

Evidence Briefing – November 2017

Remembering Yesterday, Caring Today – participants' voices

Summary

The participants of RYCT were uniformly positive about their experience. They reported that their expectations were exceeded. RYCT was far more enjoyable than other groups they had been encouraged to join. Participation resulted in immediate positive impacts, not least in terms of feelings of connectedness. The creative activities were embraced – although participants expressed personal preferences – and the resultant reminiscences were enjoyed and shared. The fun that underpinned each session was welcomed. Participation improved wellbeing for people with dementia and family carers alike. In addition, there were important impacts:

- 1) the people with dementia and their family carers reported deeper and renewed understanding of each other
- 2) the new memories created by participation in RYCT were welcomed, as well as the opportunities it afforded to meet other people
- 3) participants said that they felt validated by the process; their experiences were celebrated, and their contributions valued
- 4) recalling memories had positive effects for family carers; they remembered things they had forgotten and discovered things they had never known, they also valued hearing - and sharing - others' reminiscences
- 5) the techniques they had learnt for recalling the past could be used at home, sustaining and continuing the learning

The positive health effects of participation lasted as long as RYCT did. The nature of dementia – as a condition of continuous cognitive decline – meant there were few lasting long-term effects on the health of the person with dementia, despite some participants' hopes that participation would reverse its effects. Participants requested opportunities to participate in RYCT in the future, in addition to other opportunities – which they also embraced and valued.

Introduction

Remembering Yesterday, Caring Today is a structured, twelve-week, closed group programme which uses reminiscence techniques to improve the wellbeing of people with mild to moderate dementia and their family carers. People with dementia attend with a family carer – usually a partner, son or daughter. The purpose of the group is to engage each one fully and equally.

Each session lasts for two hours and includes interactive exercises and opportunities to talk to others. There is a tea break approximately half way through which features

homemade cake. Each session has a familiar rhythm, but the focus shifts each time. The 'curriculum' follows phases of our lives, from childhood and school, to leaving home, socialising, getting married, having a family, travelling. Typically, each session contains an element of mime, role play, music and singing, drawing, group discussion and listening. But these activities are not the purpose of the work; they are the means to unlock memories, to share memories and to revisit the past.

The delivery is led by two facilitators, with experienced volunteers in supporting roles and a cadre of apprentices – trainees, usually drawn from people who are skilled in creative arts who are looking to work with people with dementia and their carers. All participants – including the facilitators, volunteers, apprentices, people with dementia and their carers – begin the session in a large circle. The venue is a welcoming and non-clinical setting.

Remembering Yesterday, Caring Today has been developed over 20 years, across the world, led by Pam Schweitzer MBE, and promoted by the European Reminiscence Network. The European Reminiscence Network aims to promote best practice in reminiscence work and to share experience across national frontiers. The Network now has partners in 20 countries and associates in USA, Canada, India, Australia and the Far East.

<http://www.europeanreminiscencenetwork.org/>
<http://www.rememberingtogether.eu/>

In the past, RYCT has been financially supported by the European Commission and the National Lottery.

Current research and policy

- I. Social networks maintain and enhance the health and wellbeing of vulnerable people, people with long term conditions, as well as older people in general, including carers. Conversely, loneliness and social isolation can lead to a) poor mental and physical health and b) reduced life expectancy (Griffin, 2010; Davidson and Rossall, 2014).
- II. Structured group work can build social networks. It provides regularity and rhythm by meeting at the same time, at the same venue and following familiar formats which bring routine and ritual - central facets of effective group practice (<http://infed.org/mobi/group-work-principles-theory-and-practice/>).
- III. The importance of providing therapeutic opportunities for people with dementia and their carers to be creative, harnessing the arts, is well established (Beard, 2012; Young et al, 2016) and was supported by the All Party Parliamentary Committee (APPG, 2016).
- IV. Participation in arts based group activity brings routine and opportunities for expression and interaction - critical in maintaining wellbeing and managing associated low mood and anxiety, common amongst people with long term conditions, including dementia, and their carers (Stevens, 2012; Craig, 2014).
- V. Reminiscence activities are useful in improving the wellbeing of people with dementia and their carers (Shik et al, 2009). To be effective, they must be culturally appropriate and relevant.
- VI. The Government's has recently refocused policy in health and social care from crisis intervention to preventative measures - keeping people as well as possible for as long as possible. In addition, person centred care which seeks to tailor

services and responses to the needs and aspirations of individuals is critical (HM Government, 2011).

