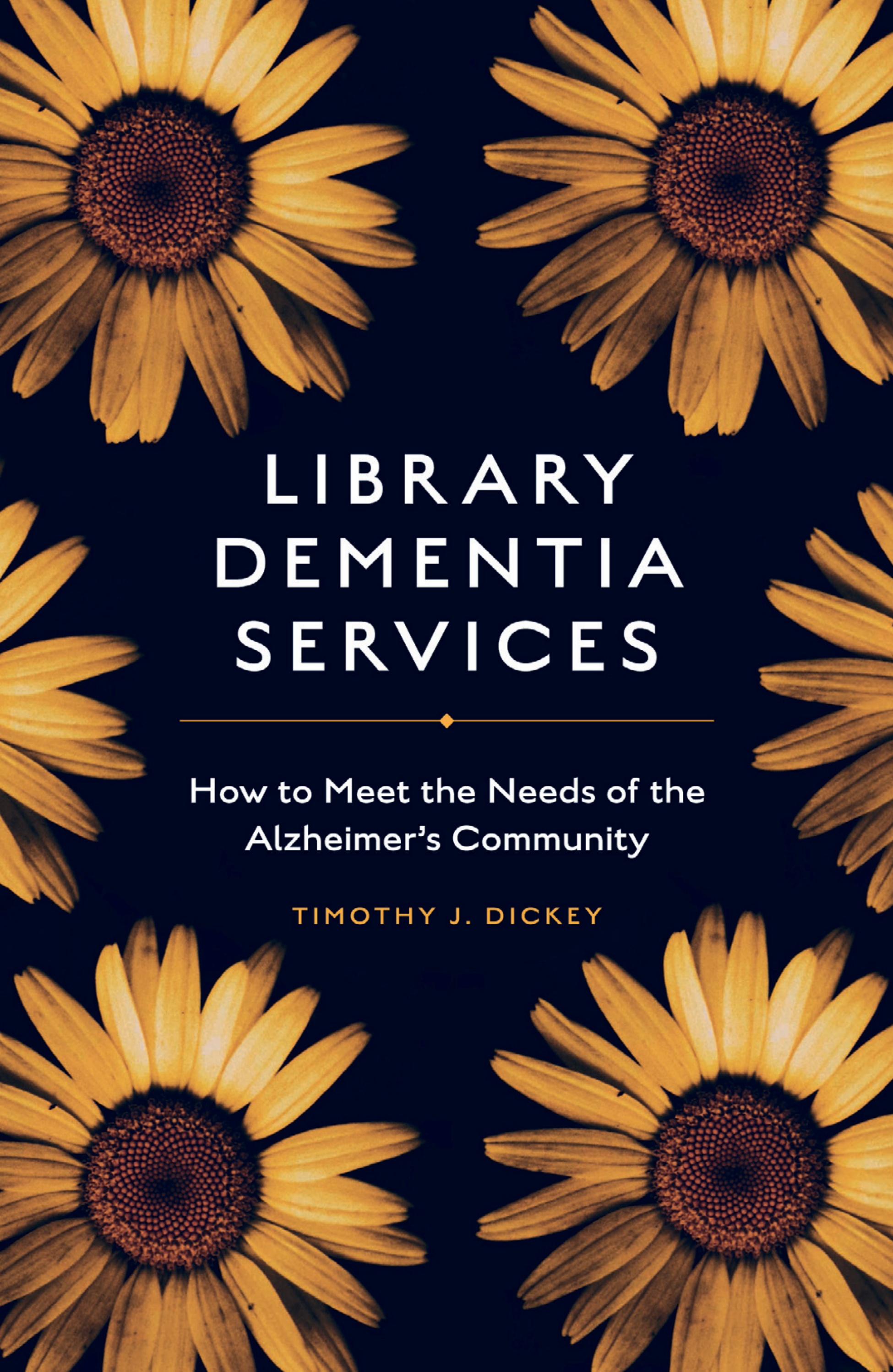

LIBRARY DEMENTIA SERVICES

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How to Meet the Needs of the Alzheimer's Community

TIMOTHY J. DICKEY

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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.

