer training and rather more on ensuring that the person with dementia remained at the centre of the sessions and participated fully throughout. We cut down on the overall length of the project, reducing it to 12 sessions, and we reduced the amount of time in which the carers and their people with dementia met separately. The jury is still out on this decision and many modifications have been made in subsequent versions of the project.

We gained further EU funding to publish our project and its findings across all participating countries in book form. In 1999, we launched our joint publication “Reminiscing with People with Dementia” at a conference in Stockholm, Sweden, and translations appeared in several other EU languages over the following years (Bruce, Hodgson, & Schweitzer, 1999).

Lars Rasmussen of the European Commission then challenged us again to find a way to demonstrate the effectiveness of our work scientifically. As someone from completely outside the research field, I reacted negatively to the idea, since I felt that the informal response of the families had been so positive. I cited their continued attendance at the sessions, despite all sorts of practical difficulties, and their enthusiasm to carry on meeting after the project formally ended, as evidence of the project’s success, but I was persuaded that we should initiate or

participate in research which would give more ammunition to our claims for the project. From there began ten years of trials of various kinds in the UK and other partner countries in the hope of finding results of sufficient statistical significance to warrant adoption of the project on a massive scale.

These efforts at evaluation varied from questionnaires addressed to participating families before, during, and after the project concerning what had worked well for them and any changes they planned to make in their daily living as a result of the project, right through to a full-scale randomized controlled trial. New RYCT groups involved in these trials were financially supported by charitable trusts and foundations and by research bodies. This funding enabled training of further professional group leaders and session fees for them to run 12-week reminiscence groups for families living with dementia. All these continued to produce positive results, especially those which took into account anecdotal reports and responses to qualitative questionnaires. Results consistently included reduced carer stress, reported improvements in quality of life and improved autobiographical memory.

A typical response by carers to the qualitative evaluation was as follows:

*I'm sure I speak for a lot of family carers here when I say that we have really appreciated these reminiscence afternoons. I'm a different person completely from when we first started meeting. I was a wreck. Now I feel I've got a lot of friends, everyone's friendly and I can talk to everybody here in the group. It's a great project. A marvellous thing. (John Pettit)<sup>1</sup>*

A typical comment from a participant with dementia was:

*I would like to say how much I have enjoyed meeting you all and thank you for your friendship. I mean all of you, helpers as well. I felt shy at first of mixing with strangers and did not really want to come. But even after the first week I looked forward to the next Tuesday as I felt warm and welcome and we started to talk openly about our experiences. We laughed, talked about old films and sang songs from days gone by. These weeks have brought me out of myself, so I thank you all once again. It has been great. (Bill Parker)<sup>1</sup>*

The lay summary of findings from a three-centre randomized control trial involving 65 dyads funded by the

Medical Research Council in the UK, included the following:

In total, 65 caregiver/person with dementia pairs were recruited for the trial. Patients were in the mild to moderate phases of dementia, living at home. Changes in memory across the life-span were evident for those people with dementia attending reminiscence groups, and their care-givers rated the quality of life of the person with dementia as having improved. The level of depression in care-givers whose relative had attended a reminiscence group was lower after the end of treatment (Woods et al., 2009).

This Medical Research Council funding also enabled the publication of a detailed project manual, setting its ideas in the wider context of positive dementia care. The manual, "Remembering Yesterday, Caring Today: reminiscence in dementia care," has sold in the thousands and remains the basis of the project (Schweitzer & Bruce, 2008).

It was decided to go for a bigger study of the RYCT project and financial support was granted by the Department of Health Institute of Research in the UK to what became known as the "REMCARE" project. Many hopes were pinned on this three-year "gold standard" single-blind randomized control study, the largest non-pharmacological trial to date to win DOH funding. I was always wary of this kind of research with its blunt instruments of measurement, especially in relation to a multi-faceted, delicate, highly personal psycho-social intervention like RYCT, but I went along with it as I was extremely keen that many more families should be enabled to participate in the project.

The results were deeply disappointing (Woods et al., 2012). There were some positive findings (albeit not statistically significant) for the person with dementia, including some improvement in autobiographical memory, and in quality of relationship. However, the main finding was an increase in carer stress. This result was so very difficult to reconcile with carers' expressed well-nigh universal enthusiasm for the project, as to appear to some to be a rogue finding. How could a project designed to alleviate stress, reduce isolation, promote new friendships and reinforce crucial central relationships within families coping with dementia at home possibly cause harm?

