

# Promoting dementia-friendly libraries: Setting up book groups to encourage reading and community inclusiveness for people living with dementia

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*The benefits of reading for the general population, and the benefits of reading in reducing the incidence of dementia, have been the subject of research. However, there has been very little research done on the benefits of reading appropriate works for those living with dementia. This discussion paper outlines the experience of one community in New Zealand, Nelson, in setting up and running a dementia-friendly book group in the public library, and describes the benefits and limitations of this project.*

*A particular set of classical texts was used for these book groups. These were selected and adapted as a result of an earlier feasibility study on the value of book groups for people living with dementia. The feasibility study (Rimkeit & Claridge, 2017) indicated that participants enjoyed the book groups, but preferred adaptations where the original texts were shortened, but the original lexis and syntax were retained.*

*Both the Nelson Public Libraries experience and the feasibility study suggest the book group reading, whether in libraries or residential care facilities, can be enjoyable for people living with dementia, and it is hoped that other libraries in New Zealand will join the discussion on how best to make public libraries dementia-friendly, to vitally support this group of citizens to enjoy a good read.*

*This paper invites librarians and appropriate academics to become involved in a multicentre study of dementia-friendly book groups in New Zealand, Australia, the UK and the US, with an international consortium of universities now interested, using quantitative and qualitative research to investigate the benefits of reading for those living with dementia.*

## Dementia-Friendly

The number of citizens living with dementia in our communities has risen staggeringly, with New Zealand now home to some 65,000 people experiencing this disability, with this set to increase to over 100,000 by 2030 (Alzheimers New Zealand, 2017). Our communities need to become dementia-friendly if we are to avoid marginalising a large section of our population. Many of those living with dementia have enjoyed ludic reading through their lives, but find following literary narratives harder and harder.

Creating a 'dementia-friendly community' is the talk of the town. Communities are encouraged to provide inclusive living for the growing number of citizens who are living with dementia. Libraries are community spaces that can take the lead in developing dementia-friendly strategies. As the Public Libraries of New Zealand website proclaims, "We're the heart of every community. We mirror, reflect and service our community according to their needs" (Public Libraries of New Zealand, n. d.).

This discussion paper outlines the experience of one community in New Zealand, Nelson, in setting up and running a dementia-friendly book group at the public library. The benefits and limitations of this project are described, with the hope that other libraries in New Zealand will join the discussion on how best to make public libraries dementia-friendly, to vitally support this group of citizens to enjoy a good read.

Dementia is the umbrella term for diseases that cause progressive loss of brain function. While the disease type (such as Alzheimer's, Vascular, Lewy Body, Frontotemporal) often dictates which symptoms are prominent, short-term memory loss, impaired language skills, and reduced planning abilities are commonly seen. Age is a major risk factor for dementia and physical frailty is sometimes present. For some people, when the dementia advances, behaviours can become challenging for loved ones and community members.

"Nothing about us, without us" is the underlying strategy for dementia advocacy. Kate Swaffer, an eloquent academic and writer with younger onset dementia, has been a strong advocate for reducing the stigma, or "spoiled identity", and improving the quality of life for people living with dementia (2014). It is now understood that hearing the voice of the person with dementia is imperative in forging real change for reduction in stigma and improved services within our communities. A person living with dementia spoke of his experience to Alzheimer's Disease

International (ADI): “Having dementia is very tough but having a city who excludes dementia - that is really tough” (Alzheimer’s Disease International, n. d.) A recent *Lancet* article describes what dementia-friendly communities might look like. “In these communities, people with dementia and their carers are empowered, supported and aware of their rights” (Morgan, 2017).

A group of researchers in Christchurch recently asked people living with dementia about which changes might make it possible for them to live better in their post-earthquake communities (Smith, Gee, Sharrock, & Matthew, 2016). From semi-structured interviews, the emergent themes included:

- Engagement in community and social life (one art appreciation group called themselves Artzheimer’s);
- Accessible and accommodating leisure and activities (which included the recommendations to have access to a mobile library if their own community library was not yet rebuilt);
- Respectful and responsive businesses and services (in this group the public library was specifically mentioned);
- Raising awareness and building understanding (one participant commenting: “We get put into a situation in shops that people don’t understand”);
- Provision of accommodating and safe physical environments (e.g. avoid shiny floors, provide good signage).

Lin (2017) provides an up-to-date review of the concept of dementia-friendly communities in research and practice, and identifies the lack of robust research into how such communities impact on health, health care costs, or quality of life of the person living with dementia or support persons. There is a notable dearth of research into how libraries can serve the needs of readers with dementia.

