



Reading is Caring

Year 4
(August 2023 – March 2024)
Executive Summary

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Executive summary

Reading is Caring supports people living with dementia and those who care for them (professional carers and family care partners) by adapting shared reading into a tool that benefits health, wellbeing and connection.

Reading is Caring first launched with Scottish Book Trust in 2019, where it began as a pilot programme in the Scottish Borders, later expanding into Edinburgh and the Lothians, and, as of 2023/24, into Fife.

Year 4 of this programme ran from August 2023 to March 2024, combining both online and in-person sessions with anyone caring for a person living with dementia. In Year 4, two-thirds (67%) of respondents reported attending workshops online, and the remaining one-third reported attending an in-person session either in a library, hospital or care centre.

The sessions reviewed a range of each person's needs, tailoring the programme to the person's diagnosis (both their specific dementia and how it manifests), their communication, environment, likes and dislikes, life story, as well as their care partner's needs and preferences. The programme considers all of these factors to ensure that participants leave with a personalised package of support – what relevant and appropriate pieces they will read, how they will read it, what techniques and approaches they feel confident in.

This personalised aspect, [as outlined in previous evaluations](#), is what sets Reading is Caring apart from other dementia support programmes.

Context

There are over 90,000 people living with dementia in Scotland¹. It is most common in older people but can affect people in their 40s and 50s or even younger. Around 3,000 of these people will be under the age of 65 years.

Dementia is an umbrella term for over 100 different types of diseases and symptoms, and it's possible to have more than one type. Dementia can affect every area of human thinking, feeling and behaviour, but each person with dementia is

different – how the illness affects someone depends on which area of their brain is damaged.

By 2031 it is projected that there will be approximately 102,000 to 114,000 people with dementia in Scotland, a 75% increase².

Lived experience can be lonely, isolated, affected by stigma; with loss, trauma and financial hardship experienced by many. Significant waiting times for assessment and the absence of a seamless diagnostic pathway acts as a barrier to early diagnosis and treatments and inconsistent approaches to commissioning and delivery of post-diagnostic support (PDS) means that people may not receive the support they need, when they need it³.

Aims

Overall long-term aims of Reading is Caring:

- Person living with dementia is able to live well with it
- Improved end of life person-centred care
- A more resilient and skilled care workforce
- Long-lasting memory making
- Reduced government spending

Outcomes for people living with dementia:

- Enjoy the experience
- Spend enhanced quality time with care partners
- Foster sense of self
- Improve mental health and wellbeing

Outcomes for family care partners:

- Develop skills and knowledge
- Develop confidence in using shared reading
- Enjoy the experience
- Spend enhanced quality time with PLWD
- Improve mental health and wellbeing

Outcomes for professional carers:

- Develop skills and knowledge
- Develop confidence in using shared reading
- Share enhanced quality time with PLWD
- Enjoy experience

Methodology

There are five primary methods of gathering evaluation data throughout this programme, as follows:

1. Digital surveys of care partners (16 responses)
The survey was sent out to a total of 21 people – 16 of the full course attendees, and 5 who attended an hour-long session, shortened at the employer's request.
2. Postal survey responses from care partners (3 responses)
3. Written reflections from programme team after each session
4. Monitoring stats across session attendees; digital engagement; and media coverage
5. Ad hoc feedback

Ethics

In order to ensure evaluations are ethical, Scottish Book Trust aligns with best practice in the sector, as outlined in Third Sector Research Forum's 2021 guide to applying ethical research principles framework⁴, which includes consideration of, the need for the research, integrity, accountability of the researchers, confidentiality and safety.

Main findings

In Year 4 of Reading is Caring, the programme team put forward two primary amendments to their process and delivery, namely a format change to the sessions (from two three-hour sessions to one three-hour session, and an optional follow-up), and a development of the programme leaflet to better target professional carers and family care partners, and to better cater to those with access needs.

