

**MARGE**

**Reading is Caring Evaluation  
(Year 3)**

**Executive Summary**

**Written by independent evaluator  
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This report has been written using the Scottish Book Trust's accessibility guidelines. As a result, there is minimal use of design features, with alt text added to any infographics to allow for ease of readability on screen readers.

The findings in this report relate to evidence captured and made available between August 2022 and July 2023.

Please note that this report includes direct testimonials and content related to palliative end-of-life care which some readers might find triggering.

Any enquiries about this report should be directed to Koren Calder.

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**“Reading is Caring has a massive impact on patients’ quality of life and also the relationships of relatives and their loved ones. It can bring magic moments and that’s worth a great deal to people.”**

**(Professional Care Partner)**

# 1 Executive summary

## 1.1 About the programme

Reading is Caring (RiC) uses reading to support people living with dementia and anyone who cares for them. Through a free workshop programme, family and professional care partners are trained to create personalised and shared reading experiences for those they look after. The ultimate aim of the programme is to use reading in a positive way, to support the relationships and wellbeing of people living with dementia (PLWD), and those who care for them.

This report shares evaluation findings from year 3 of the programme, covering the period August 2022 – July 2023. Workshops were delivered in a variety of formats, in direct response to the flexible needs of care partners identified in year 1 and 2.<sup>1</sup> These included:

- 1-hour, one-off sessions, delivered either face to face or online, typically with dementia cafes or dementia support groups e.g. Dunbar Dementia Friends Group. These sessions operate as a fast-track introduction to RiC, giving care partners the opportunity to learn more about the approach, its benefits, and to sign up for the core online training programme.
- 4-hour training sessions attended twice (a total 8-hour experience) either as a 1-1 or in small groups. In these tailored sessions, participants are encouraged to explore the life story of the PLWD. As a result they have time to reflect on their relationship, learn shared reading story skills and gather specific reading materials and objects for life story (and often sensory) book boxes.

A pilot with libraries was also delivered in year 3. These were designed to be delivered as 1-hour sessions over 6 weeks at the following libraries: Musselburgh, Penicuik, Craigmillar, and South Queensferry<sup>2</sup>.

Reading is Caring is funded entirely by donations to Scottish Book Trust. The programme is generously supported by Better World Books, the D'Oyly Carte Charitable Trust, The DWF Foundation, The Hugh Fraser Foundation, The William Syson Foundation, The Nancie Massey Charitable Trust, and donors who wish to remain anonymous.

## 1.2 What is the evaluation setting out to measure?

The logic model framework for RiC was refreshed at the start of year 3<sup>3</sup>. It outlines a series of intended outputs and outcomes for PLWD, Family Care Partners, Professional Care Partners<sup>4</sup> and Library Staff. This evaluation report assesses whether these outputs and outcomes have been met, to review whether the programme has achieved its aim. It also considers unintended outcomes for each beneficiary. A process evaluation has also been conducted to reflect on: project aims and ambitions, the recruitment process, project design, project management (including evaluation) and staff support.

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<sup>1</sup> The programme was also able to be more agile and maximise on opportunities available in face-to-face settings due to Covid-19 restrictions being lifted this year. However, it should be noted that there continued to be implications on attendance and engagement of face-to-face sessions, especially at the beginning of the year and for those continuing to be cautious or shielding.

<sup>2</sup> Not all sessions went ahead due to attendance levels. This is also highlighted in section 4 (process evaluation).

<sup>3</sup> Available on request.

<sup>4</sup> Outcomes are defined as the benefit, difference or change the project team want to make for beneficiaries as a result of Reading is Caring (Year 3).

## 1.3 Headline facts and figures



### 1.3.1 Profile

Although there are no set targets based on profile, findings suggests that the programme is reaching those in the most deprived communities of Scotland (with n=13 trainees residing or working with PLWD in SIMD 1 – SIMD 3<sup>5</sup>). The majority of trainees were aged between 45 – 65 years old, identified as female, heterosexual, and White/White Scottish/White British<sup>6</sup>.

