

V i e w m e t a d a t a , c i t a t i o n b a r n o d C u g s
p r o v i d

Sandra Montgomery. Trends in Caregiving Literature for Alzheimer's Disease Patients and a Survey of Selected Public Library Collections. A Master's paper for the M.S. in L.S. degree. April, 2006. 50 pages. Advisor: David Carr

This study describes an overview and analysis of recent literature about the challenges that adult children of Alzheimer's disease patients face when caring for their loved one at home. It also includes a survey of the Alzheimer's disease collections at Chapel Hill, NC Public Library, Durham County, NC Library, and the Wake County, NC Library System and an evaluation of the materials available to adult and child patrons at each library in light of the best resources available currently.

Headings:

Alzheimer's disease—caregivers

Alzheimer's disease—sandwich generation

Alzheimer's disease—fiction

TRENDS IN CAREGIVING LITERATURE FOR ALZHEIMER'S DISEASE
PATIENTS AND A SURVEY OF SELECTED PUBLIC LIBRARY COLLECTIONS

by
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Introduction

When you were a young adult, did you ever think that you would be caring for your aging parents? Probably not, if you are like most adults. However, as people live longer because of advances in diet and medical science, more adults are no longer able to care for themselves, thereby creating a demand for all levels of elder care.

For a variety of reasons, among them financial and moral, many older adults end their lives being cared for at home by their adult children. In some cultures, this is expected; children grow up knowing that they will eventually care for their parents. Indeed, they see their parents caring for their grandparents. In American culture, however, we do not grow up with that expectation and it can be very unexpected and surprising when it happens.

With couples marrying and having children later and with more women in the workforce, the introduction of elder care into a family's life can be challenging as well as surprising. The "Sandwich Generation" is the popular term invented by Carol Abaya, a nationally syndicated newspaper columnist, for adults who care for their aging parents in their home as well as their children, all at the same time (<http://www.thesandwichgeneration.com>). These adults are handling issues related to adolescence at the same time that they are handling elder care issues. Members of the Sandwich Generation who care for parents with Alzheimer's disease face unique challenges for themselves as well as other family members. They juggle career; possibly a marriage or partnership; logistics related to children, school and sports; and at the same

time they are trying to figure out the changes in their elderly parent. Trying to maintain their elderly parent's dignity and safety while keeping their home accessible to teenagers and their friends can be an overwhelming challenge. Further, it can be hard to meet career obligations in light of the huge changes at home. The same adults who painstakingly prepared for childbirth and childrearing are being blindsided by the onset of Alzheimer's disease in their elderly parent.

The members of the Sandwich Generation who have a parent with Alzheimer's disease are suddenly asking many new questions. Their aging parent does not look sick or act sick, yet much must be done to keep him or her safe and mentally and physically stimulated. Much of the work must be done discreetly so that the patient does not feel insulted. Additionally, the smoothing over of the patient's behavior in daily life can at times be daunting. How do you explain the unreturned phone calls when the caller was assured by the Alzheimer's disease patient who politely answered the phone that a return call would be placed shortly? How do you explain to a teenager's friends the need to answer politely and warmly the question that Nana has asked them five times? How do you keep your teen-age daughters comfortable with inviting friends over to the house when odd behavior happens every time a friend visits? How do you explain lost papers and unaccounted-for messes to your spouse? How do you tell your boss that you must leave work in order to go pick up your parent who has been found wandering in your neighborhood? And how do you encourage the caregiver to replenish the energy needed to handle the different challenges that come with every day? These adults need answers to these questions as well as to the financial and medical questions that arise with an older parent.

Thus, this situation creates a unique information need. The people who are thrust into this situation are often surprised by it, or at least unprepared. They have not thought about the day-to-day realities of caring for a loved one in their home. Not only are there the basic needs of their aging parent, but also the needs of the rest of their family, their career demands, and their very own needs.

Suddenly there are new errands, new dietary restrictions, new time constraints, new child-raising issues, and new space constraints. Not only that, but there are emotional considerations as well. Their parent might not be happy with the change and may long to still live on their own. The spouse and children of the caregiver may not be happy about this change and may not be supportive and eager to help.

