

Serving a Forgotten Population: Those with Alzheimer's & Other Dementias

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Abstract

The stigma attached to a diagnosis of Alzheimer's Disease or a related dementia is enormous, and those living with dementia often speak of the negative, and almost immediate, social impact of the disease. According to Alzheimer's Disease International, there were approximately 50 million people worldwide living with dementia in 2017 and this number could reach 131.5 million by 2050 (n.d.). The social isolation that affects many people living with dementia is best combatted by knowledge and understanding. There are many ways that libraries can put their mission statements into action with regard to this devastating disease. People living with dementia are coming into libraries every day. Library staff need training to recognize those who may be affected and to develop effective communication techniques to meet their special needs. In addition to purchasing books and other materials about the disease and how to cope with it, libraries can help those living with dementia and their caregivers find medical information available from underused sources such as Medline Plus from the National Library of Medicine. Libraries are uniquely suited to host educational events and community discussions. Outside organizations such as the Alzheimer's Association can provide informational sessions held in the library. There are also several model projects developed by libraries across the country that demonstrate how libraries can provide direct programming and services to those living with dementia. Libraries can play a significant role in reducing social isolation among those living with dementia and improving the quality of their lives.

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Introduction

The stigma attached to a diagnosis of Alzheimer's Disease or a related dementia is enormous, and those living with dementia often speak of the negative, and almost immediate, social impact of the disease. It is important to recognize that the true experts about dementia are those living with it. One such gentleman, Bob Savage, described his experience with these words, "Within two days after I got my diagnosis, I realized what it was like to be stigmatized... One day, I'm this guy; the next day, I'm that guy. It just shows how pervasive this whole stigma is against dementia" (AlzheimerSpeaks, 2018, 24:05-24:35). Fear of this stigma keeps many people from seeking essential support and making invaluable plans about their future care in a timely manner. It also keeps the general public uneducated about this disease and how it affects the person, their family, and the wider community. Dr Jacob Roy

Kuriakose, Chairman of Alzheimer's Disease International, states:

Low levels of understanding about dementia lead to various misconceptions resulting in perpetuation of stigma which is prevalent in most countries at various levels. People with dementia are often isolated, or hidden, because of stigma or the possibility of negative reactions from neighbours and relatives to behavioural and psychological symptoms. The idea that nothing can be done to help people with dementia often leads to hopelessness and frustration. (Batsch & Mittleman, 2012, p. 2)

Library workers, along with the general public, are not immune from holding negative views and demonstrating misunderstanding about dementia. Education and information, the stock and trade of libraries, are the only real defenses against perpetuating these stereotypes. Libraries, as respected institutions in their communities, are in an ideal position to take on a leadership role to increase awareness of the true nature of this disease. Individuals living with dementia should continue to be welcomed into the libraries they have been using all their lives and be treated with the respect accorded to all patrons.

A wide variety of non-pharmacological interventions, therapies ranging from art and music to pet and exercise, have been identified as beneficial for improving the quality of life for those living with dementia. Among the psychosocial practices described in a review article published in *The Gerontologist* are reminiscence therapy, validation therapy, and meaningful activities (Scales, Zimmerman, & Miller, 2018, S95; S96). Library collections are huge resources that can be easily mined to help stimulate memories and provide a continuation of everyday activities that help to provide a person-centered environment so important to the wellbeing of those living with dementia. The body of literature on the topic of library service to persons living with dementia is very small. One of the earliest efforts to raise awareness among librarians was the *Guidelines for Library Services to Persons with Dementia* published by the International Federation of Library Associations (IFLA) in 2007 (Arendup Mortenson & Skat Nielsen).

There is much librarians can and should be doing to ensure that the resources they oversee are being used to engage, entertain, and stimulate those members of their communities living with dementia. This article first provides a brief overview of the basics of this disease and then demonstrates how libraries can take a proactive role in serving this neglected population.