## 1.4 Key findings

The below narrative provides an overview of the top-level findings structured by the four target beneficiaries<sup>7</sup>.

### 1.4.1 Person Living with Dementia (PLWD)

- Although we are reliant on family and professional care partner feedback, there is strong evidence to indicate that people living with dementia have enjoyed the RiC experience. This is attributed to the tailored, personalised approach with both reading format and content.
- Large format books were frequently referenced and well received this year, predominantly due to the short narratives and illustrations (which aid conversation) and the physical size

<sup>5</sup> SIMD 1 the most deprived, and SIMD 5 being the least deprived.

<sup>6</sup> See Appendices for more detail on profile.

<sup>7</sup> There are several limitations within the methodology which should be noted: these can be reviewed in the main report along with the list of data sources drawn upon for evidence.

(which allows the PLWD to see clearly and/or hold the book themselves which gives some agency).

- It is evident that care partners are shaping and developing RiC approaches following their experience with training, to fit the specific needs of the PLWD. The genuine encouragement and permission that care partners are given by the SBT team to ‘make it their own’, positively contributes to this person-centred approach.
- Independent observation and a range of anecdotal examples from care partners highlights how RiC provides a meaningful focus for two-way engagement and gives the PLWD an opportunity to spend more quality time with their care partner. From RiC inspiring conversations with loved ones, through to encouraging verbal or non-verbal behaviour for the first time that day, the programme provides temporary respite from the everyday routine of living with dementia.
- Having the opportunity to engage in a shared reading or Life Story Book Box experience temporarily shifts the power dynamic, creating a more equal balance between the PLWD and their care partner. Being able to make decisions, however small, empowers and gives agency to the PLWD at a time where they may have little control over other aspects of their life. The report finds that the SBT team are positively enabling both the PLWD and care partner to create this agency through their tailored, person-centred approach.
- Anecdotally we know that RiC is having a positive impact on the mental health and wellbeing of the PLWD, for example by improving mood, providing a sense of calm, increasing frequency of speech, and encouraging them to be more present. The programme continues to meet four of the five recommended daily actions or steps of the NEF Five Ways to Wellbeing (2008),<sup>8</sup> as it did in year 2.

#### 1.4.2 Family Care Partners

- Family care partners rated their experience of the training highly, and subsequently enjoyed their shared reading experience. The personalisation of the training and overall personable and empathetic nature of the trainers were particularly praised. Trainees are highly likely to recommend the programme to others, and as such, there is an opportunity for SBT to exploit this through providing bespoke ‘recommend a friend’ marketing materials to share with others.
- There were few suggestions for improvement, but when raised these tended to be practical ideas related to the training experience – such as being made aware that sessions would take place on a 1-1 basis.
- The RiC programme has encouraged family care partners to learn new skills and knowledge across four core areas: understanding dementia, techniques in shared reading, ideas for putting together Life Story Book Boxes and specific knowledge on reading materials. They have been keenly supported through highly rated after care (by email/phone) from the SBT team, and through cross-pollination of ideas between participants at training sessions.

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<sup>8</sup> <https://neweconomics.org/uploads/files/five-ways-to-wellbeing-1.pdf> and <https://neweconomics.org/2008/10/five-ways-to-wellbeing>

- The level of personalisation is frequently cited as setting RiC apart from other dementia support programmes. This should continue to be utilised as a key unique selling point in marketing materials.
- The findings indicate that a critical success factor for developing confidence in shared reading is having highly empathetic trainers, who provide reassurance and encouragement. This approach 'normalises' shared reading, making it feel less 'awkward' and has frequently had the impact of changing family care partner perceptions about what may or may not work with the person they're caring for. Those who have used RiC over a long period of time are now flexing the model and introducing new elements such as music to enhance the experience further.
- The programme is providing a constructive way for family care partners to continue enjoying activities together with their loved one, often generating a renewed sense of connection with the PLWD. RiC is giving families the simple permission of finding time and space to engage in something meaningful. One of the key highlights for several family care partners has been finding out that the person they are caring for can still engage with them in a positive and interactive way.
- There are several health and wellbeing benefits for family care partners who have tried RiC since their training experience. These were described as improvements to mood, being less stressed/more relaxed, and feeling helpful rather than helpless, with evidence across four of the five ways to wellbeing<sup>9</sup> recorded in the findings.
- There is some evidence to indicate that those taking part in the library pilot have experienced a greater connection with the library service (for example an increased awareness of what the library has to offer), however further research is needed to draw any robust conclusions.
- The findings include some powerful unintended outcomes, including how RiC has encouraged family care partners to return to reading independently; using RiC journals to support the grieving process; being inspired to think creatively and purchase or borrow new types of book which are then recommended to others; the ripple effect of RiC to other family members or professional care partners; using RiC in traumatic circumstances including end-of-life experience; and RiC exceeding expectations.

