

Engaging People Living with Dementia with Library Materials

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Objectives

- Define and describe dementia; identify challenges & strengths
- Share needs identified by people with dementia
- Outline and discuss basic communication strategies
- Share dementia-friendly library best practices
- Discuss reading materials for people with dementia: theory and practice
- Share library example: process & materials
- Introduce Shared Reading, Memory Cafes, Digital Resources
- Propose future activity
- Wrap-up/Q & A



(Wakefield, 2017)

What is dementia?



Dementia describes a **group of symptoms** that indicate a **LOSS** of

- **memory,**
- **thinking and judgment,**
- **language, and/or**
- **behavioral norms**

enough to interfere with day-to-day function.

(NIH, 2021; NLM, 2021)

Major Dementias

More than 100 conditions including

- Alzheimer's Disease
- Vascular Dementia
- Lewy Body Dementia
- Frontotemporal Dementia
- Mixed Dementia

Dementia symptoms are sometimes reversible.

Differs from delirium.



(AGS, 2022; NIH, 2021; NLM, 2021)

Statistically Speaking

Alzheimer's disease (60-80% of all dementia cases) affects 10% of adults age 65 and older.

70% of people with dementia live in the community.

26% of these community residents live alone.

Three general stages:

- Mild – independent function
- Moderate – difficulty with daily tasks
- Severe – need fulltime assistance



(Alzheimer's Association, 2022)

Dementia: The Challenges

- Experiencing memory loss, poor judgment, and confusion
- Difficulty speaking, understanding and expressing thoughts, or reading and writing
- Wandering and getting lost in a familiar neighborhood
- Repeating questions
- Using unusual words to refer to familiar objects
- Taking longer to complete normal daily tasks
- Hallucinating or experiencing delusions or paranoia
- Acting impulsively



(NIA, 2021)

Dementia Strengths

- **Long-term memory:** May be comforting or frightening
- **Procedural memory:** Remembering how to do things
- **Increased sensitivity to sensory stimulation:** Sounds, light, body language, facial expression, tone of voice
- **Use of non-verbal skills to communicate:** Especially facial expressions, body language, tone of voice
- **Reading**



(AGS, 2019; Billington, 2013; Ellis & Astell, 2017; Kawai et al, 2002; Lykkesket et al, 2014)

People with Dementia Want to...

- Be safe and be able to find their way around.
- Access local places that they know and where people know them (banks, shops, cafes, post offices, churches, libraries, etc.).
- Keep their social connections so they feel that they still belong to the community.
- PS: Their families want this too!



(Smith, et al, 2016)

Communication: Basic Strategy

BUILD TRUST & RAPPORT



(DCS, 2020)

Communication: MESSAGE Strategies

M: MAXIMIZE Attention

E: Watch your EXPRESSION and body language

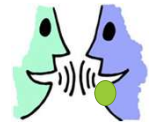
S: Keep it SIMPLE

S: SUPPORT their conversation

A: Assist with visual AIDS

G: GET their message

E: ENCOURAGE and ENGAGE in communication



(DCS, 2020; Smith, et al, 2011)

Communication: RUSA Library Guidelines

- Visibility/Approachability
- Interest
- Listening/Inquiring
- Searching
- Follow-up



(ALA, 2008; Dalmer & Campbell, 2018)

Dementia-Friendly Libraries: Best Practices

- Wear name tags.
- Train staff and volunteers about dementia and on communication strategies.
- Provide materials that help caregivers and materials that appeal to people with dementia.*
- Consider cultural and ethnic interests.
- Offer individual appointments to help select materials.



(DFA, 2017)

Dementia-Friendly Libraries: Best Practices

- Display dementia-related books, DVDs, etc.
- Offer resource bags for check-out, e.g., themed materials, reminiscence kits, Tales & Travel.



(DFA, 2017)

(DFA, 2017)

Preserving identity, dignity & independence



Tales and Travel Book & Reading Program



- Tales & Travel Memories
 - <http://talesandtravelmemories.com/>
- Tales & Travel Adventures
 - <http://talesandtravelmemories.com/memory-cafes/>

Tales & Travel in action



How Tales & Travel Works



IFLA Guidelines - 2007

International Federation of Library Associations and Institutions
IFLA Professional Reports, Nr. 104




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**Guidelines for
Library Services to Persons with Dementia**

Helle Arendrup Mortensen and Gyda Skat Nielsen

<https://www.ifla.org/files/assets/hq/publications/professional-report/104.pdf>




Person-Centered Care


- Treating the person with dignity and respect
- Understanding their history, lifestyle, culture and preferences, including their likes, dislikes, hobbies and interests
- Looking at situations from the point of view of the person with dementia
- Providing opportunities for the person to have conversations and relationships with other people
- Ensuring the person has the chance to try new things or take part in activities they enjoy.