Where does a new caregiver go to get information? It is likely that many resourceful caregivers will either look on the internet or go to the library. A search on Google will give the caregiver access to the Alzheimer's Association (<http://www.alz.org>), the website of the National Institute on Aging (<http://www.nia.nih.gov/alzheimers>), the Alzheimer's Disease International website (<http://www.alz.co.uk/>), the American Health Assistance Foundation (<http://www.ahaf.org>), and the Alzheimer's Foundation of America (<http://www.alzfdn.org>). Some caregivers, however, do not have internet access in their home. They will very likely end up at the library.

How well equipped are our public libraries for these caregivers who are eager to do a good job and need a lot of support? Twenty-five percent of Alzheimer's patients are cared for in the home, and so it is very important that libraries are prepared for these

caregivers' needs. It is, therefore, important that the public library is well equipped to serve this population.

A home caregiver can feel very isolated and can lack a sense of community. The role of the public library is to build community and to serve the communities that it builds. The caregiver community is fragmented and fervent, tired and inspired, emotional yet driven, and at times very exhausted when giving in to exhaustion is not possible. Therefore, the library needs to have ready a collection that meets several different information needs simultaneously. The caregiver needs to have access to how-to information, to information that provides insight into their situation, and also to information that gives them hope and inspiration, and possible meaning to their experience. A strong collection will meet all three of these needs. I believe that the best collections will meet the need to find meaning in this experience; I believe that this is an essential need of the caregiver. How many available sources talk about laughter and having fun and living each day to the fullest? Although one of the most widely read guidebooks states that "love is not dependent upon intellectual abilities" (*The 36-Hour Day*, p. 213) and that it is important to laugh and share affection with your loved one, the book spends only a half-page out of 339 pages on its section entitled "Laughter, Love, and Joy".

While this might be a reflection on our society's grim views on aging, the ability to make meaning can greatly enhance a difficult situation. As more and more people find themselves in the care giving role, the ability to serve their loved one while growing a sense of meaning and poignancy within themselves can make a huge difference in the

quality of their experience. The library's role in our lives can be one of enhancement as well as one of coping.

This paper will look at the Alzheimer's disease resources available for the Sandwich Generation in the public libraries of the Research Triangle area, where caregivers are likely to look for answers to questions to help themselves and their children in caring for their elderly parent. I will evaluate the sources available, develop a selected list of useful resources, and then I will see how many of them are available to users of the Durham County Library, the Wake County Library, and the Chapel Hill Public Library. I will also look at the resources available to librarians in building these collections.

Are there resources for librarians? Where would a librarian look to find suggestions about collection building and reference questions? Possibly, a librarian would first look at the American Library Association website, which offers several good starting points. They might also look to organizations that deal with the disease. In this paper, I will evaluate possible places for them to look and recommend the places that I found most useful. It is important, too, to examine the needs of the other generation within a family. A librarian will need to serve them, too.

“Grandma just told me that I am useless...in front of my friends.” A statement such as that one could be said by thousands of youngsters who are living with or near a grandparent who has Alzheimer's disease. A study of the situation of families who have a loved one with Alzheimer's disease living in their home would not be complete without a look at the information needs of the young people in the home. Alzheimer's disease currently affects approximately 4 million people in the United States (Magnuson, 1999).

That number is expected to grow as life expectancies increase. Not all families want their loved one to spend their last days in a rest home nor can some families afford the high price of Alzheimer's disease care. More and more grandparents are moving in with their children and grandchildren. In fact, the majority of Alzheimer's disease patients live in a household setting and are cared for by family members (Barrett, 2004). In the struggle to cope with the issues that they face, not much time is left for parents to prepare their children for life with a confused, unfamiliar grandparent or to address the feelings a child experiences under these new circumstances. In this paper, I will discuss how to help grandchildren in grades 4-7 learn ways to cope with their sick grandparent, and I will recommend works of fiction for helping them deal with their new situation. The books which I have chosen help children to understand the situation on their own level. With proper care and preparation, the grandparent and grandchild can come to accept and enjoy one another and grow to have a tender, positive relationship that greatly benefits both of them.