### 1.4.3 Professional Care Partners

- Professional care partners experienced high levels of satisfaction with the training and have subsequently enjoyed delivering RiC in people's homes and in broader care settings. As with family care partners, this was commonly attributed to a range of factors including the knowledge and empathy of the trainers, personalisation, permission to flex the RiC model, and usefulness.
- There were limited suggestions for improvement, although professional care partners agreed with family care partners in terms of being more aware of the online group size beforehand; and another proposed having multiple copies of the handbook so that they

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<sup>9</sup> <https://neweconomics.org/2011/07/five-ways-well-new-applications-new-ways-thinking>.



could always have a clean reference copy. Findings also indicate that it will be necessary to more readily ensure future training and promotion materials are inclusive for those with lower literacy levels or learning difficulties such as dyslexia.

- Continuous staff training on dementia healthcare is reportedly limited due to budgets, with professional care partners often having to undertake training ‘beyond the basic’ in their own time. Whilst this is identified as a potential barrier to professional care partner attendance, it has positively benefited those engaging with the training in terms of increasing and improving their skillsets. For example, they have learnt shared reading techniques and ideas for personalisation, where to find reading materials, and gained a greater knowledge of dementia which has subsequently empowered them. This highlights that RiC is potentially helping to fill a knowledge gap in dementia healthcare training, although other further research is needed to more robustly evidence this. Having free, flexible, and online training options were critical success factors professional care partners’ engagement in the programme.
- Evidence suggests that professional care partners have increased their confidence in shared reading, predominantly because of the SBT team’s encouragement and permission to flex the model to include their own creative ideas.
- Professional care partners report that RiC provides a helpful way to spend quality time with the PLWD, carving out space and time to focus on getting to know them better. It takes conversations away from typical medical or personal care-based tasks, providing a sense of ‘normality’ and enjoyable conversations instead.
- There were several unintended outcomes for professional care partners, including delivering RiC through using games such as ‘Call to Mind’<sup>10</sup>; developing long-term friendships with families; the opportunities to use RiC alongside doll therapy<sup>11</sup>; and inspiring more person-centred care conversations between care partners. Life Story Book Boxes were also particularly motivating for professional care partners, with one trainee expressing the importance of creating these early in the dementia journey as a way of futureproofing memories before it is too late.

#### 1.4.4 Library Partners

- There is some evidence that library staff have gained new skills and knowledge about how to welcome PLWD into the space, and how to more readily support their care partners, for example through providing options for socialisation, giving book recommendations and signposting to dementia support groups.
- SBT has successfully distributed RiC training DVDs to libraries across the target areas, and these are well placed to provide these to library users as part of their dementia support signposting. However, exploring additional digital engagement options for those without DVD players is recommended.<sup>12</sup>

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<sup>10</sup> <https://livingmadeeasy.org.uk/product/call-to-mind-board-game-for-dementia-care>

<sup>11</sup> <https://www.dementiauk.org/get-support/living-with-dementia/doll-therapy/>

<sup>12</sup> The evaluator recognises that SBT are building an online learning portal which will provide a useful alternative.

