

Libraries as Key Collaborators in Cultivating Dementia Friendly Communities

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What is Dementia?

- General term for loss of memory and thinking abilities severe enough to impact everyday life
- Includes many causes: Alzheimer's Disease, Vascular Dementia, Lewy Body Dementia, Pick's Disease and others
- Not a part of “normal” aging!
- Encompasses problems with memory, thinking and behavior

Variations in Dementia

- Each person with dementia and their care partners have unique experiences.
- There are many challenges along the journey of dementia.
- The type of dementia, age at diagnosis, other physical problems, vision/hearing issues, and mental health concerns may affect the illness trajectory.

10 Warning signs of DEMENTIA

1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks at home, work or leisure
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationships

6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgement
9. Withdrawal from work or social activities
10. Changes in mood and personality

What is the Dementia-Action Collaborative?

- A state-wide collaboration of public-private partners convened in April 2016 to begin implementing the *Washington State Plan to Address Alzheimer's Disease and Other Dementias*
- The DAC includes a range of appointed members: including persons with dementia, and family care partners.
- It has developed foundational tools and resources to use in a variety of places.

Dementia Friendly Principles

People with Dementia:

- Are respected community members
- Are able to confidently participate in their communities (including libraries)
- Can stay connected to family, friends and neighbors while having chances to develop new relationships

- Are encouraged to enjoy meaningful lives (access to education, recreation, work or volunteering, cultural enrichment and more)
- Will have access to early diagnosis and post diagnostic resources for themselves and care partners, including medical care, education and support, financial/legal services and advance care planning

- Will have a voice in their community and leadership roles in anything that impacts them
- Will be able to navigate their neighborhoods and public spaces with a physical environment that is supportive and clear
- Will have transportation options that help persons stay involved in their community
- Will have housing options that provide the level of support wanted, in a setting they desire

Adapted from Washington State Dementia Action Collaborative 2017

Tips for interacting with people with dementia

- Most important: Demonstrate accepting attitude by kind non-verbal communication and tone of voice!
- Be patient.
- Speak clearly.
- Account for vision and hearing concerns.

- Listen closely to what a person is saying. Do not correct.
- Smiles go a long way in communication.
- If confusion seems present, gently re-direct, and then move on with the conversation.
- Respond gently if a person is distressed.
- Get to know the likes and interests of patrons, and be proactive with suggestions if asked.

Dementia Friends

- A “train the trainer” program which began in Japan, and has now moved to the United Kingdom and the US
 - In 2018 the WA DAC began field testing the program here. Initial trainings in Seattle and Yakima
 - People who attend the training become dementia “friends,” and commit to positive actions to change the life of those with dementia
- Emphasizes that it is possible to have good quality of life with dementia
- Affirms that persons are more than their dementia; they are still valuable parts of the community

<https://dementiafriendusa.org/become-a-dementia-friend>

Why Dementia Friendly Libraries?

- Are multigenerational spaces
- Place to connect with community
- Serve patrons of all socioeconomic status
- Value inclusion and diversity
- Value respect of everyone
- Are places of kindness
- Are “safe” spaces for all patrons
- Committed to lifelong learning
- Neutral location with no stigma attached to visiting

How Can Libraries Help?

- By being welcoming places with supportive staff. Smiles are universal!
- By utilizing education about dementia and care partner issues.
- By helping develop “dementia-friendly” reading material pioneernetwork.net/reviving-the-joy-of-reading/

Education and Resources can:

- Reduce fear and support people with memory loss and their care partners by presenting clear information.
- Connect people to local resources such as the Alzheimer's Association or Alzheimer's Society of Washington or the local hospital education department.
- Help to reduce stigma related to dementia.

Libraries can also help by:

- Hosting support groups
- Hosting special activities e.g., AARP Careversations, Memory Cafés (where persons with dementia and care partners share a low key “normalized” social situation)

- Providing displays and pamphlets. Displays increase awareness, and show that the library is “seeing them” and is reaching out to include people with memory loss.
- Offering resources such as books, memory kits, DVD’s and other materials
- Programming, especially using creative arts such as music and art
- Using mobile and outreach services to connect with homebound persons and their carers

Memory Café



Partnership with Alzheimer's Association



Activities

Creative Storytelling

Music



Websites

- <https://www.dshs.wa.gov/altsa/dementia-action-collaborative>
- <https://www.timeslips.org/about>
- <https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/expert-answers/music-and-alzheimers/faq-20058173>
- <https://www.alz.org/help-support/caregiving/daily-care/art-music>



Pocket Pond 2
(TriggerWave LLC)



Live Butterflies
(Sea Lion Games Inc)



Zoola Animals
(INBAL Tal)