In spite of much research, Alzheimer's is still a mystery to us, particularly to children. How does a self-sufficient, successful individual become unable to handle daily life, while still looking so normal? How is it that they sound just like they have always sounded, yet they say those harsh words? How can they not know you when you have been a part of their life for all of your life? It just does not make sense. Yet, that is the reality of Alzheimer's disease. For children, an adult's erratic behavior can be extremely confusing and even frightening, especially when the adult is one they have known, respected, and loved forever.

On the other hand, that grandparent who can now say such terrible things still has the capacity to love and to enjoy life, but differently. Those still wonderful qualities can be masked by the disease, and the caregiver must learn that the parameters of daily life are now different. For instance, we teach our children to tell the truth and to not be rude. How, then, should a child react when their sick grandparent calls them by a different name? Normally, the child might politely correct the speaker. In interacting with a person with Alzheimer's disease, the child learns that simply enjoying the conversation is more effective than worrying about who the grandparent thinks they are. If a child can learn to accept the fact that the grandparent does not love them any less, but just cannot help the fact that they have lost the ability to identify people, even their own grandchild, the child can then enjoy the conversation along with the grandparent and can maybe even learn something new and unexpected.

As we learn to converse, we are taught that it is okay to tell a person if we have already heard what they are about to say. In the case of an Alzheimer's disease patient, it is different. Relatives of Alzheimer's disease patients must learn that Alzheimer's disease patients do not realize that they repeat themselves, and they cannot correct themselves because they have lost the ability to remember. Therefore, to bring this to their attention will often embarrass, humiliate, or even anger them. However, if we look at conversation as an enjoyable pastime, rather than solely as a means to exchange information, we can learn to view a repeated story or question as a way to enjoy each other's company. The challenge, which can be treated as a game, becomes to think of a new question to ask about the story, to answer the same question in a different way, or to make it feel like it is the first time you have heard the story. The end result is that the

child learns to be patient with their grandparent while continuing to love and respect her or him.

A child also learns that the grandparent comes to depend on the child for help or reassurance. This role reversal can be disconcerting until the child adjusts to it. Once the adjustment is made, it can become a source of self esteem and a confidence builder. It is interesting to note that in a study of families who cared for a grandparent with Alzheimer's disease in their home, the children described the care giving situation as a mostly positive influence on their family relationships. They also described how it increased sibling sharing, since they helped each other and were able to share a laugh over the sometimes odd behaviors they encountered (Beach, 1997).

Coping with a sick grandparent in the home can mean many changes for a child. In addition to the points that I have described above, the child may need to share a bedroom or switch bedrooms, they may have to take on more housework, it may be more difficult for them to have friends over to visit, and their parent(s) may have less time for them. These changes can affect children differently. A child who is not adequately prepared for these changes may become embarrassed or depressed and may withdraw from activities or struggle with schoolwork.

This paper, therefore, will examine the information needs of an entire family that might be faced with caring for a loved one with Alzheimer's disease in their home. What is available to the librarian and what are the best sources for the librarian to make available to the patrons? This study will explore these questions.

Literature Review

What resources are available to the librarian striving to build a collection about Alzheimer's disease for Sandwich Generation caregivers? A librarian might first look at available databases for guidance, starting first with scholarly resources and then proceeding to the American Library Association and the Alzheimer's resource websites.

A search of the Library Literature database under the keywords *Alzheimer's* brought up 16 scholarly articles, and one of them entitled "Creating better subject access with multiple vocabularies: upgrading the subject heading list for the Alzheimer's Association" might be useful to the librarian wishing to collect for Alzheimer's sources (Smith, 1999). A search including *caregiver*, *elderly*, and *dementia* produced no information.

A search of the Library and Information Science Abstracts (LISA) database under the same keywords brought up one article from 1999 that reviews the Alzheimer's.com website, but that website is no longer available on the internet. Another search, this time using *Alzheimer's* and *caregiver* brought up 35 scholarly articles of studies about caregivers, but no articles related to collecting resources for them. Another search on the keywords *Alzheimer's*, *caregivers*, and *library* brought up no hits. A subsequent search on *Alzheimer's*, *collection*, and *library* also brought up no hits, and adding *bibliography* also produced no hits, nor did a search of *sandwich generation*, *Alzheimer's disease*, and *library*.