- Library staff satisfaction with the RiC programme was high. RiC is seen as a unique programme which can play an integral role in helping library services achieve their strategic goals around dementia; it complements rather than duplicates existing library offers to support those living with dementia and their care partners.
- Library staff are time poor and have limited capacity for building audiences. The pilot revealed that working with libraries who have existing connections with dementia community partners and routes into audiences was therefore most successful. One library partner suggested it may be possible to work with libraries in community settings outside of the library space in the future, to improve access and reach more people.

#### 1.4.5 Overall summary and recommendations

The report gives the following series of recommendations, drawn from the findings across both impact and process evaluation.

- The SBT team have achieved their targets for year three by being responsive to the needs of the target audience, and successfully offering a variety of engagement opportunities from one-hour shorter sessions through to ‘deep dive’ online training workshops. Providing a choice of training offer should continue into next year (with family and professional care partners trained separately wherever possible) to ensure the RiC programme is inclusive and accessible. Formally outlining a user ‘training pathway’ both internally and externally to show the intended learning progression ladder may be useful for demonstrating both the benefits and expected achievement levels of each training type. This could potentially be incentivised in some way e.g. through certification/badges to encourage participants to continue their journey of learning when they can.
- The last three years have been a period of testing and experimentation for the RiC programme, with SBT staff also having to readily adapt to changing situations including the impact of Covid-19 on programme strategy and delivery. It would be beneficial for staff wellbeing and workload to aim for a period of stability over the next twelve months. Drawing on their strong evidence base of what works well and less well; and the recognised long lead-in time for partnership development, staff should be confident in taking a more consistent approach in 2023/24 which puts their learning into action and focuses on depth rather than breadth. As identified through process evaluation, piggy backing on existing community social prescribing partners (such as Be Able<sup>13</sup>) is likely to be a better use of SBT staff time, rather than engaging directly with GP surgeries which has proved a challenge.
- Although the RiC programme is having a hugely positive impact on both care partners and PLWD, the direct and indirect impacts (due to the potential ripple effect of training) may not always be obvious when simply considering the monitoring data from the programme. It is vital that any presentation to funding bodies or to senior management includes the qualitative story of impact highlights, so that the figures are not presented alone. They only tell one side of the story and do not show the depth and potential breadth of impact.
- There are some practical areas for improvement highlighted in the findings. However these are easy-to-remedy pointers around the training programme such as managing expectations

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<sup>13</sup> <https://www.edinburghhsc.scot/livingindependently/beable/>

on training attendee numbers, adjusting one of the recommended scripts that references mortality, and sending multiple handbooks to professional care partners. Pending further funding and once a new member of RiC staff is in place, building in training elements identified on the long-term plan will become more realistic, for example undertaking a training needs analysis with care partners. This will identify areas such as existing knowledge about dementia and personalisation needs more readily in advance.

- The evaluator recognises that the SBT team are already investigating ways to make their marketing materials more sustainable, accessible and inclusive; however, it may be worth some specific conversations on the barriers due to the name of the programme. For example, how can RiC be more accurately portrayed through videography, photography and copy given that it is challenging to get across what 'Reading is Caring' means. Similarly, the term 'reading' may be a barrier for engagement and does not necessarily convey the reality of RiC, for example shared storytelling through podcasts, photography or other conversation stimulus referenced in this report. In addition, segmenting promotional communication by target audience (e.g. family care partner and professional care partner) would help streamline copy and ensure different barriers and drivers are responded to. It may also be necessary to review training content to ensure it is accessible for a wide range of audiences including those identifying as neurodivergent or with learning difficulties such as dyslexia.
- There is a huge opportunity to maximise word of mouth as a marketing tool, given the positive ratings with satisfaction and high propensity to recommend. Consider providing bespoke 'recommend a friend' incentivised print for participants to pass onto others, and use testimonials from those who have experienced RiC. Proactively provide a way for those attending shorter RiC experiences such as the 1-1 sessions at dementia support meetings to opt-in for more information via a mailing list (rather than expecting them to get in touch).
- There are various potential striking key messages raised in the findings that could be useful to incorporate into copywriting for both promotional communication and fundraising purposes. For example, community partners suggested that RiC is set apart from other dementia support schemes due to its aftercare and the personalisation; and family care partners did not expect to experience a renewed sense of connection with the person they are looking after. Professional care partners seemed particularly responsive to the opportunities of Life Story Book Boxes this year. Use the intended and unintended outcome data outlined in the report to help copywrite powerful key messages.
- The evaluation has highlighted opportunities for further research which could provide more robust data. For example, the SBT team may wish to commission a more detailed and specialist research study into the impact of RiC on PLWD's wellbeing; they may also want to consider why the project seems to attract those at the later stages of their dementia journey; and to what extent RiC is plugging a gap in dementia healthcare training for care workers.
- It is not currently within the remit of SBT, nor possible with the RiC staff team capacity to provide continuation of support to bereaved care partners. However, it may be useful to create signposting materials which list location-specific reading groups and community organisations that can support family care partners who are grieving.