From the assembled evaluation methods – including digital surveys of care partners, postal survey responses from care partners, programme team reflections, ad hoc feedback, and monitored stats and digital engagement – four themes emerge as the key outcomes from Year 4 of Reading is Caring:

- Engagement and enjoyment
 - 'Reading with someone you love so, so much with dementia with a book they can connect with somewhere (their home), a space they are comfortable and feel safe in, to read a book together. Get the book that the person living with dementia thoroughly enjoyed, and read together and can open up other conversations.'
- Shared memories
 - 'We do read a bit of poetry, but I've contacted relatives who live away, asking them to write a letter/card every so often, giving updates on their lives/families etc. We read those together. I'm also exploring old newspaper cutting from when he was in his 20s (Keira's idea), which has been a really good way of stimulating further memories/conversation.'
- High-quality training and workshops

- 'The training was excellent, format etc., and the trainer Keira was a lovely caring, understanding empathetic lady and lovely to speak to. The format was excellent ... and most importantly having the right person(s) to deliver the training like Keira is absolutely essential.'
- 'I think it is an ideal resource. It allows a really intimate shared space, something that can easily get lost when supporting people living with dementia.'
- Programme legacy
 - 'It gives us a strong sense of connection. It is something we can do together and both enjoy. It adds value to our very stressful lives.'
 - 'Reading is very important.'

Survey data provided quantitative insights into the impact of Reading is Caring – some highlights are included below (for sample size, refer to Methodology):

- 100% of respondents agreed that they 'enjoy the shared reading experience' and 89% agreed that the person they care for 'enjoys the shared reading experience'
- 100% of respondents also reported that, as a direct result of shared reading, they have 'a sense of being more connected to the person they care for'
- 81% of respondents agreed that they 'learned something new about dementia'
- 100% of respondents agreed that 'the training was delivered in a safe space where I felt comfortable sharing my experience with the trainers/other participants'
- 94% of respondents would recommend the training to others in a similar caring role
 - 75% of respondents rated the usefulness of the training as 'Excellent'
 - 94% of respondents rated the trainer as 'Excellent'
 - 81% of respondents rated the format as 'Excellent'
- 94% of respondents agreed that 'the training helped develop my confidence in using shared reading and life story book boxes'
- 88% of respondents agreed that they 'gained useful skills in how to deliver shared reading / create life story book boxes'

Conclusion

Reading is Caring is evidently fulfilling its programme aims to improve end-of-life person-centred care, nourish quality time between PLWD and their care partners, develop professional skills for carers, and enhance mental health and wellbeing for all participants.

The programme's emphasis on tailor-made support for health and wellbeing, both for PLWD and their carers, allows for quality time and shared memories between both.

It has proven benefits in advancing health and medical welfare through this person-centred approach, as shown in participants' feedback below.

The programme's advancement of medical welfare and care for those experiencing challenging circumstances around living with dementia – and those tackling the loss, isolation or loneliness that can occur after a dementia diagnosis – has led to positive feedback from all participants, emphasising their enjoyment, appreciation and value in Reading is Caring as a person-centred programme

This evaluation report authored by Scottish Book Trust Research & Evaluation Manager Éadaoin Lynch with support from Reading is Caring programme team members Koren Calder and Keira O'Sullivan.

Appendix 1

All quotations and anecdotes provided by Reading is Caring participants are included below.

- 'I just wanted to say how much I enjoyed the session with Koren.

You might like to mention to Koren that I read the fairy tale *The Ugly Duckling* with my sister tonight using some of the ideas she had suggested and I cannot tell you how much my sister engaged with it and really enjoyed it. So already can see the benefits so please thank Koren so much from me.'

- 'Just to thank you once again for a very helpful and encouraging training. I am sure Mum and I will enjoy trying out the ideas.'
- 'Thank you very much for the poem to print off, and for the links and resources.'

Yesterday after your workshop I went and did paired reading with Mum of the 'hot baths' story, I was delighted with how she was reading, with intonation and expression and understanding, we both laughed about the story, and she remembered that although they always had a bath at home, she did used to go to Warrender Park baths to swim when they lived in [childhood home] and some other memories and it gave rise to nice conversation generally.'

