

BIBLIOTHERAPY: READING FOR WELLBEING IN OLD AGE

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1. INTRODUCTION

Managing the challenges presented by dementia will be the overwhelming priority of health care in the 21st century.^[1]

This is a quote from Lynne Pezzullo, Access Economics director and health analyst and author of a 2009 Access Economics report commissioned by Alzheimer's Australia, predicting that over 1.1 million Australians will have dementia by 2050 – quadrupling current figures.

If these predications come true, then the challenges for the care of those suffering with dementia will not be met by interventions based in medicine alone but will necessitate interventions of a social nature, as more people spend more time in institutions. Commonly, people in aged care facilities sit for long periods of time, often socially isolated in their rooms, and this can have a negative impact on their wellbeing. This highlights the need to promote intervention focussed on wellbeing, to increase the possibility of individual re-engagement with life and even re-emergence into society.

It is thought that bibliotherapy (a read-aloud reading intervention) may have a positive impact on the wellbeing of people living with dementia. Recent studies are contributing to the data now available as a result of several years of delivery of bibliotherapy programs, and these studies indicate that such programs deliver positive wellbeing outcomes.

Today, bibliotherapy is recognised internationally. It involves the provision of carefully selected and evaluated books, including non-fiction texts (that offer physical and mental health information) along with fiction and poetry (to provide a more creative form of therapy). More specifically, three strands of bibliotherapeutic practice can be identified internationally: self-help bibliotherapy, Books on Prescription schemes, and creative bibliotherapy.

For self-help bibliotherapy, book collections represent a resource of appropriate titles for people with a broad range of conditions (including depression, anxiety, bereavement, eating disorders and physical illness).

Books on Prescription schemes are run in partnership with librarians and health professionals, who recommend a book to a patient, and provide the patient with the title details as a 'book prescription'. The patient then takes that book prescription to a library to have the prescription filled by borrowing the recommended book.

Creative bibliotherapy predominantly uses prose and poetry to provide a more creative form of therapy, through facilitated reading groups. The belief is that when someone makes a connection with a particular story they can often begin to better connect with their lives on a personal and emotional level. Since 2010, the State Library of Victoria in partnership with the Public Libraries Victoria Network and Victorian Health Promotion Foundation (VicHealth) has been delivering Book Well facilitated reading groups in a range of settings across Victoria. Some of these were involved with aged care groups, in which some of the participants had various stages of dementia.

This paper is my personal reflection on bibliotherapy and includes my thoughts on the therapeutic benefits of reading and of programs such as Get Into Reading and the Book Well program. It explores and focuses on the impacts and effects that creative bibliotherapy may have on the wellbeing of those experiencing various stages of dementia.

2. THE INSPIRATION: GET INTO READING

The Book Well Program in Australia particularly targets people who are vulnerable due to their situation – such as the homeless, the long-term unemployed, new arrivals in Australia, residents in aged care facilities, and those experiencing physical and mental health problems. The Victorian program was inspired by the United Kingdom's renowned Get Into Reading program. The training of Australia's Book Well Program facilitators was the first course of this kind offered outside the United Kingdom. To put this in perspective, we first need to go back to the UK.

Get Into Reading was set up in 2001 by Jane Davis, the founder and director of The Reader Organisation, a UK charity responsible for pioneering the use of books and reading in therapeutic ways in community settings. Davis, as the facilitator in her first Get Into Reading class, wasn't sure if the fourteen people who signed up *could* read, so she prepared to read aloud the poem she had selected, Tennyson's 'Crossing the bar'. The following describes her account of those beginnings of Get Into Reading:

. . . it was F who made a perceptive comment about how easy it is to get stuck in life. And at the end of the session it was also F who said, 'So when are you bringing in the good stuff? Shakespeare? Tolstoy? . . . I'd never have thought of reading Shakespeare with that group . . .

. . . I started to read and had not got far into the poem . . . when [D] started to cry. There was real pain in her response. I said, 'Shall I stop?' but . . . she . . . simply said, 'Go on.' I went on. D continued to cry . . .