Dementia Basics

The number of people affected by Alzheimer's Disease or other forms of dementia is already huge and is predicted to soar as the Baby Boomer generation ages. According to Alzheimer's Disease International (n.d.), there were approximately 50 million people worldwide living with dementia in 2017 and this number could reach 131.5 million by 2050 (para.1). The Alzheimer's Association (2019a) reports that 5.8 million Americans were living with Alzheimer's in 2019 (p. 17) and that number is projected to grow to nearly 14 million by 2050 (p. 22). The Alzheimer's Association (2019a) also reports that one in ten Americans over the age of 65 has been diagnosed with Alzheimer's Disease or another form of dementia (p. 17). Dementia often goes undetected, with rates of underdetection going as high as 53.7% in Europe, 62.9% in North America, 93.2% in Asia (Lang et al., 2017, pg. 3).

A report issued in the U.S. on the "Living Arrangements of People with Alzheimer's Disease and Related Dementias" indicates that 81% of people with dementia are still living in the community,

with only 19% living in residential care settings or nursing homes (Lepore, Ferrell, & Wiener, 2017, p. 1). It is highly likely that many of these people are still visiting their libraries as they had done throughout their lives, though there has not yet been a study to document this.

Dementia is not a monolithic disease and care needs to be taken to refrain from placing all those living with dementia into the same stereotyped group. According to the Alzheimer's Association (2019b), there are many types of dementia, although Alzheimer's with traditional short-term memory loss accounts for 60-80% of the cases (para. 2). Long-term memory is often preserved until the late stages of Alzheimer's. Other types of dementia include vascular dementia, Dementia with Lewy Bodies, and Frontotemporal Degeneration. These dementias affect different parts of the brain than those impacted by Alzheimer's and memory is often preserved. While it is outside of the purview of this article to describe all symptoms of each of the various dementia types, readers can access the Alzheimer's Association's (n.d.) list of ten early signs and symptoms of dementia to begin their own research into this topic.

Dementia is a progressive disease. There are several stages of dementia, often designated as early, middle, and late. Many people are not diagnosed until they reach the middle stage of the disease. People can remain highly functional far into the middle stage of the disease, which can last for many years. Each person progresses through these stages at their own pace. There is a tremendous amount of variability among those diagnosed with dementia.

It is important to remember that each person living with dementia is still an individual with his or her own experiences, interests, and abilities. The focus should be on the abilities that are retained, rather than on those that are lost. Person-centered care is becoming the gold standard for dementia care. According to the British Alzheimer's Society (Alzheimer's Society, n.d.), the key points of person-centered care are:

- 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; and
- ensuring the person has the chance to try new things or take part in activities they enjoy.

The Role of the Library

The social isolation that affects many people living with dementia is best combatted by knowledge and understanding. This is where libraries can play an essential role. The mission statements of most public libraries contain inclusive language about serving all people of all ages. There are many ways that libraries can put their mission statements into action with regard to Alzheimer's Disease or other forms of dementia.

It is a misconception that people living with dementia can no longer read. Michelle S. Bourgeois,

a professor at the University of South Florida states, “All of my research demonstrates that people who were literate maintain their ability to read until the end stages of dementia” (Freudenheim, 2010, para. 3). In the United Kingdom, a study was conducted on the *Get Into Reading* literature intervention designed by The Reader Organization (Gallagher, 2017). The study sought to identify the effect of the reading sessions on the severity of dementia symptoms over a six-month period. Many positive results were identified that “illustrate how powerful literary language helps establish attention in group members...stimulating new thoughts...provoking concentration... and...calmly shared enjoyment” (Billington, Carrol, Davis, Healy, & Kinderman, 2013, p. 170). People living with dementia may not read in the same way that they did in the past, but that does not mean that they cannot benefit from books and reading opportunities. Existing library programs, one such being *Tales & Travel Memories*, described in more detail below, demonstrate that non-fiction books richly illustrated with photographs on topics of interest to each person are very useful in stimulating memories and providing topics for conversation.