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KNOWING YOUR USERS: ALZHEIMER'S DISEASE, RELATED DEMENTIAS, AND CAREGIVERS

The global increase in dementia cases, expected to rise from 50 million in 2019 to 82 million by 2030 and 152 million by 2050 (World Health Organization, 2019), will impact more and more librarians and other public service professionals in the immediate future. Libraries in the United States and elsewhere are already serving adults with dementia, as well as the millions of additional family members who are as unpaid 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 (Dementia Friendly America [DFA], 2015).

Despite the 2007 publication of the International Federation of Library Associations (IFLA) *Guidelines for Library Services to Persons with Dementia*, however, the profession has sometimes struggled with standards of service. Similarly, museums and other cultural heritage institutions have innovated in dementia programming, but without establishing complete professional standards. The textbooks (for instance, Roberts, 2018; Wentz, Jaeger, & Bertot, 2015) and courses in library and information schools have not yet offered a comprehensive approach to this vulnerable, well-defined, and growing population.

The opening chapter of *Library dementia services* presents a comprehensive overview of the global epidemic in Alzheimer's and related dementias, as well as the impact on the even larger community of those providing care for loved ones in cognitive decline. This information provides a solid foundation for understanding the individual patrons who are living with dementia, and for making practical recommendations for library dementia services in the remaining chapters.

We will continue by surveying findings in dementia treatment and prevention that are vital to information professionals. Contemporary medicine has unfortunately 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 mental stimulation, and ongoing social activity. Two of these aspects are already central to what libraries and cultural heritage institutions within our society offer on a regular basis – lifelong learning and connections to the community.

HISTORY OF ALZHEIMER'S DEMENTIA

In 1906, Alois Alzheimer made the first modern diagnosis of the syndrome which now bears his name: cognitive decline that is clinically more severe than the simple effects of human aging. Current estimates of worldwide dementia cases have reached 50 million, and diagnoses of dementia continue to increase (World Health Organization, 2019). Dementia and cognitive impairment also deeply impact tens of millions of unpaid dementia caregivers (Alzheimer's Association [AA], 2019a). The first *World Alzheimer Report* (Alzheimer's Disease International [ADI], 2010) termed the syndrome an epidemic and urged the global community make dementia research and care a priority.

Cognitive impairment has actually been known for a long time. In antiquity, the Ancient Greeks, the Egyptians, and the Chinese knew cases of dementia in older adults; as early as 700 B.C.E., the Greek doctor Solon documented a decline in "intelligence" starting in one's late 50s (Morley, 2018). The Roman physician Galen specifically described irreversible cognitive damage within aging brains (IFLA, 2007). Shenk (2001, pp. 44–45) quotes the Roman poet Juvenal's poignant observations of senile dementia: "Worse than any loss in body is the failing mind which … cannot recognize the face of the old friend who dined with him last night, nor those of the children whom he has begotten and brought up." Esquirol and Philippe Pinel provided the first modern definitions of dementia around the turn of the nineteenth century (de Waal, Lyketsos, Ames, & O'Brien, 2013).

Western medicine reached a watershed year for dementia studies in 1906, when Dr. Alois Alzheimer documented a case of the *early-onset* dementia: 56-year-old Auguste D, whose husband had committed her to Dr. Alzheimer's care five years prior. Her social behavior had declined precipitously, as well as her memory and her capacity to perform the activities of daily living (ADLs; for good narrative accounts of Alzheimer's case see Jebelli, 2017; Powell, 2019). Her case was intriguing to the medical community because of the severity of her symptoms and her young age. In the same year, researchers in Japan and Liberia correlated "senile dementia" with protein buildups in the brain, physical deposits that had been known in the medical community since 1892 (Morley, Farr, & Nguyen, 2018). Through much of the twentieth century, research into Alzheimer's disease, and more basic research into cognitive aging and declining memory took place in parallel threads (Morley et al., 2018).