An exploratory search on the *Library, Information Science & Technology Abstracts* database (LISTA) yielded no articles on dementia-friendly library spaces and no articles on what a dementia-friendly library service might look like. It yielded some articles about dementia and about how reading can be beneficial in the prevention of dementia. It also cited articles on visual and tactile memory aids for those living with dementia, such as memory boxes. There was one brief article where author Anne Vize talked about her book *Reading in the moment*, a collection of pieces designed to be read aloud to those living with dementia. She recommends as suitable (2015):

*Stories or articles with a small number of characters, who are clearly named and present throughout the piece, and a straightforward plot will help lessen the risk of confusion. Although a piece with a lower reading level may be useful, this does require careful selection, as it is all too easy to select a piece with might be seen as demeaning or insulting in your quest to find a piece which is manageable for the reader... Selecting a piece which sounds wonderful aloud, and which can be read in a melodic, interesting and relaxed fashion can be effective.*

## People with Dementia are Adult Readers

The only guidelines found on providing library services to people living with dementia is the International Federation of Library Associations and Institutions (IFLA) 2007 Report Number 104. It shows an unhelpful lack of understanding of the needs of this adult group of readers. *The Guidelines for Library Services to Persons with Dementia* (Mortensen & Neilsen, 2007) recommend that “Children’s picture books with big clear illustrations are appropriate.. Children’s materials may also be incorporated into activities [for reading aloud] as they can be finished in a single setting.”

Family support persons may also offer children’s books to their loved ones with dementia. This is probably done in the mistaken belief that dementia causes the person to ‘regress’ to the state of a child. This ‘de-development’ model suggests that dementia causes the person to lose linguistic knowledge, to the level of a child learning to read. But linguistic studies have suggested that for common dementia types, such as Alzheimer’s disease or vascular dementia, language comprehension might be compromised by “attenuated span capacity, difficulty focusing attention, encoding and activation of long-term knowledge, rather than from loss of linguistic knowledge” (Bayles, 2003).

Hence ludic readers who have now developed dementia may not need to have the vocabulary of once-loved literary classics ‘dumbed’ down, as they are more likely to have retained understanding of irregular syntax and low frequency lexis. Books written for the adult learning to read English as a second language (which rely on high-frequency words and simple syntax), and children’s books, may sometimes be over-simplified and infantilising for the skilled English reader living with dementia.

One of this paper’s authors, an old-age psychiatrist, finds anecdotally that patients with dementia are insulted when children’s books are offered to them to read. A feasibility study into the use of adapted readers for people with dementia, by this author and an applied linguist, supports to use of adapted text (Rimkeit & Claridge, 2017). An adapted version of Charles Dickens’ *A Christmas Carol* (Claridge & Rimkeit, 2015) was presented to 7 people living with dementia, together with the original Dickens version and a children’s version. The adaption was simplified from Flesch Kincaid readability level 6 to level 2 (recommended for elementary school children in grade 2 or 3), and was printed in large font. It had original illustrations on each page, and was 1496 words long. The original version was in large font, readability level 6, with no pictures, and was 32,398 words long. The children’s version,

perhaps surprisingly, was Flesch Kincaid level 5, nearly as 'hard' as the original. It was illustrated with rather childish pictures, and was 750 words long.

Participants dismissed the children's version as being childish. They liked the format and illustrations in the adapted version, but said language 'lost the original voice of Dickens.' The original Dickens was too long, and there were no illustrations to break up the text, but despite that, participants reacted with great enthusiasm to the language itself. Dickens' description of Scrooge as a 'squeezing, wrenching, grasping, scraping, clutching, covetous old sinner,' elicited 'piss off you old bastard' from one of the group.

It was clear that syntactical and lexical complexity were not as problematic as volume of words, and the thread of the plot. The next set of books, adapted by Dovetale Press (Claridge & Rimkeit 2016a, 2016b, 2016c, 2016d; Rimkeit & Claridge 2016). ([www.dovetalepress.com](http://www.dovetalepress.com)), were designed to retain the 'voice' of the original authors, while reducing the volume of words and adding memory aides, such as 'Cast of characters' and 'Chapter Summaries.' Illustrations were used to provoke discussion. For instance, the Katherine Mansfield stories were illustrated with Van Gogh, Modigliani, Klimt, Macke and Cezanne paintings, designed to evoke discussion within the storyline and maintain a respectful content for adult readers. It is hoped that the reader living with dementia will benefit from:

- Enjoyment of the music and rhythm of a literary classic.
- Enjoyment of the beauty and inventiveness of the language.
- Enhancement of personal identity by stimulating memories.
- Stimulation of cognitive performance by evoking memories linked to the text.
- Improvement in empathy with others through connections with their options and feelings about the text.
- Book groups may also reduce the stigma for people living with dementia if book groups are held in the public library, the hub of community.