A search of the American Library Association was more fruitful (<http://www.ala.org>). There is an excellent website with resources for librarians who serve the Sandwich Generation (<http://www.ala.org/ala/pla/resources/libraryservices>). These resources include articles, books, magazines, newsletters, websites, directories, organizations, and videotapes and cover topics such as financial matters, options for parents' living arrangements, and emotional issues surrounding caring for one's parents. This website would be an excellent starting point for any librarian who is building a collection or helping a patron. In this bibliography, they include 6 articles, 70 books, 17 directories and other similar resources, 15 newsletters, 19 organizations, and 2 videotapes. It is not an annotated bibliography, but it does give a good indication of the wide variety of sources that are available.

The Alzheimer's Association is very helpful as well. They provide excellent pamphlets, books, and videotapes. In conversation with the branch of the Alzheimer's Association in Raleigh, the consultants there seem to focus their local resources on institutionalized care giving, rather than home care. However, their written materials provide an excellent balance of both types of care.

One very useful booklet available for sale at the Alzheimer's Association is entitled *Pressure Points: Alzheimer's and Anger*, by Edna L. Ballard, Lisa P. Gwyther, and T. Patrick Toal (Durham, NC: Duke University Office of Creative Services and Publications, 2000). It gives insight in to what is happening when an Alzheimer's patient gets angry and useful advice about what to do in that situation. This is a resource that families will need to have close at hand as the disease progresses, because anger can be particularly enigmatic on one hand and hurtful on the other hand. It is the type of

resource that will be read in its entirety and then referred to frequently. Further, it is written in a style that is accessible to adults and children alike.

Another booklet offered by the Alzheimer's Association is entitled *Steps to Success: Decisions about Help at Home for Alzheimer's Caregivers* (Washington, D.C.: AARP Andrus Foundation, 2002) and is written by Lisa Gwyther, Edna Ballard, and Juliessa Pavon. It was funded by the AARP Andrus foundation for research into the relationships between people with dementia and their caregivers. This booklet looks at available options for caregiving at home. It discusses the different types of home assistance available, what to look for when hiring help, and lists agencies to rely on in such a search. The advice is positive and helpful.

Another useful tool available at the Alzheimer's Association is a collection of brochures entitled the "Action Series" (Chicago: Alzheimer's Disease and Related Disorders Association, Inc., 1996). This series is available for free at the Association and includes the following titles: *Steps to Planning Activities: Structuring the Day at Home*; *Steps to Enhancing Communication: Interacting with Persons with Alzheimer's Disease*; *Steps to Assisting with Personal Care: Overcoming Challenges and Adapting to the Needs of Persons with Alzheimer's Disease*; *Steps to Understanding Challenging Behaviors: Responding to Persons with Alzheimer's Disease*; *Steps to Enhancing Your Home: Modifying the Environment*; *Steps to Understanding Financial Issues: Resources for Individuals with Alzheimer's Disease*; *Steps to Understanding Legal Issues: Planning for the Future*; and, *Steps to Understanding Financial Issues: Resources for Caregivers*. These booklets are small, usually about 20 pages, and in pamphlet size. They include checklists and succinctly-listed steps to take about each topic. They should be included

in a public library collection. It can be difficult for a caregiver to go to Raleigh during business hours to avail themselves of these booklets. It is possible to order them over the internet, but I believe that it is wise to have them available in a public library setting for a caregiver to use. If the public library is their main source of information, then these are an integral part of the collection.

The Alzheimer's Association also has another series of pamphlets that are for varied audiences. This series is called the Topical Series. Several topics within this series include *How to be a Long-Distance Caregiver* and *Living with Early-Onset Alzheimer's Disease* (Chicago: Alzheimer's Disease and Related Disorders Association, Inc., 1999). These topics do not apply to the situation that I am covering here, but I believe that this series should also be available in the public library.

The final brochure that I believe has a place in the public library setting is entitled *Caregiver Stress: Signs to Watch for...Steps to Take* (Chicago: Alzheimer's disease and Related Disorders Association, Inc., 2002). In a very straightforward style, this brochure give 10 ways to reduce caregiver stress, tells the reader that dementia caregivers are more likely to have depression and anxiety, and that they are not alone because 70% of the 4 million Americans with Alzheimer's disease are cared for at home. It also gives 10 signs of caregiver stress. It therefore gives a quick, yet thorough, description of the feelings associated with caregiver stress and offers some excellent suggestions about dealing with it.