You could feel everyone in the group suffering, a mixture of social embarrassment . . . and real pain on behalf of D, and perhaps a bit of pity for me, too, as the person responsible for trying to sort the situation out. There was a sense of goodwill mixed with the pain. Everyone wanted it to be all right, not just stop and go away, but to be somehow right . . . Yet here was this stranger with her very recent bereavement. It was my job to bring about a solution and I didn't know how to do it . . .

'Go on, read it again,' D insisted . . . This time as I read she cried, and she spoke about the lines of the poem, and others spoke too, about what the poem might mean . . . When it was over, she . . . thanked me. F . . . leaned over and covered her hand with his own. 'Well done, kidder,' he said. 'You were brave.' I realized then that I had stumbled into something important – that getting literature out of the university, out of the classroom, was going to have real social consequences.^[2]

In the context of those with dementia in aged care facilities, the social consequences are about building positive and supportive relationships between residents of a facility and developing a sense of community within the facility. Recent data, collected from participants, partner organisations and reading group facilitators, show Book Well groups facilitate the

formation of relationships among the participants, provide opportunity for stronger understanding to develop between aged care workers and the participants and, in some cases, lessen tensions between participants.

3. THE EMERGENCE OF BIBLIOTHERAPY IN AUSTRALIA

3.1. The 'reading cure'

The use of books and reading in therapeutic ways has previously been approached from a very clinical perspective in Australia, with health and wellbeing information being offered in the form of brochures and self-help books. For many converts, the idea of using books therapeutically in other ways first reached them in an article entitled 'The Reading Cure' by Blake Morrison in *The Guardian*.^[3]

Sally Heath, the former editor of *A2* in Melbourne's newspaper *The Age*, having rights to reproduce Guardian copy, reprinted 'The Reading Cure' on Saturday 29 March 2008. She expected Melbourne readers would be interested.

When no one inquired about the Get Into Reading program, she thought she would see if she could get funding or interest from groups to set up a similar scheme in Melbourne. VicHealth said it would fund half the cost of the UK trainers travelling to Melbourne and the State Library of Victoria agreed to fund the other half and oversee the project.

3.2. The Book Well Program facilitator training

In January 2010, the State Library of Victoria began management of the Book Well project. The first objective was to train twenty Victorian program facilitators. The second objective was to evaluate the project.

In March 2010, three trainers from the UK Reader Organisation trained twenty Victorians over five days in the many strands of facilitating read-aloud groups. Training was provided on the understanding that each facilitator would commit to the eventual implementation of a Book Well pilot program and would assist with evaluation of the program, for reporting purposes.

4. WHAT HAPPENS IN A BOOK WELL GROUP

Put very simply, Book Well works like this:

- Each week, small groups, usually of no more than ten people, listen to short stories and poetry slowly read aloud.
- The group members then respond to what they have listened to. For some, this may be to voice their thoughts; for others it may be to just think thoughts. There is no pressure for anyone to speak and, at times, the members of the groups share an undemanding silence. It is an opportunity to be with people without the pressure of the expectation of having to interact.
- The groups usually run for approximately one-and-a-half hours and include the sharing of refreshments.

For groups whose participants are experiencing various stages of dementia, the Book Well basic model is adapted to make it more accessible. Shorter, stand alone, texts and poetry are chosen to assist with dementia-related issues, including loss of short-term memory, poor concentration and drowsiness due to medication. Texts used are printed in a larger font to assist those who want to read along, although some prefer to actively listen rather than follow the written word. The facilitator reads slower and louder and also takes time to

describe pieces in the story that need explanation or connecting. The groups sessions are often shorter in duration than the usual group session timeframe.

Reading in old age requires a different approach from reading at other stages of our lives. In old age, physical capabilities, and therefore associated activities, may be reduced – but older people are still able to participate in useful activities. A woman in her late eighties, living in an aged care facility, said about attending a Book Well group, 'I enjoy most, and look forward to the most, doing something with my brain. This group has changed my mental health – yes! For the better.' Another participant from an on-site aged care setting in regional Victoria said: 'This gives us mental stimulus. Aged care doesn't take that into account.'

5. EVALUATION OF READ ALOUD GROUPS IN AN AGED CARE SETTING

5.1. The 2010 Book Well program

In 2010, sixteen Book Well pilot groups took place across Victoria. Ten of these were involved with aged care groups, of which some of the participants had various stages of dementia.