## The Nelson Experience

Nelson Public Libraries are experiencing a growing number of users who are living with dementia. This can present as confusion or frustration when trying to use library services, or requests for help from those who have enjoyed reading, but who are finding that treasured activity slipping away.

To try to meet the needs of this particular group of library users, librarians have been trying to source reading material that might be appropriate for those living with dementia, knowing their Quick Reads are either too basic or simplified in the wrong way, i.e. language and not narrative. The only other options in the collections are short stories, but these are anthologised into books, and although short are often complex narratives.

The library also sought help from specialists in dementia. Alzheimers Nelson were invited to present to staff on concerns when providing services to people living with dementia. This presentation focussed on the increasing incidence of dementia-related conditions in our population, and on the physical and social requirements for catering for those developing dementia.

The most important take home message was that dementia is not easily recognised in a library context. Staff were told to look out for users "wandering aimlessly in our stacks", a description that would capture most library users looking for something to read.

The physical barriers for those living with dementia were also of great interest. Advice was not to change things around, not to have all the white toilets, for all things to be calm and clear. The after half the Nelson library had just been rearranged, with the public toilets upgraded to make them sparkly white, and having the library zoned so quiet places are those furthest from the main doors.

Nelson statistics supported the anecdotal experience of increasingly encountering those living with dementia. Alzheimers Nelson have a client base of around 650 people. And the local DHB have calculated that 30 percent of people diagnosed with dementia do not use Alzheimers Nelson services, hence, there are roughly 1000 in the Nelson community presently who would benefit from dementia-friendly environments and services.

Nelson Public Libraries librarians wanted to know how to work with the individuals who were asking for help. Alzheimers Nelson did not know of any dementia-friendly writing, and neither did library colleagues. Memory boxes were the most often resource recommended by colleagues - which were already provided by the library to those in residential aged care. Of concern were resources for those living with dementia in the community.

Some measures were taken after the Alzheimers Nelson presentation, such as adding permanent inserts into all books dealing with dementia with contact details for Alzheimers Nelson. These inserts also advising people about the Alzheimers Nelson monthly drop-in sessions that were started at all of the Nelson libraries.

The Library then discovered a new source of reading aimed at people living with dementia. In October 2016 Dovetale Press launched a series of five books that were carefully constructed for people living with dementia and other forms of cognitive impairment: *A Christmas Carol* by Charles Dickens (Claridge & Rimkeit, 2016a) (ISBN 978-0-473-37294-1); *Poetry for the Restless Heart* (Rimkeit & Claridge, 2016) (ISBN 978-0-473-37292-7); *The Adventure of the Blue Carbuncle* by Arthur Conan Doyle (Claridge & Rimkeit, 2016c) (ISBN 978-0-473-37293-4); *The Garden Party and The Doll's House* by Katherine Mansfield (Claridge & Rimkeit, 2016d) (ISBN 978-0-473-37291-0); and

*Little Women* by Louisa May Alcott (Claridge & Rimkeit, 2016b) (ISBN 978-0-473-37295-8).

After a business case to purchase a set of the books had been approved, librarians met with Dr. Sally Rimkeit, a specialist in old age psychiatry and co-editor and co-founder of Dovetale Press, and Alzheimers Nelson to discuss the possibility of starting a book group using the Dovetale books.

The Dementia-Friendly Book Group started in March 2017. Nelson Public Libraries partner very closely with Alzheimers Nelson, with the latter selecting the members, reminding people of the sessions, and providing a volunteer to come to each session. The group meets weekly for an hour, and takes a week off after every three or four sessions. Sessions are very relaxed; the group meets in a small quiet meeting room and coffee and tea are provided. All participants wear name badges and the books are read aloud, with discussion along the way. The best reading method is each member of the group reading a page in turn, which engages those members who find it hard to concentrate when being read to.

On the whole, the response to the group has been very positive, with only one man deciding the group was not for him. At the end of the sessions group members often say how much they have enjoyed the hour. Membership does fluctuate, but one woman has been attending since sessions started, and three members have been attending since they first joined the group.