- VII. Structured activities have been seen to be beneficial in the early stages of dementia – there is no claim to reverse or cure, but to slow progression, maintain wellbeing and counter low mood and anxiety (Zeilig et al, 2014).

Methodology

The purpose of the evaluation summarised in this briefing is to understand the value of RYCT for participants as well as to strengthen current practice. It is recommended that health and social care commissioners consider the content of this briefing to support funding decisions and resource RYCT interventions in their localities.

The evaluation was focused primarily on outcomes – the direct benefits to participants. Observations about process and delivery were also noted. The evaluation used qualitative research methods to build an in depth understanding of participant’s experiences. These included one-to-one in-depth interviews, workshops, participant and non-participant observation, as well as analysis of the content of emails and letters from participants. 11 sessions were observed in the 2016/2017 Camden cohort, supported by Camden Carers. Self-reported changes over the course of RYCT were also analysed. 26 people were interviewed. Where possible, findings were analysed in relation to themes established through published research. In addition, themes emerged from interviews and observations.

Key themes

1. **Dementia can lead to social isolation and loneliness.** Several participants explained how, as dementia progressed, opportunities to socialise reduced. On occasion, friends withdrew, unable to adapt to the changing circumstances. On other occasions, the person with dementia and their partner withdrew from friends, wishing to conceal the challenges they faced. The reasons for this were varied. They described the stigma they felt, the embarrassment that disinhibition in public places brought, and the discomfort they felt when ordering meals in restaurants, for example. Most public places were not dementia friendly. For some, the initial period after diagnosis was characterised by anger, confusion or denial. Old friends were sometimes lost in the period of transition.
2. **Participation in RYCT built friendships and widened social circles.** Participants agreed that participating in RYCT created opportunities to get to know others – both people with dementia and carers – who were, as one participant put it, ‘in the same boat’. They could talk about their situations without fear of being judged or misunderstood, ‘everybody knows, there’s no need to explain’.

3. **Several participants expressed uncertainty of the benefits of participation initially.** A small number worried whether the group was for them at first – if they had not pursued dementia specific activities to date, for example. However, having attended, met others, and receiving support, they became more confident in coming to RYCT. They also became more confident in naming the illness. As such, they could take practical steps to prepare for the future. These participants noted that it was unlikely that they would have been ready so quickly without the support of the group, and the reassurances of others.
4. **Establishing trust was critical.** Participants reported that facilitators created a safe environment for participants. This included ensuring physical safety as well as clear boundaries and reassurances. The more willing participants were to share personal stories and anecdotes, the warmer and more productive the group work was. When participants were confident that they would be well received, they participated more fully. Participants commented how the inexperience of apprentices in the early sessions sometimes created momentary confusion, and slowed the establishment of trust. However, as confidence grew, and relationships were built, these issues dissolved.
5. **New friendships emerged.** On occasion, couples socialised outside of the group. Some of the participants had known each other previously, but attending RYCT together had enabled them to cement their friendships, ‘we knew each other from a distance, but had never spoken before’, said one. The person with dementia and the family carer, seldom spent time apart. Participation in RYCT provided opportunity to mix with others, including the apprentices. As one participant noted, ‘we can talk to other people which is good for us both’.
6. **Meeting other people in similar circumstances was beneficial practically.** Participants heard about other opportunities to socialise, additional sources of help and support, and how to access other groups. ‘We heard about other groups here’, said one participant, ‘like this, it has become an important part of our week’. The success of attending groups depended largely on how advanced someone’s dementia was and how happy they were to settle and interact.
7. **Participants enjoyed coming to the weekly meetings.** Their participation was stable. On occasion, GP or hospital visits clashed and prevented attendance. However, they prioritised attendance at RYCT sessions over other events.
8. **Participants enjoyed RYCT activities.** At the heart of RYCT are creative activities – role play/acting, singing and music, drawing and crafts. People with dementia and their family carers drew significant pleasure from creative tasks, as well a sense of achievement, which strengthened self-esteem and improved mood. It was particularly striking how animated – or concentrated - people with dementia became when engaged in a favoured activity. Participants who were generally quiet would engage enthusiastically. Often, activities were undertaken jointly by participants in twos, or in small groups. The process of validation – where individuals’ efforts and contributions were celebrated – was positive. As one family carer said, ‘my wife was delighted when [the apprentice] said how much she liked the picture she had drawn’. Another noted, ‘[my husband] hasn’t danced like that in years’. Creative activities built a sense of

