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

(NA, 2022)
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; Dufresne & 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.

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

Guidelines for Library Services to Persons with Dementia

Hele Arendrup Mørtensen and Gyda Skat Nielsen
### 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


### New Purposes for Reading

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

### 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 Folktales

A tale from Australia

A long time ago in the Australian outback there lived a girl named Bridie who loved to dance. She was a problem child. Her parents were sick of her. They sent her to a dance school, but Bridie refused to go. She wanted to be a dancer, not a problem child. Her parents didn’t understand. They thought Bridie was too young to dance. Bridie was determined to prove them wrong.

Eventually, Bridie became famous for her dancing. People came from far and wide to watch her dance. She was a natural talent. People said she had found her calling. Bridie was happy. She knew she had found her true passion. She continued to dance, and everyone admired her. She never looked back, and her parents were proud of her. She proved them wrong and showed them that she had the talent to be a famous dancer. She lived happily ever after.
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.

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.

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.

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.

Read a newspaper or magazine article together and discuss it.

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

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

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.
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.

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

Seasonal Reading Activities

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.

Seasonal Reading Activities

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

More studies on shared reading


Memory Cafes

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 cafés.

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://talesandtravelmemories.com/memory-cafes/

More digital resources

Local history – Champaign (IL) Public Library
  • Let’s visit...Downtown Champaign, Il
    • https://www.youtube.com/watch?v=01Du1iDcZgY

Rush Alzheimer’s Disease Center
  • Black History Month Activity book – Feb. 2022

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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