Research Shows that People Living with Dementia can Read

- Bourgeois, M. (2001) Is reading preserved in dementia? *The ASHA Leader*. <https://doi.org/10.1044/leader.FTR2.06092001.5>
- Claridge, G. and Rimkeit, S. (2018). Can she still read? How some people living with dementia responded to the reading experience. *Extensive Reading World Congress*, 4, 266-275.
- Benigas, J. and Bourgeois, M. (2011). Evaluating oral reading and reading comprehension in patients with dementia: A comparison of generic and personally relevant stimuli. *Non-pharmacological Therapies in Dementia*, 2(1): 41-54.



New Purposes for Reading



- Stimulate memories
- Encourage conversation
- Participating in an enjoyable activity
- Feelings of competence
- Joy of lifelong learning

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A different kind of reading



- In a social setting
- Active, not passive, roles
- Invitations to read out loud
- Browsing through non-fiction

Types of literacy materials

- Short fiction
 - Folk tales, excerpts from classic fiction
- Non-fiction
 - Color photographs
 - Person centered
 - From adult and children's collections
- Local history
- Poetry
- Song lyrics
- Word searches or other word games



Content matters

- Literature and non-fiction
- Personally relevant – Bourgeois study
 - Training your horse – Effingham (IL) Public Library
 - Local history – chocolate factory
- Lifelong learning – magic happens!

Sample Tales & Travel Folklore
WHY BROLGAS BIRDS DANCE
A tale from Australia

A long time ago in the Australian outback there lived a girl named Brolga who loved to dance. This was a problem because, in those days, girls were not allowed to dance. They could only clap their hands and stomp their feet while the men did the dancing.

One night, as the men danced, Brolga couldn't contain herself. She jumped up and began dancing with them. The people of her tribe were shocked at this behavior. At first they were very upset. However, when they saw how beautifully Brolga danced, they let her continue.

Eventually Brolga became a famous tribal dancer. People came from near and far to watch her dance. Several men became infatuated with Brolga and wanted to marry her. She refused all offers because she wanted to dance, not cook and clean and bare children. One magician, named Broolie-Broolie, wouldn't take no for an answer. He watched Brolga's every move waiting for an opportunity to capture her.

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Person Centered = Individual Interests



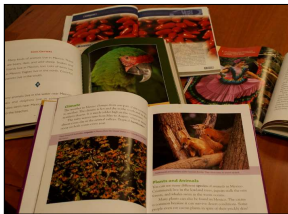
- Books
- Magazines
- CDs – country music
- DVDs - westerns
- Personal Interests
 - Motorcycles
 - Old West
 - Vietnam War
 - Home Improvement

Format matters

- Font size/line spacing
- White space/reduce clutter
- Books written for persons living with dementia
 - [Reading2Connect](#)
 - [Nana's Books](#)
 - [The Sunshine on My Face](#) and other books by Lydia Burdick



Selected Children's Non-Fiction Titles



- IFLA Guidelines
- "Terminology" confusion
 - Non-fiction for grades 3-8
 - **Not** fiction, picture books or beginning readers
- Respect for children's book publishers
- We must always respect the dignity of these adult users



Olathe, KS

Olathe is a suburb of Kansas City with a population of about 150,000 people. In Olathe, the library is a department of the City of Olathe. We have a main library and one branch location.

Olathe is located in Johnson County, Kansas. Johnson County has its own library with 14 locations. Our service areas overlap and we work closely with them.

A Little About Us...



Library to You is a free delivery service of library materials to patrons who can't physically get to the library. We deliver materials to about 200 patrons per month. We also do monthly off-site browsing sessions at 4 locations and monthly programming at 8 different care facilities.

Our programming is primarily geared toward individuals who are not receiving book deliveries, most of whom are living with some form or stage of dementia.