- The SBT team has successfully deposited DVDs across a large range of care and library organisations. However, these are difficult to track in terms of usage and not everyone has access to a DVD player. The evaluator supports the intended move to an online platform on SBT’s website which will host the DVD content and provide a choice of digital engagement method.
- As outlined in this report, there has been a huge amount of learning from the library pilot this year. Working with a flagship library in each target area with strong local connections to dementia support agencies and organisations is likely to prove more successful than building an audience from scratch<sup>14</sup>. The SBT team should also be confident in discussing delivery opportunities outside the library space if this works better for audience engagement.
- SBT may wish to explore whether enthusiastic and supportive library staff in 2023/24 could potentially be trained to deliver RiC as a pilot, working within their own organisational safeguards. However, it is advised that any volunteers drawn from the community should – certainly for the time being – be recruited solely for areas of the programme which can be delivered safely, appropriately, and ultimately more usefully. For example being community ambassadors and promoting RiC to others.
- Exploring opportunities to present at relevant health care sector conferences may be a worthwhile PR exercise and partnership development opportunity. Delivering a paper may not be feasible in 2024 due to staff capacity, however researching and registering to receive call for paper opportunities in 2025 could be actioned.
- Consider what is going to represent best value for money in terms of conducting programme evaluation in year 4. If the SBT team feel it is feasible within their time constraints to undertake evaluation in-house, budget could be saved and put into programme delivery, or spent on exploratory research rather than evaluation e.g. researching longitudinal impacts that could be used for advocacy rather than evaluation purposes.

#### 1.4.5.1 Project aim achievement summary

Project aim	Status
To support the relationships and wellbeing of people living with dementia and their carers through personalised shared reading and Life Story Book Boxes	Achieved

#### 1.4.6 Sample testimonials

*“It was just so amazing to find something that actually gave Mum some comfort and joy for a period as well.” (Family Care Partner – Depth Interview)*

*“The highlight was one PLWD volunteering and reading the Daffodils poem from start to finish and everyone clapping after he had done this. He could not*

<sup>14</sup> This is planned by the SBT team for year 4 and beyond. Evidence from this report supports this approach.

*stop smiling. His carer said to me as I was leaving "I have never seen him do that and I didn't even know he knew that poem!" (SBT staff member – Anecdotal Reflections)*

*"She hadn't spoke to me all day that day, but spoke when she saw a butterfly on the Lost Words page." (Family Care Partner – Depth Interview)*

*"Allowed Mum to reconnect with stories she's loved in the past. Also it's reconfirmed her identity as a reader. She's always had books around and loved reading, so this reminded her of who she is." (Family Care Partner – Survey)*

*"We were all convinced that Mum couldn't read anymore. Like, she just didn't seem to, but she actually started reading with me [through RiC]. And we figured out what was wrong with her glasses. So that was actually really joyful, because we were all pretty sure that Mum could not have the ability to do that anymore, and she absolutely could. That was actually from Keira's guidance that she said try and let her read. I don't think I would have attempted it. I just thought my mum can't read anymore." (Family Care Partner – Depth Interview)*