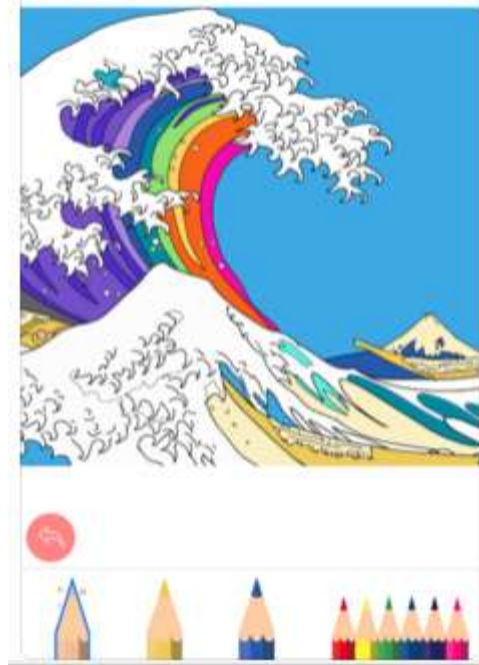




Unblock Me
(Kiragames Co.)



Coloring Book: Colorgram
(Sunwoong Jang)

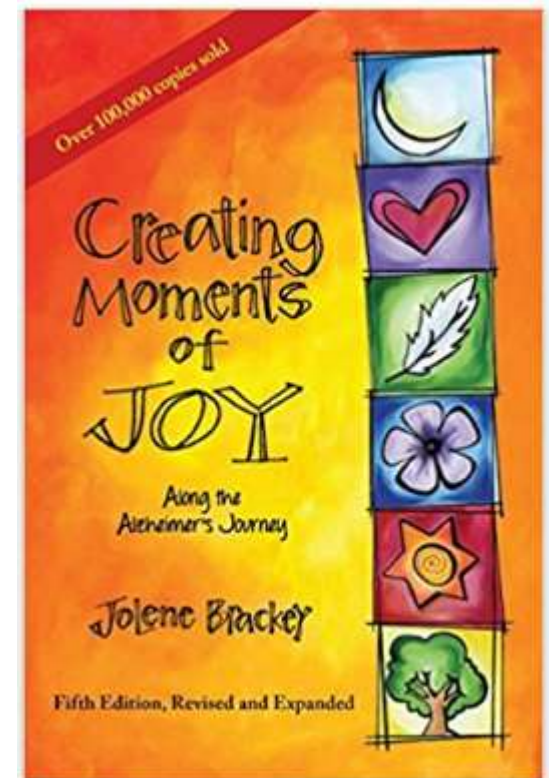


Finger Paint Magic
(Meritum Soft d.o.o.)



Caring for Caregivers

- Consider providing a space for caregivers to come together, share resources, and network with others in similar situations
- Self-Care events
- *“Creating Moments of Joy Along the Alzheimer’s Journey: A Guide for Families and Caregivers”*
by Jolene Brackey



Inclusive programming

- Design programming for all that is accessible to people experiencing memory loss (as well as their caregivers!) and consider burying the lede if that better aligns with goals

Meet Me at the Movies – movie clips with guided reminiscence

Creative Arts – live in the moment!

Your suggestions?

Outreach Services and support

- Bring materials care partners can share with people with dementia:
 - Materials they can read aloud. Include photos and other images.
 - Short text, simple storylines.
 - Subjects they can related to: animals, gardening, food, local history, celebrities from youth, WWII and military, farming, aviation industry.
 - Magazines like Reminiscence and Nostalgia
 - Videos: classic movies, television shows, animated shows.
 - Music! Especially if you can choose something with a personal connection.
 - Ongoing Readers' Advisory interview— connecting to past.
 - Materials for the care partner's enjoyment.
 - Keep collection of donated/discarded materials that do not need to be returned.

Examples of kits and other materials

- Ramsey County (MN) Library partnered with local Dementia Community Action Team and senior living facilities to create Memory Minder kits that checkout for 3 weeks with interactive activity, book with colorful illustrations, CD with soothing music to spark memory and a care partner book. Three different levels to correspond to early, middle and late-stage dementia. All 60 kits were checked out within one week. New kits will focus on Lewy Body Dementia and helping children to understand. <https://www.rclreads.org/about/library-news/memory-minders-kit-caregivers>.
- See story about this project at <http://publiclibrariesonline.org/2018/07/memory-minders-meaningful-engagement-for-those-impacted-by-dementia/>

Examples of Existing Outreach Programs

- St. Charles (IL) Public Library Outreach Services:
 - Educational and Engagement Kits around themes with information, photos, props people can touch
 - Caregiver themed kits with DVDs, CDs and coffee table books
 - Memorable Pets (www.memorablepets.com) provide security and comfort
 - Holiday sing-alongs at care facilities– include instruments
 - “Reading to Residents” at care facilities– animals are popular
 - “Attic” Memory wagon– filled with vintage items
 - Fidget quilts
 - David J. Kelsey “Reaching for Memories: Expanding Services and Programming to Patrons Living with Alzheimer’s Disease.” *Public Libraries*, Vol. 57, No. 4, July/August 2018, pp. 26-29.