Staff Training

People living with dementia, many of whom may be undiagnosed, come into libraries every day. Library staff members may be uncomfortable dealing with this population due to lack of knowledge and training, and library staff members are not alone in this. In the U.S., a national initiative called Dementia Friendly America (DFA) (n.d.) seeks to pull together all aspects of a community, including the library, to confront the stigma of dementia and help transform entire communities into more informed and dementia friendly places. The Library Sector Guide posted on the DFA website enumerates many ways that libraries can provide services and programs to those living with dementia (Dementia Friendly America, 2016). One of the first suggestions is training of library workers.

All library staff members, from the administration, to reference librarians, circulation clerks, shelvers, and maintenance staff, would benefit from training to recognize those who may be affected by dementia and to develop effective communication techniques to meet their special needs. Training should include basic information about what dementia is and how it affects individuals with regard to memory, language, decision making, behaviors, and so on. Tips for improving interactions would include maintaining friendly body language and tone of voice, actively listening to the person and giving reassurance that the person has been heard, giving only one instruction at a time, allowing time for the person to process the information provided, accepting their “reality” and avoiding correcting them. Such training should be a priority if libraries hope to work effectively with this population and provide them with the dignity and respect they deserve.

Educational Programming Partners

As a neutral and public space found in almost every U.S. city, town, or county, libraries are uniquely suited to host educational events and community discussions on the topic of dementia. Outside organizations such as the Alzheimer’s Association can provide informational sessions held in the library that are open to the public. The following list of organizations may help to identify some possible partners in the United States:

- Local chapters of the Alzheimer’s Association can be located at https://www.alz.org/local_resources/find_your_local_chapter

- Search for local Area Agencies on Aging at <https://www.n4a.org/>
- Medical research centers affiliated with local universities and hospitals

Special Collections

Libraries are uniquely equipped to develop special collections about Alzheimer's Disease and other forms of dementia to help educate the general population about these diseases. There are also a growing number of books being published to help those who are caring for those living with dementia. According to the Alzheimer's Association (2019a), over 16 million Americans were providing unpaid care to this population in 2018 (p. 33). These family members and friends are looking for the type of information that libraries can easily supply.

In addition, libraries in the U.S. can help those living with dementia and their caregivers find medical information available from sources such as the National Library of Medicine. One often underutilized resource is Medline Plus (U.S. National Library of Medicine, n.d.), a free database designed for patients and their families written in language that is easy to understand. Patrons can use MedlinePlus to learn about the latest treatments, look up information on a drug or supplement, find out the meanings of words, or view medical videos or illustrations. Another important database is PubMed Central, a free full-text archive of 5.3 million medical and scientific journal articles (National Center for Biotechnology Information, n.d.).

Innovative Programming

In addition to providing these more traditional methods of providing library services, libraries across the world are proactively developing innovative outreach programs and services aimed directly toward this underserved population and their care partners. As mentioned earlier, the *Guidelines for Library Services to Persons with Dementia* developed by IFLA served as an inspiration to libraries worldwide to begin offering services to those living with dementia (Arendup Mortenson & Skat Nielsen, 2007). In the U.S., numerous model projects have been developed that demonstrate how libraries can provide direct programming and services to those living with dementia to positively affect the quality of their lives.

Tales & Travel Memories.

In 2008, inspired by the IFLA Guidelines and by her own experience caring for her husband with a young-onset dementia, Mary Beth Riedner began developing a book and reading program for persons living with dementia in residential facilities. *Tales & Travel Memories* is an award-winning program that takes participants on an imaginary trip to different parts of the world using library materials. Incorporating the tenets of person-centered care, Riedner created a program using non-fiction books from both the adult and children's collections that can be used to stimulate both long-term memories and conversation.