coherence in the group; they served to identify common ground and experiences. They also gave clues for initiating discussions at home and in the future.

9. **Family carers found support.** Participation in RYCT gave family carers a momentary rest and gave them opportunities to play and create. Over time, as friendships emerged, they were likely to meet up outside of the group, which provided extended opportunities for support. The opportunity to meet other carers was highly valued; the challenges they faced were, on occasion, daunting and isolating. Carers found caring for their partners increasingly challenging, as their needs intensified. Communication between people with dementia and family carers often became strained, and external friendships altered as social opportunities reduced. Meeting people facing similar challenges meant that experiences were exchanged; advice and information were shared. Whilst other people might express empathy, meeting other carers brought a stronger source of support and encouragement to keep going.
10. **Participants identified the specific benefits of reminiscence.** Participation in creative activities had a clear intrinsic value. However, in RYCT they were carefully selected and used in the service of triggering memories, to recall and share past events and in so doing, reinforce participants' identities. Creative activities triggered discussion about the past – these ranged from work and family life, to trends and fashions that they followed to pop songs they liked and momentous political events in which they engaged. Participants particularly enjoyed the sessions which focused on school days and weddings – where laughter and tears were common, and memories were shared and re-enacted. It reminded them of who they were, and who they still are, as individuals as well as what they had achieved together.
11. **Participants felt valued and respected.** Participants reported that they felt as though they had lost the respect of others, that their views and opinions had ceased to be valued, that few people showed interest in them or their achievements any more. As one participant commented, 'we fought for so much, to be together, to have a family, nobody sees that anymore'. People often spoke down to them. Participants reported the opposite about RYCT. According to family carers, the interactions with the facilitators, volunteers and apprentices affirmed participants as individuals. They felt that their stories were celebrated, and their interests valued. Apprentices focused on making participants feel important, ensuring that they remained at the centre of the reminiscence activities. Participants became animated when they, and others, spoke about their past.
12. **RYCT had a deep, positive and affirming impact on participants.** They demonstrated in their interactions with each other, as well as in the evaluation interviews, a renewal of intimacy with each other. They reflected how, by retracing their steps through life, and reflecting on important moments – their childhoods, working lives, holidays – that they had, in some measure, re-found each other. The stories and anecdotes they recalled, the photos they unearthed, and recollections of the places they visited had reminded them of the adversity they had overcome, the joys they had shared, and the longevity of their relationships. One participant spoke eloquently about how she had not simply rediscovered the joy of spending time with her mother, and reconnected with memories of her childhood, but she had discovered new things about her that she had

never known. She had learnt about her life before she married and had children. Participation on RYCT had enabled her to understand her mother better, she said. She had been reminded about incidents in her mother's life that she had long since forgotten, as well as discovered things hitherto unknown.

Several family carers spoke about the fact that their relationship had not always been easy since diagnosis, and spending time together on RYCT had allowed them to recapture a sense of fun and closeness which had been missing for some time. One reflected that in focusing on his mother's worsening circumstances and growing needs, he had stopped being curious. RYCT had restored his curiosity in his mother. As a result, it had been a time for healing. There were new memories that he would cherish. And there was a new-found peace in their relationship that he welcomed.