The illustrations are a great stimulus for discussion, as is the style of language used in each book. As with already existing bookchats run at the library, discussions in the group are wide ranging and often very funny. Very broadly, *A Christmas Carol* generates discussion of personal experiences; the poetry book discussion of emotions; *Sherlock Holmes* of logic; Katherine Mansfield of social arrangements; and, *Little Women* of male and female differences and of sensory experiences (such as the textures of fabrics, or feeling warm or cold). The Sherlock Holmes discussion has been very interesting as it is the Holmesian logic that many of the group members think hilarious - for example that Holmes deduced a hat's owner to be highly intelligent because of the hat's large size, or that the owner had fallen onto bad times because the style of hat was three years out of date.

Discussion can also be very moving, as members often tell of personal tales relating to the text. One woman told us of a frightening experience when she got lost when taking her dog for a walk - this in response to Raleigh's poem *To a Lady with an Unruly Dog* in the poetry collection. Another woman exclaimed about her dementia: "it's a shit" at one session when describing reading a book and putting a yellow post-it note where she had got to, and then returning to her bedroom to find dozens of books lying around all with yellow post-its stuck in them.

Another woman shared that she had gone to bed for a month after her diagnosis and found it hard, hard work to come to the point where she could accept her situation and carry on. One gentleman who had run his own business said he found his dementia liberating in a way, as he didn't have to be intelligent or responsible anymore. As well as responses to the texts, the book group discussions provide a forum for people with dementia to talk about feelings which may otherwise be buried.

The results of research on the benefits of reading for members of communities, for empathy, belonging and civic participation, have been accepted for some time now. In the Nelson Public Libraries Dementia-Friendly Book Group, participants living with dementia experience the benefits of reading adapted classics with others.

## Conclusion

It is highly probable that more quantitative and qualitative research on the benefits of reading for those living with dementia would support arguments for increased targeted resources in public libraries. In addition, research to support guidelines for those interacting with, and providing spaces for, those living with dementia could be very beneficial for planning and staff training.

We encourage a discussion on how best to develop dementia-friendly libraries, but this needs to be done in close collaboration with those experiencing dementia and their family support people, as in the "Nothing about us, without us" perspective. Furthermore, evidenced-based research is warranted, both quantitative and qualitative, assessing the effectiveness in improving quality of life and enjoyment of reading for people within our communities living with dementia.

We call for librarians working directly with their communities, and academics looking to enhance evidence-based librarianship, to become involved in a research project already underway at the University of Otago. This project, now a pilot randomised controlled trial (RCT) and qualitative study in New Zealand, tests the design for a multi-centre study of dementia-friendly book groups in New Zealand, Australia, the UK and the US, with an international consortium of universities now interested. Any public libraries participating will be sent a facilitation manual.

All data gathered for the project will be managed by the University of Otago health statistician Dr Dalice Sim, to maintain the strict confidentiality of all participants. The goal is to test the effectiveness of book groups in residential aged care facilities and in the community. And as the library is the "heart of every community", assessing the benefits of dementia-friendly book groups in public libraries dovetails with this goal.

## Acknowledgement

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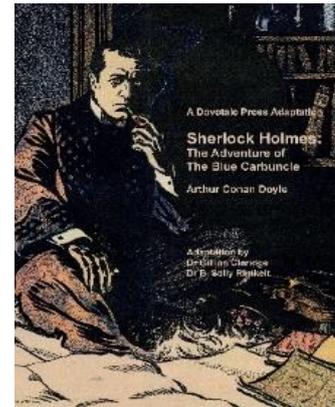
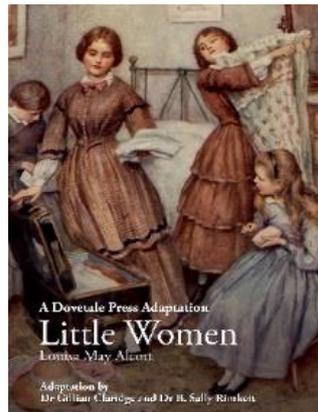
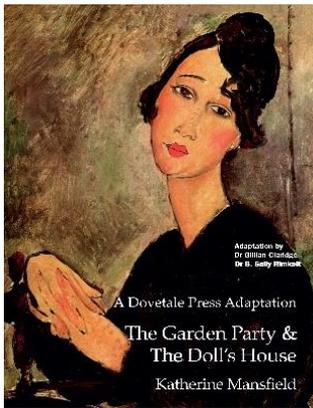
## References