The *Tales & Travel Memories* program incorporates oral reading by the participants of folk tales from the chosen locations, as well as interesting facts about the area (Tales & Travel, n.d.). This is followed by time to browse through books richly illustrated with color photographs about the destination. Books can be carefully selected from either the adult or children's collections to offer a wide variety of materials that people with differing abilities can enjoy. Other senses and abilities can be engaged by a wide variety of activities, including choral reading of poetry, singing

songs related to the chosen location, passing around souvenirs or other objects, distributing adult coloring pages, and sampling cuisine from the area. In a lighthearted atmosphere, participants become actively engaged in the activities to the best of their current abilities. This library program can bring a feeling of acceptance and community to these often socially isolated individuals.

In partnership with the Gail Borden Public Library District in Elgin, IL, the program was expanded to over a dozen local memory care facilities. A research study funded by the National Network of Libraries of Medicine showed that the *Tales & Travel Memories* program was effective in engaging participants both socially and cognitively (Lytle, 2016). A *Tales & Travel Memories* website was developed thanks to a Carnegie-Whitney grant from the American Library Association (Tales and Travel, n.d.). The website provides sample excursions for 12 countries as well as 31 folk tales made freely available through a Creative Commons license. Libraries are encouraged to adapt the program for their own communities and *Tales & Travel Memories* programs are burgeoning across the U.S.

Tales & Travel Memories was designated as a Best Practices Honoree by the Library of Congress (n.d.) for their 2017 Literacy Awards. This honor reinforces the idea that universal literacy does not stop with a diagnosis of dementia.

Stories for Life.

The Springfield-Greene County Library in Springfield, Missouri, in the U.S., seeks to provide quality programming and materials directly to those with Alzheimer's and related dementia living in a residential care facility or at home. Stories for Life is their dementia inclusive program brand that covers outreach programming, memory cafés and reminiscing kits (Springfield-Greene County Library District, 2013).

The original outreach program was created in 2012 by Tysha Shay to reach community members residing at residential care facilities throughout the county. Staff provide a monthly thematic outreach program that lasts 30-45 minutes and is designed to inspire, entertain, and engage the residents. The goal is to provide books, information, and multimedia resources to help resident's memories bubble up to the surface.

Residents reminisce and learn about a range of topics. Some of the most requested topics revolve around local history information. Programs discussing the Frisco Railroad, orphan trains, and rural medicine have provided some of the best participant involvement. Participants also often request topics for the following months. Examples have included Famous Missourians, Ozarks Music, St Louis World's Fair, Missouri Caves, and Olympic History. Shay commented that this means that residents are driving their own programming, which is pretty incredible.

In 2017, the Springfield-Greene County Library also introduced themed reminiscing kits to reach residents at facilities staff cannot visit and those still residing at home. Each kit was designed and developed by following the principles of person-centered care, which aims to respect the dignity of people with Alzheimer's or other types of dementia and reflect their varied interests, life experiences, and current abilities. The kits have different elements to engage all the senses and various levels of materials to connect with folks no matter what stage of the disease they are in. There are over 30 kit themes. Many of the kit themes were taken directly from successful elements of the outreach program. Popular kits include Animals, Pioneer Days, Route 66, Ozarks

Music, Remembering the 1950's, and Rural Medicine (Springfield-Greene County Library District, 2013).

Serving diverse groups.

Librarians are becoming increasingly aware of the special needs of diverse groups within their communities. The *2019 Alzheimer's Disease Facts and Figures* report states that “although there are more non-Hispanic whites living with Alzheimer's and other dementias than any other racial or ethnic group in the United States, older African-Americans and Hispanics are more likely, on a per-capita basis, than older whites to have Alzheimer's or other dementias” (Alzheimer's Association, 2019a, p. 21). As part of its recent renovation, the Woodson Regional Library, a branch of the Chicago Public Library that serves a large population of African Americans, was made into the city's first Dementia-friendly library. In that role, Woodson provides culturally relevant programming and education around Alzheimer's disease and memory loss. A newly formed library health advisory board, comprised of academics, researchers, health professionals, clergy, librarians, and caregivers, aims to create awareness about this insidious brain disease that adversely affects African Americans at a ratio of two to one (Chicago Public Library, 2018, para.15).