- 'In the last few weeks we have been reading chapters of *The 39 Steps*, as it is a short book with only ten chapters, so we do a little at a time, taking it in turns to read each paragraph and dialogue. My Mum is keeping up well, she laughs at appropriate times and it gives rise to some talk about Scotland where it is partly set, as well as the difference in customs now as it was written in 1915.'

I chose it because it is also a very familiar story, and one night we had Mum round for some supper and all watched the oldest film version of the book, with Robert Donat, which of course Mum remembered. We would like to try and stream another more modern version and watch that too, we can't decide between Robert Powell or Rupert Penry Jones versions! Perhaps my Mum would remember better the Kenneth More one.

We still go to the library regularly, this is a vital community resource which gets us out, with a purpose, and speaking to others even if just the librarian, it is stimulating and gives rise to conversations. At the moment we have out a book of short stories which I think we could also read together.

Although I only read with Mum about once or twice a week, I still see it as good thing to do, I think it gives her confidence that she can still read albeit with support.'

- 'I am really grateful for the time and the training as it enabled me to have more tools and confidence to lead a reading activity and make it more interesting. Thank you for your gentle and kind manner in delivery of the training as that really makes all the difference.'
- 'Thank you I really enjoyed meeting you too and the workshop sparked so many ideas.'

Mum is napping at the moment but hope to do some reading with her later and try out the nature box.'

- 'Yes, all fine for Monday morning at 9:30. Been getting good results with the nature box and extending it into the garden 😊'
- 'Really sorry but Mum is not interested in my reading to her.'

I also find it putting too much of a strain on my voice after teaching for three hours.

I've decided to wait until I've retired.

I'll have much more available time then.'

- 'Thanks for the opportunity.'
- 'I just wanted to give you a very quick update on how much I'm enjoying using the techniques and principles of the Reading is Caring programme.'

I have recently started work with a family as PA for their daughter with complex needs. Whilst there's no dementia present, there's an overlap of similar needs.

At interview, I spoke of my Reading Is Caring training and I'm convinced this helped me get the position! The family are hugely supportive of the technique and I'm delighted to say that reading together and enjoying poetry, books and magazines is an important part of our day.

One of the titles you kindly shared during the workshops was the National Trust poetry tome, *I am the Seed*. The family purchased this for us to enjoy together, and we read from it each day. I have adapted some of the poems as Story Massages. It's proving very successful to aid communication, as well as relaxation and fun too.

Tomorrow's 'poem of the day' is Judith Nicholls' *Windsong*. I'm sure you'll be aware that this gorgeous work is on the back cover of the book, and lends the collection its title.

I'm happy to attach my adaptation for Story Massage, and we will be enjoying this tomorrow.

Thank you for opening the door to – literally – a new chapter in my career. I thoroughly enjoy using the techniques you taught me. It's a real pleasure to embed Reading is Caring into our days together.'

- 'Thanks Keira, I really enjoyed the sessions. I'll feed everything back to our wellbeing co-ordinator who I am sure will be keen to work with you in the future.'
- 'Thank you very much for all the links, they look very interesting. I really enjoyed the workshops and have picked up lots of helpful tips and information.'
- 'Thank you for [sending across personalised suggestions] – that was really kind. I'm with him now and I've just shown him the article on my iPad (so I could zoom in) and he loved it. I've read the whole article with him, and he remembered quite a few of the other names.'
- 'You'll be pleased to know that my father's still doing well [...]

He's a bit slower, a bit more forgetful, but I've persevered making notes of his life, experiences and hobbies – then revisiting them with him, reading over the notes.

I've also had some success asking family to send newsletters. [...]

He'll be 95 this week, and my daughter is having all the notes made into a proper book for him. He'll love it.'

- 'What a lovely surprise to receive your beautiful 'Daffodils' greetings card! It really made my day 😊

I've put my lovely pin badge on my work lanyard. If we're out in the community or at an activity, I always have my lanyard on, so it will be a good talking point and conversation starter about the Reading is Caring resource and ethos.