People involved in the research began to look at previous surprise findings in earlier research studies concerning carers and sought psychological explanations for this unexpected finding. Of course, there may be many reasons why carer anxiety increases over time when coping with a deteriorating condition such as dementia, and it is possible that those in the intervention groups were more aware, and more self-aware as a result of their participation. Further, any intervention which brings carers together can lead to a focus on difficulties and anxieties. However, such

<sup>1</sup> Both John Pettit and Bill Parker gave permission for their names to be linked to their quoted comments.

tendencies were offset in the RYCT project by specifying and structuring the content of carer sessions, focusing on the positive and on what the people with dementia can still do, rather than on their deficits. Perhaps the instruments of measurement had been too focused on negative matters, such as stress and depression, so skewing the results?

I began to consider leaving the family carers out of the RYCT groups. This variant has, in fact, been tried, over the years and it does have the merits of giving plenty of time and focus to the people with dementia and time off for the carers, but it misses out on so many positive elements. For example, when the carers are not present to support their person and to give useful background information and clues to the group leaders, then it is difficult to establish what their person might be meaning by some small, rather broken utterance. And when the person with dementia finds it possible to express an important idea or memory, or be particularly creative or witty in the session, then it is a pity for the carer not to be there to appreciate this success, to see what led up to it and to have the chance to try to stimulate similar responses at home.

The situation concerning the findings of the REMCARE study has been exacerbated by the fact that no qualitative element to this research study has yet been published, so there has been no chance for those families in the intervention groups, many of whom had described the weekly sessions as a “life saver,” to share their positive experience of the project. I understand that findings will shortly be published which were garnered during the project and that these will hopefully help to offset the negative finding.

I think it is true to say that there was universal dismay that a project which had apparently “proved itself” a hundred times over could not yet prove itself “scientifically.” Everyone concerned had eagerly awaited the results of this study, hoping for the irrefutable evidence that the project “worked.” Colleagues across the European partner countries had also pinned their hopes on a definitive positive result, inviting those of us involved to share what were expected to be our very positive findings at conferences in European cities. When these were not forthcoming, how were we all to react and what would be the effect of the research findings on the practice (Woods, 2012)?

I had been the trainer and consultant to the project and had had a chance to visit all the groups across the country, to train their leaders, and then to hear how they were progressing. Of course, there were considerable variations in skills levels of those group leaders delivering the project, so quality might have been uneven. But the subjective response of participants had shown a high level of satisfaction across all groups, thus demonstrating that the RYCT model followed by all was robust enough to survive these variations.

For me, the most positive result of this largest trial of the project was that 350 families living with dementia across England and Wales were able to participate fully in the “Remembering Yesterday, Caring Today” (RYCT) project, with trained staff to lead the groups, resources available, and a tried and tested programme to follow. Without the funding raised for the research project, this would not have been possible.

A further study entitled SHIELD (Support at Home Interventions to Enhance Life with Dementia) will shortly report on its findings which include the use of RYCT groups with families living with dementia, and preliminary findings are positive (Melunsky, Crellin, Dudzinski et al., 2013). Here are a few of the comments made by family carers who had participated, comments which are much more typical of carers’ reactions across all projects:

*I didn't feel so alone, just knowing that other people were in the same boat.*

*He was just normal like the rest of them. I do find it a bit embarrassing, sometimes. It was good in the group not to have to keep apologising for him.*

*Now we have more things to talk about.*

*We could share something together.*

*I realised there were things that you could do. I found it helpful to discover an activity I could share with L... Rather than just sitting looking at each other, we could share something together.*

After considerable thought, and some angry private and not so private moments, I decided that the important thing was to ensure that the project itself was not buried. After all, it was now in its sixteenth year and a huge number of participants from RYCT groups across the UK and way beyond had sung its praises, so perhaps we needed to consider different approaches to measuring its impact, while still bearing in mind the REMCARE findings and ensuring that we carefully monitored carers’ reactions to participating in the project.