*"A chance to show care and empathy outside of the physical caring role. My client has become more relaxed and is opening up to personal memories – able to show signs of happiness at events being recalled. Less agitation and more peacefulness after our reading sessions." (Professional Care Partner – Survey)*

*"I think it's improving the comfort and wellbeing of the people that I am providing care for." (Professional Care Partner – Depth Interview)*

*"It was really useful to have a tailored session, thinking about my father's interests and life history and what might suit him. This approach is very valuable." (Family Care Partner – Survey)*

*"Being a carer is tough, but this has been such a positive experience. Thank you!" (Family Care Partner – Survey)*

*"I feel like Playlist for Life for example, they might just say to a family care partner here are the resources, and maybe the organisation is less engaged beyond that. Whereas I felt like Reading is Caring were still largely taking responsibility for the programme after – if you ever needed the expertise of Keira, or Koren, then they would be there and available for that." (Community Care Partner – Depth Interview)*

*"We had a bit of fun remembering poems which we had learned at school. This is not something that I would have thought of doing." (Family Care Partner – Survey)*

*"Many thanks for the opportunity to take part in this training. I can see it's already making a difference to my father and is helping us to have some quality time together." (Family Care Partner – Survey)*

*“There is a need for more spaces for carers to come together and to be able to talk, and actually this offers a different way for them to do it, if you like. It offers them a specific project to do but also the space to meet other carers and get that peer support, which is really, really important.” (Library Partner – Depth Interview)*

*“I wanted to thank you and Keira for your help, support and "caring". I found it immensely helpful, interesting, and thought provoking. I am sure it will help [PLWD named] but will also enhance my reading, not to mention bringing me back to poetry.” (Family Care Partner – Emailed Feedback)*

*“I've got a journal with really special kind of titles or poems, my own little journey – or journal, journey of remembering. It kind of feels, at the moment, like this has been really quite a precious thing, a very personal thing. I think it's probably really helpful in this sort of grief period, it's almost kind of like it keeps you connected, and I've got something that I can go back and pick up this journal and read one of my favourite pieces...” (Family Care Partner – Depth Interview)*

*“I've never read like that before, it was really quite profound. My emotional response to that surprised me. It's really accessible isn't it.” (Professional Care Partner – Video)*

*“This training has positivity impacted my skillset. I am gaining confidence in delivering sharing book experiences, and I'm already seeing the positive difference this is making to my clients.” (Professional Care Partner – Survey)*

*“I do feel like this is a springboard of good things to come. My confidence will grow, and I think it's surpassed my expectations of what this course was going to be about. I'm really excited with it. It's a chance to care for someone beyond their physical needs and a lot of the time I think that's overlooked. This is such a beautiful way to bring in an element that's vital to someone's happiness. Making each visit count, making each day count. I'm really really thankful for you. This is one that I can see as useful, practical, and enjoyable. For me it's the balance of that power between carer and cared for, that's one of the really nice things about this project.” (Professional Care Partner – Video)*

*“When I have been reading together, I think it's going that one step deeper for me. It's been me sharing something of me rather than 'I have heated up this meal'.” (Professional Care Partner – Depth Interview).*

*“We found a shared interest in poetry.” (Professional Care Partner – Survey)*

*“I think it gives the staff more awareness of people living with dementia, and what they're looking for.” (Library Partner – Depth Interview)*

*“Really valuable training well put together; thank you very much.” (Professional Care Partner – Survey)*

*“The online format of the workshops was ideal for my schedule. The timing between workshops was well suited to trying out the ideas and regrouping in*

*the second session to consolidate and discuss my experience.” (Professional Care Partner – Survey)*

*“Keira was terrific. She was very, very personable.” (Professional Care Partner – Depth Interview)*

*“It’s really engaging and run by people that are clearly passionate about it. And also clearly had lots of knowledge built up as well, which is always nice. You’re not listening to somebody who is just reading off a textbook.” (Professional Care Partner – Depth Interview)*

*“The follow up has been terrific. It wasn’t just a case of do one workshop and you are kind of on your own and then do the second workshop and you’re finished. It has felt really quite personalised.” (Professional Care Partner – Depth Interview)*

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