As is the nature of serendipitous moments, I happened to notice my first daffodil in bloom today. It's been a glorious early-Spring day here in the Scottish Borders. The verse, *I Wandered Lonely as a Cloud* by William Wordsworth is a perfect choice for sharing as these little heralders of Spring brave the mixed weather and cheer us with their yellow flower heads.

Thank you for taking the time to pen a thoughtful note, and for the ongoing support.'

- 'Thank you so much for the training last week. It was so helpful, I really appreciate your time, and there was lots of food for thought that I can take into my role at the care home. I'll definitely look at sourcing a copy of *The Lost Words*. I started reading a fascinating book by Sally Magnusson about her mother's experience of dementia – *Where Memories Go*. She had been a journalist and retained a love and capacity for language even as her dementia became very advanced.'

- 'I didn't know if you would like a little feedback to yourself.

I thought the format of the course was excellent. It was delivered excellently ... and most importantly with a course like Reading and Caring, it is absolutely essential that they have people like yourself Keira ... caring, understanding,

empathetic and so easy to talk too, to deliver the Reading and Caring Workshops.

The only thing I added was to perhaps bring along to use with people living with dementia some books that depicts pictures and 3D books. With short term memory I feel with the picture there of what is being read keeps the person living with dementia much more engaged... especially when the dementia is much more further on.'

- 'Many thanks for sending on these resources – I think they'll be super useful in the day centre!

Also I wanted to thank you for sending the Scottish Book Trust books in the post to us, I just received these yesterday and will bring them into placement today, so hopefully we get some reading sessions in soon!

Thank you very much again for facilitating the workshop and for all the great work you do!

Appendix 2

Some reflections captured by programme teams are included below.

- October 2023 – Dunbar

'Theme was Changes / Autumn. We covered a poem that was a true story written by an Indian gentleman with help from his son about the experience of living with dementia. At one stage in the poem the line is, 'all you need is love, love is all you need'. One of the people in attendance who is LWD at this point burst into song the Beatles 'All You Need is Love' and the whole group carers and others LWD started to join in, so I paused the reading and we all sang! This was followed by my concluding poem about walking along a riverbank kicking the leaves. This prompted another who is LWD who was listening to get up and go out of room only to return with his own poems he has written since the last session about his garden, and we asked him to read a few which he did to the group – each one was about four lines long and were lovely!'

Appendix 3

All feedback from postal forms is included below.

From Family Care partner:

Something you've enjoyed

The course was excellent. I enjoyed taking part.

Something you're more confident in doing because of the programme?

Reading aloud and expressing myself

From Professional care partner (volunteer):

Something you've enjoyed

I was delighted to receive the card* and the pin badge, it helps me feel a part of an ongoing initiative and a wider group, beyond just the Reading is Caring training.

I found a copy of *The Lost Words* in my local charity shop. I bought it and I'll be using it at an Alzheimer's Scotland activity session.

*I read this poem at my friend's wedding.

Something we could improve

The training was excellent. I had mine 1 to 1. It would have been great to have a few more people in the session to promote wider discussion.

Something you're more confident in doing because of the programme?

Tailoring shared reading for individuals and individual situations. In terms of genre, type of material, pace, etc. etc. I feel I've gained a useful 'toolkit' of skills and techniques.

Use the rest of this space to share any thoughts or comments about Reading is Caring with us. Your feedback is anonymous.

Excellent initiative. I'm so grateful to have the opportunity to participate 😊

From Family Care partner:

Something you've enjoyed

Paired reading with my Mum (94!) – wasn't doing this before the course. Enjoyed many of the sample reading materials. Enjoy using reading to expand conversation with my Mum.

Something we could improve

Cannot think if anything, but someone else sourcing reading materials is really helpful so maybe build on this? Don't always have the time and libraries are limited.

Something you're more confident in doing because of the programme?

More confident in what materials will work; in accepting the value of, e.g., a poem, just a chapter/short story – with my Mum's limits of concentration, still worth it.

Use the rest of this space to share any thoughts or comments about Reading is Caring with us. Your feedback is anonymous.

Felt fortunate that I had a 1:1. The tutor fitted around my self-employed work schedule. I learnt more about how dementia affects people also.

References

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