Evaluations from aged care facility partners illuminated how reading aloud can have positive wellbeing effects with dementia patients. Some of the specific comments included:

- *Staff observed that some residents' moods are agitated or low before leaving their rooms to attend and then the same residents begin to reminisce individually and their moods are improved and enhanced.*
- *The high quality classic literature used, and the relevance of the topics selected for the lives of persons with dementia, makes these materials a natural for eliciting engagement. I think this is a great way to communicate with people in the later stages of this disease.*
- *Even those with severe dementia smile and laugh.*

The Divisional Therapist noted an improvement in the communication/recall of dementia patients.

- *Another participant, suffering depression, was buoyed enormously by the social sense of belonging to the group. She often commented after the session, 'How wonderful it was to have a conversation!'*

Perhaps the best way to talk about the benefits of Book Well for people suffering dementia is to share some stories with you. I will begin with my own Book Well group at Prague House, a low-care residential facility of St Vincent's hospital.

Some of the group members have a degree of dementia associated with alcohol or substance abuse. Despite these conditions, and the accompanying cognitive impairment, the Book Well discussions each week are articulate, and are characterised by depth and presence.

The manager of the facility joins us at times, because the activities coordinator feels it is important for management to see how much of a person suffering from dementia is still available and how the reading aloud groups reach and touch that person.

To help record and disseminate the evidence of the impact of the 2010 Book Well groups, feedback from facilitators and aged care partner organisations has been captured on video.

5.2. The 2012 Book Well program

In 2012, VicHealth offered further support to extend the reach of the Book Well program. The delivery of the second round of the program took place in February and March 2012, facilitated by seven of the earlier trained facilitators from public libraries. Groups ran for eight weeks and most were conducted in partnership with community-based organisations in

locations across regional and metropolitan Victoria. Five of these seven groups included participants, from aged care and day care facilities, suffering from various stages of dementia. This second round of programs provided an opportunity for deeper evaluation of the program.^[4] The resulting new data adds to the existing evidence base and combines with it to present a body of evidence showing that Book Well has acted as a positive intervention in regard to the wellbeing of those experiencing various stages of dementia.

Forty-two participants, five staff from partner aged care organisations, seven facilitators and the project coordinator took part in the evaluation. Fifty-three sessions were conducted in total.

Data was collected from participants via:

- postcards completed at the end of each session
- surveys
- semi-structured face-to-face or telephone interviews.

Participants could respond on the data feedback postcards in a number of ways: they could circle a face given alongside a 'feeling' word ('encouraged', 'uplifted', 'calm', 'agitated' or 'discouraged'); they could draw their own face and/or use another word to describe how they were feeling; or there was space for them to add their own comments. Some comments included:

- *Encouraged. More stimulating than I expected.*
- *Uplifted. Would like to have my family with me here.*
- *Enjoy the discussion afterwards and a tea break.*
- *I am definitely enjoying the sessions as well as the company of the facilitator and the participants.*

Facilitators took part in focus group discussions preceding and following the sessions, and in semi-structured telephone or face-to-face interviews. Each facilitator kept a journal which provided invaluable data.

Group observation was also held at three group sessions and further semi-structured telephone interviews were conducted with partner aged care organisations.

The summary of outcomes included three main positive outcomes in regard to social benefits and mental health areas, as described below:

1. Results from the facilitators, the partner organisations and the participants all indicate that the Book Well pilot made a positive difference for participants, in part by offering a different kind of social activity – not only a new opportunity to connect, but also an opportunity that fostered new ways for participants to connect with one another.

It's a therapeutic relationship in the sense of people being able . . . to listen to each other, and understand their grief and their stresses and their joys . . . our early definition of success for this group was promoting the emotional independence of the group – their wellbeing and initiative. So they can reclaim their own independent civic person. In a residential unit you can quickly become institutionalised and a patient, so a positive outcome of this is any kind of reclamation of their own integrity or independence. This group has very much been achieving those things. [Recreation coordinator aged care facility]

2. According to the participants interviewed, the partner organisations and the facilitators, the Book Well groups allowed connections to form among the participants, connections to grow between staff and the participants and, in some cases, for tensions or conflicts to be eased.