More Programs....

- Stories for Life Program at the Springfield-Greene County Library District, MO. Bring books, videos, games, various sensory materials on regional history topics to facilities. <https://thelibrary.org/seniors>
- Tales and Travel Memory Program: imaginary trip with facts, folklore, music, props/souvenirs, spices, developed by Mary Beth Riedner. Programs ready for use <http://talesandtravelmemories.com/>
- <https://www.caregiver.org/sites/caregiver.org/files/media/gilbert-vignettes-ales-travel.pdf>
- <https://www.librarymemoryproject.org/about/>
- Memory Boxes/Reminisce Kits with themed books, colorful photos, activity books, music CDs, videos, toys, games and crafts. Caregiver resources.

Commonalities of Programs

- Themes with which audience can personally connect (local history, industry, 20th century history). Community dependent. The more you know, the more you can tailor.
- Mix it up! Visual and tactile sensory stimulation is essential: videos, music, props that can be touched.
- Make it educational. Handouts must be large, clear, vibrant.
- Include time for sharing and communication.
- Always have staff members from facility present.

Websites

- <https://arapahoelibraries.org/browse/seniors/>
- <http://www.effinghamlibrary.org/forgetmenot/> (Partnership between rural area Alzheimer's Association and local library. Offers presentations to local community on aging issues. Provides educational materials, including list of top circulating.)
- <https://thelibrary.org/seniors> (Springfield Greene County Library)
- <https://abos-outreach.com/> (Association of Bookmobile and Outreach Services)
- <https://librariansdementia.wordpress.com/>
- Alzheimer's and Related Dementias Interest Group at ALA:
<http://www.ala.org/asgcla/interestgroups/igard>
- Ramsey County Library (MN) Aging and Caregiving Resources:
<https://www.rclreads.org/research/subject-guide/69/sites-for-seniors>

Tools to support the person with memory loss and their care partners

Highly illustrated books (oversize books are great!), audiobooks, and reminiscence kits such as Bifolkal

Books for reading aloud – short fiction, history, biography

Suggested books for your collection

- *Caresharing: A Reciprocal Approach to Caregiving and Care Receiving in the Complexities of Aging, Illness or Disability* by Marty Richards
- *Creating Moments of Joy* by Jolene Brackey
- *I'm Still Here* by John Zeisel
- *Loving Someone Who has Dementia: How to find Hope While Coping with Stress and Grief* by Pauline Boss
- *The Spectrum of Hope: An Optimistic and New Approach to Alzheimer's Disease and Other Dementias* by Gayatri Davi.

Books for your collection

- *Ten Thousand Joys & Ten Thousand Sorrows: A Couple's Journey Through Alzheimer's* by Olivia Hoblitzelle
- *Speaking Dementia* by Frena Gray-Davidson
- *Aging Together: Dementia, Friendship & Flourishing Communities* by Susan and John McFadden

Children's Books

- *What a Beautiful Morning* by Arthur A. Levine
-
- *Wilfred Gordon McDonald Partridge* by Mem Fox
- *Mile High Apple Pie* by Laura Langston & Lindsay Gardiner
- *Really and Truly* by Emile Revard & Ann Claire Delisle
- *Still my Grandma* by Veronique Van den Abeele
- *Grandfather's Story Cloth* by Yawg Daim Paj and Ntaub Dab Neeg

Websites with Dementia Friendly Information

- Act on Alzheimer's

www.ACTonALZ.org

Dementia Friendly Libraries

- Home4Care: Hearthside Book Club

<https://hearthsidebookclub.com>

- The Conversation Project

www.theconversationproject.org

Your Conversation Starter Kit for Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia

Dementia Action Collaborative WA State

www.dshs.wa.gov/altsa/stakeholders/alzheimers-state-plan

Washington State Plan to Address Alzheimer's Disease and Other Dementias

Dementia-Friendly Communities: An Introduction for Washington State

Dementia Road Map: A Guide for Family and Care Partners

Safety Concerns for People with Dementia Info Kit

Community organizations supporting this work

AARP Careversation

Alzheimer's Association

ArtofAlzheimers.net

ChangingAging.org

Dementia Action collaborative

Silver Kite Community Arts

Memory Café

Momentia.org

UW Brain and Wellness Center

Local hospitals

Questions? Comments?

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