Medical research has progressed slowly but steadily in its overall understanding of dementia's physical effects on the brain, its outward manifestations, and its etiology. The medical community has identified genetic links and biomarkers for the early onset of AD and has classified more than 100 different causes, as well as numerous different types of dementia (Morley, 2018; see also Kapsambelis, 2017 on genetic research). Revisions to the worldwide dementia definitions in 2011 clarify Alzheimer's as presenting on a spectrum (Devi, 2017; Lewis & Trempe, 2017). A preclinical phase is now known to exist for up to 20 years before formal diagnosis (AA, 2019a, p. 5). Medical science is also exploring the potential relationship between various levels of mild cognitive impairment (MCI) and full clinical diagnoses of dementia (Montine et al., 2012).

The worldwide literature on Alzheimer's and related dementias now comprises some 50,000 papers per year, with four dedicated professional journals and several major international conferences (including the Alzheimer's Association International Conference; World Congresses on Alzheimer's Disease and Dementia; and Dementia & Alzheimer's Rehabilitation). However, dementia research lags behind cancer research by a 12:1 ratio of published papers (ADI, 2018, p. 10), and spending on AD research is one-tenth, per capita, of the research spending on HIV/AIDS (Powell, 2019, pp. 115–118).

Many individual countries do have dedicated nonprofit advocacy organizations, such as the Alzheimer's Society in the UK and the Alzheimer's Association (US), as well as Alzheimer's Disease International (ADI), which publishes the *World Alzheimer Report* annually on different topics in dementia research, dementia care, and the global impact of the disease. The skilled nursing facility industry clamors for increased memory care workers (Health Dimensions Group, 2018), and a separate literature has developed regarding the *design* of spaces for living with Alzheimer's and related dementias (Bowes & Dawson, 2019). Nonprofits devoted to dementia-friendly practices exist to create partnerships among different sectors of society that interact with people in cognitive decline and their caregivers (such as Dementia-Friendly America).

DEFINITIONS OF ALZHEIMER'S AND RELATED DEMENTIAS

Dementia is a sweeping "umbrella term" that covers a wide range of symptoms including memory loss and mental decline, as well as loss of physical and emotional capacity, and neuropsychological symptoms. "Dementia develops when the brain is damaged by diseases, including Alzheimer's disease" (Alzheimer's Society [AS], 2019a, p. 12). There are as many as 100 distinct causes of adult dementia, from simple aging of the human brain, to various neurodegenerative diseases, to physical trauma (Morley, 2018). The first distinction to be made is when the symptoms "[affect] memory, thinking and social abilities severely enough to interfere with … daily life" (Mayo Clinic, 2019b).

Alzheimer's disease (AD) is the most common cause of adult dementia, contributing to two-thirds of all cases (Alzheimer's Research UK, 2018). AD presents on a highly individualized spectrum, and there exist many other related dementia syndromes (Powell, 2019). The bulk of medical research is focused on AD, and it is the best-known type of dementia in popular awareness; the definitions below will thus begin with AD, but the *individuality* of dementia cases must always be kept in mind.

For a definition, Alzheimer's disease is an organic and degenerative disease of the brain, which progresses slowly over time, and has no known cure; its progress begins well before symptoms appear (in some cases 20 years or more beforehand). To the best of our knowledge, it is irreversible, though the progress and severity may be slowed. Due to its prevalence among cases of adult dementia, AD in itself is often used as an umbrella term that encompasses

> *… an entire continuum from the initial pathologic changes in the brain before symptoms appear through the dementia caused by the accumulation of brain changes. This means that Alzheimer's disease includes not only those with dementia due to the disease, but also those with mild cognitive impairment (MCI) due to Alzheimer's and asymptomatic individuals who have verified biomarkers.* (AA, 2019a, p. 26)

As a result, what we once called "Alzheimer's disease" is more accurately labeled "dementia due to Alzheimer's" or "Alzheimer's dementia" – one stage in the complete spectrum of AD and its relatives. Most authors now speak of AD as a spectrum disease, comparable thus to the autism spectrum (Devi, 2017), as a "constellation of symptoms" rather than a single diagnosis (Lewis & Trempe, 2017, p. 3), or a "kaleidoscopic array of symptoms and dysfunctions, never exactly the same in any two people" (Sacks, 2019, p. 144).