- Alzheimer's Disease International. (n. d.). *Dementia friendly communities (DFCs): New domains and global examples*. London, United Kingdom: Author.
- Alzheimer's New Zealand. (2017). *Dementia economic impact report 2016*. Wellington, New Zealand: Deloitte.
- Bayles, K.A. (2003). Effects of working memory deficits on the communicative functioning of Alzheimer's dementia patients. *Journal of Communication Disorders*, 36, 209–219. [https://doi.org/10.1016/S0021-9924\(03\)00020-0](https://doi.org/10.1016/S0021-9924(03)00020-0)
- Claridge, G., & Rimkeit, B. S. (2015). *A Dovetale Press adaptation, A Christmas carol Charles Dickens*. Wellington, New Zealand: Dovetale Press.
- Claridge, G., & Rimkeit, B. S. (2016a). *A Dovetale Press adaptation, A Christmas carol Charles Dickens* (2nd ed.). Wellington, New Zealand: Dovetale Press.
- Claridge, G., & Rimkeit, B. S. (2016b). *A Dovetale Press adaptation, Little women Louisa May Alcott*. Wellington, New Zealand: Dovetale Press.
- Claridge, G., & Rimkeit, B. S. (2016c). *A Dovetale Press adaptation, Sherlock Holmes The adventure of the blue carbuncle*. Wellington, New Zealand: Dovetale Press.
- Claridge, G., & Rimekeit, B. S. (2016d). *A Dovetale Press adaptation, The garden party & The doll's house Katherine Mansfield*. Wellington, New Zealand: Dovetale Press.
- Lin, S.-Y. (2017). 'Dementia-friendly communities' and being dementia friendly in healthcare settings. *Current Opinion in Psychiatry*, 30, 145–150. <https://doi.org/10.1097/YCO.0000000000000304>
- Morgan, J. (2017). A better, fairer, and safer world for people with dementia. *The Lancet Neurology*, 16, 587–588. <https://doi.org/10.1097/YCO.0000000000000304>
- Mortensen, H. A., & Neilsen, G. S. (2007). *Guidelines for library services to persons with dementia* (IFLA Professional Reports Nr. 104). The Hague, The Netherlands: International Federation of Library Associations and Institutions.
- Papathanasiou, I., & Nielsen, G. S. (2007). *Aphasia and related neurogenic communication disorders*. Burlington, MA: Jones & Bartlett Learning.
- Public Libraries of New Zealand. (n. d.). Libraries today. Retrieved from <http://www.publiclibraries.org.nz/LibrariesToday/LibrariesToday.aspx>
- Rimkeit, B. S., & Claridge, G. (2016). *A Dovetale Press selection: Poetry for the restless heart: Classic poems of nature, love, life and laughter*. Wellington, New Zealand: Dovetale Press.
- Rimkeit, B. S., & Claridge, G. (2017). Literary alzheimer's: A qualitative feasibility study of dementia-friendly book groups. *New Zealand Library and Information Management Journal*, 56(2), 14–22. <https://doi.org/10.6084/m9.figshare.5715052>
- Smith, K., Gee, S., Sharrock, T., & Matthew, C. (2016). Developing a dementia-friendly Christchurch: Perspectives of people with dementia. *Australasian Journal on Ageing*, 35, 188–192. <https://doi.org/10.1111/ajag.12287>
- Swaffer, K. (2014). Dementia: Stigma, language and dementia-friendly. *Dementia*, 13, 709–716. <https://doi.org/10.1177/1471301214548143>
- Vize, A. (2015). Keeping the love of reading alive for Mavis. *inCite*, 36(3), 26.

## Appendix A: Dementia-friendly Book Group Inspired Art

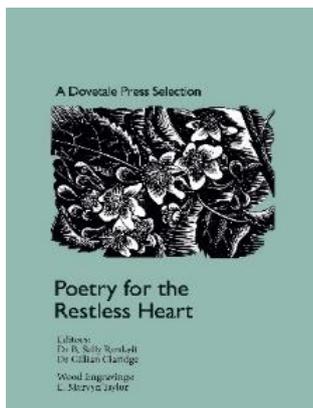


## Appendix B: The Dovetale Press Dementia-friendly Adaptations



**Start a Dementia-friendly book group at your library with Dovetale Press books**

Dovetale Press carefully constructs books for the reader who might find standard books difficult because of certain health conditions, such as Alzheimer's disease, other types of dementia, or stroke.



Classic literature has been specially selected and adapted by an applied linguist, Dr Gillian Claridge, and a psychogeriatrician, Dr B. Sally Rimkeit, to enhance the joy of reading for people with cognitive impairment.

We support dementia-friendly communities and access to dementia-friendly books and book groups at libraries.

**Your local library can order Dovetale Press books through Wheelers, All Books, or through our website [www.dovetalepress.com](http://www.dovetalepress.com)**

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