By far, the most popular program we do is Tales and Travel Memories. We've been doing them in care facilities for about 3 years now.



I like it because it is highly adaptable and there are a wide variety of topics that you can cover:

- Politics
- Geography
- History
- Culture
- Art/Music/Dance
- Food

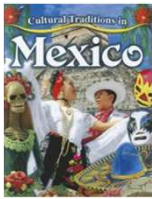


A very important part of the program is leaving time at the end for participants to thumb through books and discuss the topic.

What kinds of books do we bring?



- Children's books
- Coffee table books
- Occasionally travel brochures or maps if available



Advantages of using children's books:

- Light weight
- Less text, more pictures
- Often can be found with larger fonts
- Simplified sentence structure

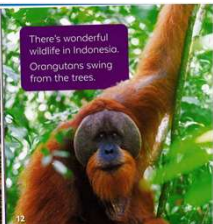
ALWAYS look through the books **BEFORE** you bring them!

Deal Breakers:



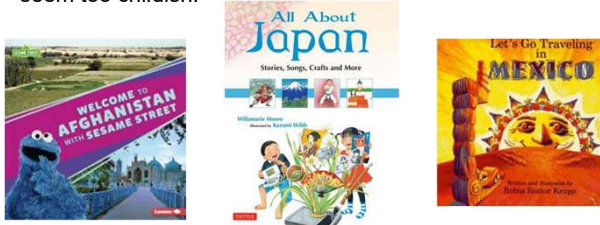
- Text is too simple—know your audience
- Page is too busy, too much going on, too distracting
- Illustrations are cartoonish

Consider your audience. Occasionally, books with extremely simple text like this might be appropriate, but for higher functioning groups, the simplicity of it might be offensive. Some examples of things I would NOT use:



Avoid books that have too much going on on each page as it can be distracting and make it hard for someone with dementia to focus on the text.

Even if they have good, relevant information, the cartoonish illustrations in these books could make them seem too childish.



Include books that further focus on some of the topics you discuss.

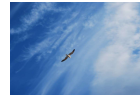


Avoid travel guides like Fodor's because they have very small text and fewer pictures.



Choose coffee table books with rich photography. Folks may not read the whole book, but they might read captions below pictures.

You don't have to just do travel programs!
You can incorporate reading into similar programs on any subject!



Some possible topics:

- Trivia
- Local history
- Seasons

Read a newspaper or magazine article together and discuss it.



Example: Stein, Jared. "Why We Love Opening Day." Gunaxin, 30 March 2018. <https://gunaxin.com/love-opening-day>

Excerpt:

"Do we really need another reason to play hooky from our lives and escape to the ballpark for a few hours? I think not. Heading out to catch your team kick off the season with your friends and like-minded fans while enjoying some of America's finest over-priced beer is the preamble to Memorial Day. Opening Day for Major League Baseball symbolizes the change of seasons from our dark, cold winters to our chirpy, sunny start of spring. Like Memorial Day, it is not officially the start of the new seasonal change, but it is, for all intents and purposes the start of the new season, and for that, we celebrate."

Local History

Is there a local history site in your area? A famous landmark? Chances are good that there is already appropriate literature written that talks about the place. Check on their website or with their visitor's center. You may need to enlarge the text for your readers. Chances are good that your readers already know something about the place. That can spark memories and good discussion.



Mahaffie Farmstead and Stagecoach Stop, Olathe, KS

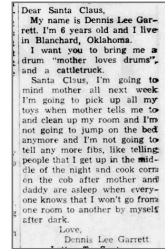
Seasonal Reading Activities

Read printed lyrics to songs as poetry, use them for a singalong or sing along with a video with captioned lyrics. This could be done at Christmas, Valentine's, 4th of July, in conjunction with a 1950's theme, or really, any time.



Seasonal Reading Activities

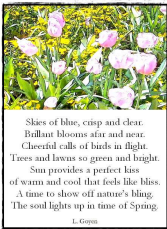
One fun reading activity we have done at Christmas time is to read letters to Santa that children have written. You can find these on the internet or by searching through old newspapers online such as newspapers.com.



The Blanchard News (Blanchard, Oklahoma) · 22 Dec 1960, Thu · Page 7

These are funny, but they also evoke childhood memories of favorite toys and Christmas traditions. This can lead to lively discussions.