Postmortem pathologic analysis of brain tissue for those manifesting Alzheimer's dementia, as well as data from structural and functional MRI and PET scans, reveal physical changes in brain size and composition. Brains of Alzheimer's dementia patients tend to be physically shrunken, with characteristic patterns of degradation in the parietal/temporal lobes and a decrease in hippocampal volume (Morley et al., 2018;

Amen includes instructive images of brain scans, 2017, pp. 40–42). In addition, the progression of the disease is correlated to two physical markers within the brain's neural network itself, known colloquially as "plaques" and "tangles."

- **Plaques** are deposits of accumulated beta-amyloid protein, which reach abnormally high levels during the progress of AD. The protein deposits create encrusted barriers between neurons in the brain (ADI, 2018, p. 8). Plaques have been found in most postmortem diagnoses of AD, though up to a quarter of all people who die with significant beta-amyloid plaque buildups have not experienced cognitive impairment (Morley et al., 2018). The presence of amyloid thus is not necessarily decisive.
- **Tangles** are twists that develop within neurons due to the elevated presence of a different organic substance, Tau protein.

Medical opinion cannot decide whether beta-amyloid plaques and/or tau-activated tangles actually *cause* AD, or should be considered *symptoms only* (see Mendiola-Precoma, Berumen, Padilla, & Garcia-Alocer, 2016, and further discussion below). As recently as 2018, ADI concluded (p. 8) that despite decades of research, "What scientists don't know is exactly how these proteins relate to one another, or what causes them to build to such damaging levels." At the very least, plaques and tangles participate in the gradual loss of neurons: the electrical pathways within our brains which allow us to make all connections between sensations and knowledge. Brain capacity is gradually and irrevocably reduced. Gaps in memory, emotional changes, and disorientation manifest during the disease's early stages; later stages include loss of the ability to perform ADLs, loss of the ability to communicate, and eventual difficulty with speaking and swallowing.

Cases across the spectrum of AD are further distinguished between "sporadic" or late-onset Alzheimer's dementia (LOAD), and the "familial" or early-onset AD (EOAD). The majority of cases (95%) are late-onset, manifesting after the individual reaches 60 or more years of age, with an extremely wide variety of contributing factors (see below for more details on potential risk factors and preventative strategies). A total 5% of cases – including Dr. Alzheimer's first documented case – appear in younger people and tend to be associated with a genetic mutation in the Amyloid Precursor Protein gene (Mendiola-Precoma et al., 2016).

Though AD is implicated in 60–80% of all cases of adult dementia, it very frequently mingles with other types of dementia. Up to 50% of dementia autopsies provide evidence of "mixed dementia" (Brenowitz et al., 2017); the most common is a combination of Alzheimer's and vascular dementia (AS, 2019a, p. 13). The most common other types of dementia are defined below; most of these syndromes are also degenerative and nonreversible (see also AS, 2019a, pp. 16–21).

Vascular dementia results from poor blood flow to the brain, through strokes or other cases of poor cardiovascular health. Up to 10% of dementia cases are related to strokes and vascular flow alone (AA, 2019a, p. 9). Vascular dementia presents even more frequently in conjunction with other types of dementia. Vascular brain injuries (due to bleeding in the brain following the buildup of blood clots) can lead to cognitive impairment and loss of motor control. The early symptoms of vascular dementia tend to feature poor judgment and difficulty with planning and problem-solving, more than memory loss (Mayo Clinic, 2019a).

Medical opinion is relatively unanimous in correlating heart health with brain health, so positive trends in cardiovascular health have actually led to some decrease in new