I think this group connects people socially and emotionally. I was in [the facility] on a Friday, and they were going in for dinner. People were passing me and

still discussing the group, which was on Tuesday morning. They were talking about the literature as they passed me, saying, 'I think in that poem. . . ' That was quite surprising to me, to notice that they were still talking about the material. [Recreation coordinator aged care facility]

3. Participant feedback suggested that their participation in Book Well was beneficial to their overall mental health. Partner organisation representatives also reported mental health and wellbeing benefits for the Book Well participants.

It was intellectually stimulating. The active process of listening is exercising the brain. This activity was unusual in that it required focus and concentration. This is important, and not many activities ask it of the participants. This is a beneficial brain exercise for these group members. [Program leader at a dementia-specific facility]

5.2.1. Case studies

This section examines four Book Well case studies to illustrate the way in which bibliotherapy works to support the wellbeing of people experiencing various stages of dementia.

5.2.1.1

Case Study: 1

'Stewart' (aged-care facility 1)

This is priceless. Never in my wildest dreams did I think I could ever attend a class like this.'

Case Study 1, stresses a key skill required of a facilitator, which is to guide and foster personal reflection and discussion. When reading to people with dementia open-ended questions need to be carefully constructed to involve thinking, reflection and memories. Sharing reflections, and personal experiences, develops behaviours of increased empathy, listening, and a deeper level of social interaction between participants.

Often there is a surprising willingness to share and help others, and none of us realise we possess this willingness until it is called upon. We underestimate the wellbeing to be found in company.

Memories connect us to things that have meaning for us. People with dementia have a different use of memory and less ability to access language. Reading to people with dementia can provide a sort of narrative to spark conversations about small things and can get them interested in talking and remembering.

In a group, people's common memories can be shared. Reviving long-term memories together in a group is beneficial because it helps people share their fear of losing their short-term memory.

5.2.1.2

Case Study: 2

'Barbara' (aged care facility 2)

I've been so lonely, living beside you all but not knowing you.

Case Study 2 demonstrates how the text chosen to be read aloud is a key factor for the success of a group. There are several criteria for selecting a text that will affect the level of engagement achieved: the text must be accessible, without too complicated a plot to follow; and must be applicable to members of the generation participating, and their values.

Quality fiction and poetry are the appropriate forms of text to read aloud – particularly the words of classic writers. But it is also true that, in the works of a number of our contemporaries, every word is considered and every line condensed and stripped bare so that the words within some short stories achieve the power of a good piece of poetry. Both fiction texts and poetry enhance awareness, with words and images that intertwine to create a story to which the reader relates and which can help us to revisit aspects of our own lives.

Over time, facilitators get to know their participants and are able to choose texts to which individual participants will relate. This offers the group members an opportunity to get to know each other in a more intimate way, and for deeper relationships to form. Eighty per cent of survey respondents said they would like to join more groups, having been part of Book Well. By the end of the sessions, 83.4% of respondents said they had made at least one or two new friends.

5.2.1.3

Case Study: 3

‘Robin’ (aged care facility residents visiting a library)

She’s gone from sitting by herself in her room all the time to going to a group and now listening to stories.

Case Study 3 shows another positive outcome of the Book Well groups – an increase in the enjoyment of reading was found by the end of the eight-week program with 62.5% of respondents enjoyed reading more than they did at the commencement of the program.

While reading assists to promote changes in perception that can heal; slowly reading aloud aids this process even further by allowing us time to personally engage with the text.

Often, if one feels lonely and isolated, listening to a text being read aloud can help to provide both an inner and outer companionship with the words, the images and then with others. A Book Well group provides social insulation rather than social isolation.

5.2.1.4

Case Study: 4

‘Heidi’ (dementia-specific day care)

I saw her eyes glowing, I perceived her as walking taller after that. It was a validation of her memory, her life experiences. Others in the group were mouthing along.

Case Study 4 highlights that poetry works extremely well in groups with people suffering dementia. Many of these participants are of a generation where poetry was learnt ‘off by heart’ and they often can recite a poem, word-for-word, along with the facilitator.