13. **RYCT gave participants more than other structured activities.** The group facilitators, volunteers and apprentices – and increasingly throughout the process as they settle and gain confidence, the participants themselves - created the conditions in which moments were recalled, tiny fragments were assembled, stories were told and retold. Sharing anecdotes – such as recollections of dancing with a famous screen actress at a ball – or actions – such as getting up to play the piano or accordion - meant that participants built strong bonds, and took delight in what each could bring. The impact of this was clear, participants renewed their identities on RYCT, they refreshed their purpose and validated their relationships. It was these aspects which differentiated RYCT from other activity-based interventions for people with dementia and their family carers.

When asked what the key difference was between RYCT and other groups they attended, participants reflected on the fact that the RYCT method encouraged participants to get to know each other, to identify shared experiences, to share their talents and interests, to connect and reconnect, and to remember. It was the interactive nature of the programme that separated it from others.

Additional observations

- A colleague from a leading dementia charity attended one of the meetings to observe the session and deepen her understanding of RYCT. She said that when she walked in she could not immediately tell who had dementia and who did not. Her reflection was that RYCT created an environment in which people, regardless of whether they had dementia or not, were participating collectively, in an equal way.
- The success of RYCT was in no small part a result of excellent administration and the dedication of colleagues who serviced the project.
- It was important that everyone could hear what was going on to encourage participants' contribution. Poor hearing is often a challenge for participants and could inhibit participation. Apprentices worked with couples to repeat and amplify key messages.
- The weekly themes, which reflected the sequence of major life events were important in creating a focus with which most participants could identify. They

brought stories and memorabilia to share and – on occasion – completed their journals/memory books.

- A volunteer brought home made cakes for each session. They were served during the tea break, half way through the session. The cakes were universally well received. It was clear that the cakes had a greater significance; they gave a clear signal of how much the participation of the couples was valued.

Apprentices

The engagement of apprentices in the delivery of RYCT is a critical factor in its success. It is built on a unique approach to training reminiscence group practitioners, whose theoretical learning and opportunities to reflect are tied closely to the delivery of RYCT.

Apprentices attend two days of intensive training exploring issues critical to the design, delivery and evaluation of reminiscence sessions. This training has been developed over 20 years and draws upon international expertise and experience. Apprentices rate the training highly and reflect upon its critical role in preparing them for the twelve sessions ahead. Apprentices follow the course detailed in Schweizer, P. and Bruce, E. (2008). Remembering Yesterday, Caring Today – Reminiscence in Dementia Care. A Guide to Good Practice: Jessica Kingsley

For the apprentices, RYCT comprises twelve 4-hour sessions which run from 1 pm to 5 pm:

- The first hour is dedicated to preparation. Apprentices learn the importance of: setting up the room; ensuring all apprentices were 'on task'; warming up physically and vocally; building supportive relationships with others; honing interactive skills; posing questions; building confidence to guide activities and work intensively with the couples.
- Hours two and three are the meat of the programme, working with the facilitators, volunteers and participants. The sessions are structured around predetermined themes such as 'school days', 'first jobs and homes', and 'trips and holidays'. A summary of the previous session is presented at the beginning of each session. The session is also summarised before its close. Apprentices are supported to develop their skills in delivering elements of RYCT over the twelve sessions, drawing upon their expertise in the creative arts, reminiscence and dementia care. Close working is encouraged, with each apprentice taking responsibility for couples each week.
- The fourth hour is spent tidying up and debriefing, and reflecting on the session - what went well, and not; sharing observations and concerns about dynamics; developing understanding of the progression of different types of dementia; appreciating the exhausting and often stressful task of caring; preparing the next week's session.

In debrief and in research interviews, apprentices said that the technical skills they had learnt in designing, delivering and evaluating RYCT sessions were useful, stimulating and transferable to other situations. It was hard work, but rewarding. In addition, they often referred to their participation as 'a journey' which had strengthened their compassion and empathy, as well as self-knowledge, and matured their approaches to working with people with dementia and their carers.

Upon successful completion of RYCT, and the submission of a 3000-word reflective essay, apprentices receive a certificate which recognises their learning and enables them to co-deliver RYCT.

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