After discussion with partners in The European Reminiscence Network, we requested and won EU funding to take forward in 12 countries a new project, “Remembering Together: Reminiscence Training” (RTRT). We would follow the RYCT protocol, but this time we would conduct a common qualitative investigation across all partner countries concerning the impact of the project on all participants and expressing our findings in a shared enquiry and report in the form of a joint website ([www.rememberingtogether.eu](http://www.rememberingtogether.eu)). A special feature we built into our new project was the creation of artistic end-products to be produced by the groups, with the help of

artists from different disciplines. This emphasis on the involvement of artists from different disciplines in leading the groups was partly in reaction against the increasing tendency in the recent history of the project for health service personnel to lead the groups. Although many health workers, especially occupational therapists and others used to group work, had led their RYCT groups really well, I missed the more playful risky element, the flair and spontaneity which artists had brought to the earlier incarnations of the project.

This decision was also a reflection of the growing interest on the part of artists of all disciplines to engage with people with dementia and their carers as an important and growing population within local communities, whose needs for self-expression and social engagement they might be able to meet. Arts programmes designed for people with dementia are now much more main-stream, with major art galleries, museums, theatres and concert halls making specialist provision for involvement of people with dementia. We are now seeing government funding being made available to support this work as the links between arts and health are ever more strongly forged and as dementia makes its way steadily up the national agenda of all European Union countries.

In all participating countries, the RTRT project proved popular and successful, as witnessed in the website created jointly by all partners (European Reminiscence Network 2011). We all wanted to carry the work forward and so we followed up with another application to the EU to introduce training and apprenticeship schemes in member states to ensure a future for the project. The new project, "Remembering Yesterday, Caring Today, Training" (RYCTT) runs for two years and culminates in June 2014 in an international conference.

The shape of the new scheme, which has been piloted in the UK, and is now being widely trialed in the partner countries, is as follows:

- applications are made by submitting a CV and a covering letter explaining how the training and apprenticeship scheme fits in with the applicant's work history and future plans;
- an initial two-day training course (the same in all countries) involves direct experience of the reminiscence process, full exposure to the project and a series of exercises focused on the needs of the person with dementia and on their carer;
- the apprentices then attend weekly sessions of a newly formed reminiscence group of people with dementia and their family carers ;
- during the ten weeks (and they must attend eight of these) they gradually build up skills in working with the families and in group facilitation;
- each session is followed by a debrief in which apprentices reflect on what has happened in the

session and what they have learned;

- then follow four further weekly sessions which are led entirely by the apprentices;
- a written assignment of up to 3,000 words gives apprentices a chance to reflect on their experience of the project and their own learning;
- the requirements and marking schemes for practice and written work are being worked out with EU partners so that we have some uniformity of approach.

Of course the scale of the new projects is small compared with the number of families we could reach through the large government-funded trial. However, by offering Europe-wide training programmes and apprenticeships, we are multiplying the trial and encouraging new people to qualify as accredited RYCT group leaders and take up the work, whether as part of their existing jobs or as free-lance session workers. The first groups of apprentices have now qualified and are already working together, with some external supervision, and running groups. Some EU partners in the current project are looking to gain accreditation for the scheme through their own universities. It is early days for this scheme, and some partners are finding they have to adapt the programme somewhat to enable apprentices to participate from a distance. I have been startled by the large number of applicants seeking admission to the scheme from a wide range of professional backgrounds.

Writing up the history of this reminiscence in dementia care idea, "Remembering Yesterday, Caring Today," with its lively action-based meetings of groups of families getting to know one another over a number of weeks and exploring their past lives together, has given me much pause for thought. Is it appropriate to promote a project whose effectiveness it has not so far been possible to demonstrate irrefutably? Rightly or wrongly, my decision has been to press on with the project, spreading an understanding of its aims and methods to new potential group facilitators while remaining open to trying different evaluation methods. Professor Faith Gibson, with whom I have shared the thoughts in this article, commented on the limitations of the RCT in relation to this kind of multi-faceted project as follows:

The importance of the existential moment of enjoyment and/or comprehension of retained abilities during a group session should not be underestimated as an important outcome but it will not be captured by the research instruments used in REMCARE. Just having somewhere to go and having fun together, even if short lived, cannot be lightly dismissed in an inexorably shrinking social world inhabited by people with dementia and their family carers. I think that further research work using both qualitative and quantitative

measures is required. RCTs may be the ‘gold standard’ according to contemporary bio/medical Cochrane Reviews but they are not the only kind of possible evaluative research.

Perhaps someone, some day will develop a more nuanced protocol for examining RYCT. Until such time, it is my hope that many families living with dementia in the community will benefit from participation, untroubled by its failure to prove itself “scientifically.”