Fiction and poetry evoke feeling, and feeling must be evoked if we are to work with human emotions. There are many who are not used to this. Slowly reading aloud assists listeners to quietly and gently begin to unravel their own inner feelings and identify with them. All aspects of life, death and yourself begin to swirl within and this is the beginning of the therapy. Words not only have a meaning but they also have sounds and rhythm. This sound and rhythm can move people into a place of willingness in a soothing way and encourage emotional response.

There is a stage of dementia at which it really does not matter who is in the text because it is the emotions the text evokes that matter.

Classic fiction and poetry, when read aloud, can paint extraordinarily colourful pictures and has the ability to captivate an individual’s imagination whether reading is enjoyed or not.

Everyone needs a peaceful place in their mind to return to for comfort and how very important this is for people with dementia.

6. UK RESEARCH ON WHICH WE CAN DRAW

The Reader Organisation currently runs approximately 200 weekly groups, of which thirty-five are conducted in aged care and dementia care settings, including care homes, hospitals, day centres, sheltered housing and community centres. These groups for older readers are funded by trusts, care services, and local primary care trusts and councils.

A recent study, entitled *A Literature-based Intervention for Older People Living with Dementia*, has been conducted by the Centre for Research into Reading, Information and Linguistic Systems (CRILS) at the University of Liverpool, in partnership with The Reader Organisation.^[5]

The aims of the study were:

1. To understand the influence that reading has on older adults with dementia in different healthcare environments.
2. To identify staff perceptions of the influence that engagement in a reading group has on older adults living with dementia.
3. To investigate any changes in dementia symptoms of older adults participating in a reading group, with specific relation to statistical analysis.

Sixty-one service users and twenty staff members were involved in the study. A total of eighty-seven sessions were conducted.

Each of the different healthcare environments was evaluated in a different way. Qualitative interviews were conducted with seven staff members who either participated in the groups themselves or had extensive knowledge of the service users who participated.

The major summary conclusions showed:

- In light of quantifiable data of limited but indicative status, together with strongly supportive qualitative evidence, engagement in reading-group activity produced significant reduction in dementia symptom severity.
- Staff interviews indicated a contribution of reading groups to wellbeing.

The specific conclusions drawn from the study in regard to memory stated that 'the current study also suggests a possible effect on short-term memory.'

7. THE FUTURE IN AUSTRALIA

Aged residents often tell facilitators how they love being read to. The patterns of intonation, rhythm, silence and sounds all create a wave of comfort which caresses an elderly person in a way that possibly only music may also manage to do.

Many participants voiced sadness at the program ending. Comments were received, such as.

I've felt happier in myself having something to look forward to on a Tuesday. Even on Sunday I start looking forward to the group.

The recent Australian, and UK, research presents evidence that bibliotherapy-based programs provide positive outcomes for the wellbeing of those participating in groups. More research is needed into why these groups work well, with the intention of creating dementia-specific training in this area.

I continue my own studies in this area through an RMIT scholarship. My aim is to assist to establish bibliotherapy as an accepted practice in Australia. My belief is that positive

wellbeing outcomes are achieved by bibliotherapy intervention because, while we are working cognitively with brains, we are working emotionally with hearts.

REFERENCES

- [1] Miller N, 'Dementia epidemic "here now"', *Age*, 1 September 2009, viewed 12 July 2012, <<http://www.theage.com.au/national/dementia-epidemic-here-now-20090831-f5ag.html>>
- [2] Hornby S & Glass B (eds), *Reader Development in Practice: Bringing literature to readers*, Facet Publishing, London, 2008, p. 78.
- [3] Morrison B, 'The Reading Cure', *Guardian*, UK, 5 January 2008, viewed 24 July 2012, <<http://www.guardian.co.uk/books/2008/jan/05/fiction.scienceandnature>>
- [4] State Library of Victoria, *Evaluation of the Book Well Program*, May 2012 (unpublished)
- [5] Centre for Research into Reading, Information and Linguistic Systems, *A Literature-based Intervention for Older People living with Dementia*, University of Liverpool, Liverpool, 2012, viewed 12 June 2012, (http://www.merseycare.nhs.uk/Library/Learning/Library_Service/reading_groups/A%20Literature-Based%20Intervention%20for%20Older%20People%20Living%20with%20Dementia.pdf)