LIBRARY DEMENTIA SERVICES

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How to Meet the Needs of the Alzheimer's Community

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INTRODUCTION

Common sense and a warm heart alone cannot cope with dementia – professional insight and expertise are also important parts of the solution. (IFLA, 2007, p. 7)

The World Health Organization estimates the number of people living with Alzheimer's disease (AD) and related dementias globally at 50 million, with growth projected to reach 82 million by 2030 and 152 million in 2050 (World Health Organization, 2019). The number of people with AD in the United States alone – 5.8 million – may also triple by 2050, as the population ages (Alzheimer's Association [AA], 2019a, pp. 17–23). These numbers, and the further tens of millions of people who are providing unpaid care to those living with dementia, should shock us all.

The global increase in dementia cases already impacts librarians and other public service professionals in the United States and elsewhere, as the syndrome continues to spread among an aging population. Librarians already serve adults with dementia and their caregivers and have been doing so for decades. Some public libraries have even dedicated Dementia Librarian roles, or at the very least staff trained as Dementia Friendly (DFA, 2015). However, despite the 2007 publication of the International Federation of Library

Associations' *Guidelines for Library Services to Persons with Dementia*, the profession has sometimes struggled with standards of service and approaches to this vulnerable and growing population. Mary Beth Riedner (2015) regards librarians as an essential part of the dementia care team, and many areas of our professional practice can positively and concretely impact those living with dementia, given good professional guidance.

Library Dementia Services is the first complete handbook for library and information professionals serving people with AD and related dementias, and with the tens of millions further who are caregivers in the dementia epidemic. Designed for seasoned professionals and library science students alike, this book opens with a complete overview of the spectrum disease known as Alzheimer's dementia and a basic understanding of the information needs of dementia caregivers. It then explores best practices, guidelines, and concrete ideas for serving those with dementia and their caregivers:

- Customer service and communication, with evidence-based suggestions for working with this population;
- Information resources to best meet the reference needs of the community, as grounded in LIS user studies and medical literatures;
- Collection development for ongoing and appropriate mental and social stimulation of those experiencing cognitive decline; and
- Programming ideas for both communities, with a wide variety of focus and content.

Lifelong learning, mental stimulation, and social connections are central to libraries' core mission. Readers, both from library and information science and in related social services and social sciences disciplines, will gain a comprehensive

toolkit for service both to those in cognitive decline and their caregivers, meeting the needs of both communities with thoughtful and innovative practices.

The first chapter of *Library Dementia Services* comprehensively surveys the global epidemic in Alzheimer's and related dementias, as well as the impact on the community of caregivers for loved ones in cognitive decline. The chapter explores the history of dementia, the scope of its epidemic spread, risk factors and warning signs, and most importantly, dementia treatment and prevention as vital concerns for information professionals. Contemporary medicine has failed to produce a pharmaceutical cure for dementia. However, research consensus is building around three major lifestyle aspects that can help prevent or lessen the effects of cognitive decline – a brain-healthy physical lifestyle, brain training and a variety of mental stimulation, and ongoing social activity. Two of these aspects are already central to what libraries and cultural heritage institutions offer on a regular basis – lifelong learning and social connections to the community, and they will be the foundation upon which our impact within the dementia community is built.

In the second chapter, readers get an overview of the communication challenges experienced by persons living with dementia, as well as best practices for communication skills. Librarians already champion the best principles of "customer service" as adapted from business literature, and our textbooks extend to different demographic targets in our user base. Here we will synthesize best practices from LIS and other public service and health communities, to offer detailed recommendations for communication and service throughout the progress of Alzheimer's and related dementias, including how to work with specific behavioral challenges common to those living with dementia. Adapting our twenty-first century customer service and communication skills to meet the needs of the Alzheimer's

community is one of the most fundamental gifts information professionals can offer.

Professional reference and information services to meet the specific needs which arise in conjunction with the disease are the focus of the third chapter. Professional information services lie at the center of our ethical practices, which include affording equal access to all. Both medical science and LIS have become more user centered and proactive in shaping our understanding of information needs; this chapter will supplement the basic LIS studies with information from the fields of psychology, medical informatics, and specific dementia literature. Distinct categories of basic information for this population are known to include medical information needs, financial information needs, legal and ethical needs, and emotional needs. We are offering information resources with more sensitive communication skills, and with respect for the special needs of the person living with dementia – cognitive decline, loss of processing speed, and the important needs for privacy, respect, and protection. The chapter features both a critical assessment of needs and behaviors and a survey of major resources.

The fourth chapter moves the conversation about best practices for libraries into the development of physical collections and materials – specifically, supporting collections which can best serve persons with dementia and their caregivers, as well as library staff who need better understanding of dementia. Building upon the IFLA *Guidelines for Library Services to Persons with Dementia* (2007) and the current LIS literature on user-centered collection development, this chapter will survey the formats, genres, and content that can best meet information needs, mindful of the users' age and level of current cognition. Genres and types of materials include picture books and books for reading aloud with persons with dementia, and stimulating music, media materials, and

"reminiscence kits." In addition, those in the early stages of dementia, their care partners, and library staff all can learn from nonfiction resources, memoirs, and even fiction titles dealing with dementia, dementia caregiving, and family relationships. This chapter will survey the material types above, with recommendations for targeting materials within the collection to the dementia community, and for making new selections to meet future needs.

Building on the evidence-based assessment of non-pharmacological interventions against dementia, the final chapter examines library programming for this community. Activity by itself benefits older adults experiencing cognitive decline, as a therapeutic agent "reducing disability and maintaining physical function, preventing behavioral and psychological symptoms and reducing their frequency/severity of occurrence, [as well as enhancing] enjoyment and quality of life." (Gitlin & Hodgson, 2018, p. 81) But there remains a lot of room for exploring a spectrum of programming options that serve the needs of those living with AD and related dementias, as well as their caregivers. We will consider general library programming for older adults, followed by a large variety of dementia-specific programs available for social interaction, reading and storytelling therapies, music and visual art therapies, gaming and technology, and others.

The global dementia epidemic confronts humanity with a lot of bad news, but librarians and information professionals can make a huge and positive impact in this community. Better communication skills serve these patrons with sensitivity and competence, and our collections, information resources, and adult programming can enhance quality of life with dementia and can in some cases even prevent dementia, or help to delay its onset. Librarians can realize our potential as partners on the care team and as support for the direct caregivers.