## References

- Bornat, J (1994). *Reminiscence reviewed: Perspectives, evaluation, achievements*. Buckingham, Philadelphia: Open University Press
- Bruce, E., & Gibson, F. (1998). Remembering yesterday, caring today: Evaluators’ report. *Conference Papers*. London: Age Exchange (for the European Reminiscence Network)
- Bruce, E., & Gibson, F. (1999a). Stimulating communication: Project evaluation part 1. *Journal of Dementia Care*, 7 (2) 18-19
- Bruce, E., & Gibson, F. (1999b). Stimulating communication: Project evaluation part 2. *Journal of Dementia Care*, 7 (3) 28-29.
- Bruce, E., Hodgson, S., & Schweitzer, P. (1999). *Reminiscing with people with dementia: A handbook for carers*. London, UK: Age Exchange.
- European Reminiscence Network (1998). *The Journey of a Lifetime Festival Papers*.
- European Reminiscence Network (1998). *Remembering Yesterday Caring Today Conference Papers*.
- European Reminiscence Network (2011). *Remembering Together website*: [www.rememberingtogether.eu](http://www.rememberingtogether.eu)
- Gibson, F. (2011). *Reminiscence and Life Story Work: a practice guide*. London and Philadelphia: Jessica Kingsley Publishers
- Kemp, M. (1999). The reminiscence aids project. *Reminiscence Magazine* 19, 3-6.
- Kitwood, T. (1997). *Dementia reconsidered*. Buckingham: Open University Press.
- Melunsky, Crellin, Dudzinski et al (2013). *The experience of family carers attending a joint reminiscence group with people with dementia: A thematic analysis* (submitted article).
- Osborn, C., Schweitzer, P., & Schweitzer, A. (1987). *Lifetimes: a handbook of memories, ideas and 30 laminated pictures (4 of each) for reminiscence groups*. London: Age Exchange.
- Osborn, C. (1993). *The reminiscence handbook: Ideas for creative activities with older people*. London: Age Exchange.
- Quinn, C. (1989). *Honouring memories: An evaluation of the work of the Age Exchange Reminiscence Project*. London: Centre for Policy on Ageing.
- Schweitzer P. (2007). *Reminiscence Theatre: Making theatre from memories*. London & Philadelphia: Jessica Kingsley Publishers.
- Schweitzer, P., & Bruce, E (2008). *Remembering yesterday, caring today: Reminiscence in dementia care*. London & Philadelphia: Jessica Kingsley Publishers.
- Schweitzer, P. (2011). Innovative approaches to reminiscence. In H. Lee & T. Adams (Eds.) *Creative approaches in dementia care*. London: Palgrave Macmillan
- Tomkins, A. (1986). *Campaign for a popular culture: A record of struggle and achievement; the GLC’s Community Arts Programme 1981-1986*. London: Greater London Council.
- Woods, R.T. (2009). *Summary RYCT Project and findings*.
- Woods, R.T. (2012). *REMCARE: reminiscence groups for people with dementia and their family care-givers: Effectiveness and cost-effectiveness pragmatic multi-centre randomised trial*. London: HMSO: Health Technology Assessment.

### **Reminiscence in Dementia Care: Advanced Notification of 2014 International Conference in London UK**

The European Reminiscence Network will be hosting an international conference on reminiscence in dementia care on June 26 & 27, 2014. It will be held at the University of Greenwich (Maritime Site). With support from the European Commission, this conference will draw together from across the world practitioners who have been pioneering creative approaches to reminiscence and life story work with people with dementia and their family, or other carers.

Partners from 12 European Union countries have been co-operating in developing the “Remembering Yesterday, Caring Today” project in their own countries, and adding to it the creation of life-story based artistic end-products, developed with support from artists, theatre workers, dancers, musicians and film makers in each country. At the conference some of these products and the stories behind them will be shared.

The European Reminiscence Network will also be show-casing its new training and apprenticeship scheme, through which dementia specialists and arts workers can become accredited as reminiscence arts group facilitators. Piloted in 2012, this scheme is now fully up and running and proving very popular.

This conference has limited places, so early booking is recommended. Please contact Marta Moreno on [mmlopezdeuralde@gmail.com](mailto:mmlopezdeuralde@gmail.com) for further details.