Memory Cafés.

Memory Cafés are a wonderful counterbalance to the social stigma felt by so many people living with dementia. Begun in the United Kingdom and other European countries, Memory Cafés are now blooming across the U.S. Memory Cafés provide informal social programming that bring together those living with dementia and their care partners to enjoy a wide variety of activities in a safe environment. Memory cafés can also be sources of information about available health resources and health literacy.

As mentioned earlier, the majority of persons diagnosed with dementia are still living within their own homes. As a respected institution in the community, libraries are natural partners for Memory Cafés. The Library Memory Project (n.d.) is a wonderful example of a collaborative project involving eight libraries in the Bridges Library System, Wisconsin, U.S. Located geographically near each other, the libraries take turns hosting monthly Cafés so that participants don't have far to travel to find a Café. The libraries work together and in partnership with outside organizations that provide expertise and assistance. Angela Meyers, Coordinator of Youth and Inclusive Services for the Bridges Library System says, “That's where [libraries are] a perfect fit for people who are experiencing memory loss. It's a place where they feel welcome and it's a comfortable place for them to return to...They know when they go that they're going to be welcome, they're going to have a good time, and they're going to maintain those connections” (Nowakowski, 2019, para. 6).

Professional Library Organization

While libraries across the U.S. have been independently developing innovative programs to serve those living with dementia, an interest group of the American Library Association entitled the Alzheimer's and Related Dementias Interest Group (IGARD) was formed in 2011 “to support librarians who serve patrons with Alzheimer's or another dementia and their care partners by providing a forum for discussion and networking.” (Association of Specialized, Government and Cooperative Library Agencies, 2018). IGARD members have presented at various conference

sessions and webinars to help spread the word about how libraries can effectively serve those living with dementia. IGARD also sponsors a free listserv where anyone interested in this important work can ask questions or share information and experiences. Working together collaboratively will enable librarians to more easily develop innovative programs to serve those living with dementia. IGARD hopes to develop official guidelines based on the IFLA Guidelines that will be approved by the American Library Association.

Conclusion

These are just a few of the ways that libraries are successfully meeting the needs of an underserved and too-often forgotten population - the many people living with dementia in their communities. However, these types of services and programs are in their infancy, and there remain many unanswered questions about how to best serve those living with dementia.

Librarians can, and do, play a significant role in reducing social isolation among those living with dementia and improving the quality of their lives. As Bob Savage, who was quoted at the beginning of this piece, says: "I have been encouraging the people that I work and live with to use the term 'living well' with dementia...As you know many people with dementia do live well and for a long time. This could in my opinion take a small step to reducing stigma" (personal communication, February 17, 2019). It is time for librarians as a profession to commit to helping Savage, and others like him, continue to "live well" using the many rich resources and sense of community that the library can provide.

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Tysha Shay (tyshas@thelibrary.org) is the Reference Manager at the Library Station, Springfield-Greene County Library District. Her passion is bringing library services to older adults and specifically those with Alzheimer's or related dementia. She developed her library's dementia-inclusive brand, Stories for Life, which includes outreach programs, memory cafes and reminiscing kits. Tysha was named a Library Journal Mover & Shaker in 2015 for her innovative work with this audience.

Kayla Kuni (kkuni@mail.usf.edu) is a librarian at Pasco-Hernando State College. Prior to working for PHSC, Kayla worked in a public library for over six years. In both academic and public libraries, Kayla has taught future business owners how to access resources that will help grow small businesses. In 2017, she was named the Outstanding Public Servant by the West Pasco Chamber of Commerce for her work with the community. Kayla is currently pursuing an MBA from the University of South Florida (USF). Prior to entering the MBA program, she successfully completed a bachelor's degree in English (2009) and a master's degree in Library and Information Science (2014), both from USF.