Seasonal Reading Activities

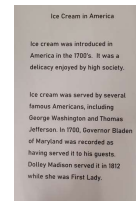


Skies of blue, crisp and clear,
 Brilliant blooms afar and near.
 Chorded calls of birds in flight,
 Trees and lawns so green and bright.
 Sun provides a perfect kiss
 of warm and cool that feels like bliss.
 A time to show off nature's bling,
 The sun lights up in time of Spring.
 L. Gump

Poetry is a good reading option for people with dementia. Choose several poems on a similar topic like "Spring" and take turns reading and discussing.

- Use short poems (maximum one page)—can be from the children's books or adult books or even found online
- Choose ones that are not "deep"—this is not a college English class!
- Focus on sensory—colors, sounds, smells. That will lead naturally to good discussions.

Choose a non-fiction book and select a just a few paragraphs to read and discuss—or simplify them into a few paragraphs yourself



Shared reading – Reader Organization

A Literature-Based Intervention for Older People Living with Dementia

An evaluation report by the Centre for Research into Reading Information and Linguistic Systems

University of Liverpool



Billington, J. (2013). A literature-based intervention for older people living with dementia. *Perspectives in Public Health* 133(3):165-73.

More studies on shared reading

Rimkeit, S. and Claridge, G. (2017). Literary Alzheimer's, A qualitative feasibility study of dementia-friendly book groups. *New Zealand Library & Information Management Journal*. 56(2):14-22.

DeVries, D. et al. (2019). The impact of reading groups on engagement and social interaction for older adults with dementia: A literature review. *Therapeutic Recreation Journal*. 53(1): 53-75.

Memory Cafes



Living Arrangements of People with Alzheimer's Disease and Related Dementias: Implications for Services and Supports


Issue Brief
October 2017


Presented by:
Michael Grune, PhD
Alma Harris, BA
Julia M. Wilson, PhD

<https://aspe.hhs.gov/system/files/pdf/257966L/vmg/Arms.pdf>



Tales & Travel at Memory Cafes





| Date | Presenter | Topic / Activity |
|---------|-------------------|------------------------------|
| Jan. 6 | Mary Beth & Brian | Tales & Travels to Australia |
| Jan. 13 | Araceli & Tommy | Music Therapy |
| Jan. 20 | HOLIDAY | |
| Jan. 27 | Araceli | Music & Movement |
| Feb. 3 | Mary Beth & Brian | Tales & Travels to Brazil |
| Feb. 10 | Tommy | Music Art |

Memory Café Tools

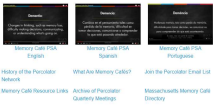
[MEMORY CAFÉ DIRECTORY](#)



[MEMORY CAFÉ PERCOLATOR NETWORK](#)


JF&CS Memory Café Percolator

The JF&CS Memory Café Percolator shares information and tools to make it easier for organizations and individuals to start and sustain their own memory cafe.

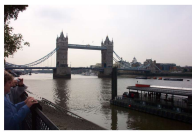


Digital resources

- Tales & Travel Adventures
- Created in response to pandemic lockdown
- Offers interactive literacy activities to virtual memory cafes via Zoom
- Eleven adventures available on YouTube and as pdf's
- <http://talesandtravelmemoies.com/memory-cafes/>



After a good night's sleep and a proper English breakfast, we need to get on the bus to go to the Tower of London on the Thames River. Here is the Tower bridge in the distance.



More digital resources

Local history – Champaign (IL) Public Library

- Let's visit...Downtown Champaign, IL
- <https://www.youtube.com/watch?v=o6DuetbBSFY>

Rush Alzheimer's Disease Center

- Black History Month Activity book – Feb. 2022
- <https://i.brainhealth.org/2022/02/16/download-your-free-copy-of-the-rush-alzheimers-disease-centers-activity-book-for-seniors/#comments>



What's Next?

- Inspiration for experimentation
- Reader's Advisory for Individuals?
 - 81% live at home in community
 - Appointments and/or questionnaire
- Partnerships
 - Dementia Friendly America – state & local members
 - Local research hospitals
 - Cooperate with other libraries

Library Services for Dementia/Alzheimer's

- Interest group ODLOS/ALA
 - No membership fees
 - LSDA Connect for ALA members
 - LS4DA Google Group
 - Come join us!
 - Openings in leadership team
 - Working Group forming to develop guidelines

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