The Alzheimer's Association is also an excellent resource for obtaining information that will help a parent properly educate a child when their grandparent has Alzheimer's disease. For instance, they have two excellent brochures that are easy to

understand and are written in a way that captures a child's interest. The first one, *Your Brain: More Powerful than a Wizard, More Complex than a Computer* talks about what happens to the brain when a patient has Alzheimer's disease. It first gives an overview of the function of our brain and then talks about what happens in a brain with Alzheimer's disease. The article is brief and is put into terms that are easy for a child to understand. For example, it says that a person with Alzheimer's disease would not remember when the next Harry Potter book will be available or their friends' names. It also gives some easy-to-grasp technical information about the brain which makes it easier for a child to understand the disease process.

Another useful article available from the Alzheimer's Association is called *Just for Children: Helping You Understand Alzheimer's Disease*. It discusses how this disease is not contagious, and it emphasizes that the patient does not mean to treat you badly. One particularly effective tool this article uses is the example of how it would feel to get separated from one's group while traveling in a foreign country with a class. It talks about feeling scared, confused, sad, mad, and alone. Then it tells the child that that is how it feels to have Alzheimer's disease. Further, it discusses how their parent, the primary caregiver, might feel tired and sad, and become upset more easily as a result. This article ends on a positive note by encouraging the child to talk with her parents. Also, it suggests activities to do with the grandparent and emphasizes that even though the grandparent cannot remember, they can feel, and need to feel, love and kindness.

Searches with tools such as Lexus Nexus and InfoTrac reveal much scholarly research on Alzheimer's disease. A closer look at scholarly journals from the past six years shows a definite change in the tone of Alzheimer's disease research from one of

hopelessness in the sense that the disease is fatal and incurable to a tone of hope in that life is not over on the day of the diagnosis and therefore there is much opportunity for quality of life in the years that remain. This change in tone is important because it changes the nature of Alzheimer's care from engaging in a pessimistic activity to engaging in a challenging activity that has rewards instead of only pitfalls. This research is important to note because it has informed many of the authors that I believe are most important to include in a public library collection about caring at home for patients with Alzheimer's disease. Researchers are focusing now on the quality of life possible for Alzheimer's disease patients, since the disease can last for many years. Below are some examples of recent research and writing about life with a patient with Alzheimer's disease and some of the new ways to look at it, both for children and for adults.

Recent studies have focused on the effects that home care can have on a child. Several articles in particular are especially useful for their positive, helpful tone and I recommend them to anyone looking for information about helping a child cope with Alzheimer's disease. In her article entitled "Alzheimer's Disease from a Child's Perspective", Sandra Winters emphasizes that support and caring from the family are essential for an Alzheimer's disease patient, and that health care providers are equally essential in helping family caregivers assess and address immediate and long-term needs. She further asserts that with "just a little guidance and instruction, positive interactions can occur between the person with Alzheimer's disease and family youngsters" (Winters, 2003). Winters' article both creates and enhances awareness of the effects this situation can have on children. She emphasizes the need for educating the child and for being attuned to changes in their behavior. Also valuable are her suggestions for activities,

including listening to music, dancing, and singing, doing simple crafts, folding laundry, washing or drying dishes, and looking at old photo albums.

Another very useful article is directed toward the school counselor. Although addressed to counselors, this article is equally helpful to caregiver parents, teachers, and others helping children adjust to a grandparent with Alzheimer's disease. Its purpose is to make counselors aware of the increasing number of families that are becoming the caregivers and to prepare them for helping children in this situation. It emphasizes that these children are often reticent about this drastic change in their home and may be embarrassed about it. They may feel discounted when their grandparent does not recognize them; they also feel embarrassment and grief. Magnuson encourages the counselor to help the child become educated about the malfunction of the brain caused by Alzheimer's disease. This article also stresses the importance of acknowledging that it is confusing that the grandparent is not held accountable for behavior while the child is. Further, Magnuson emphasizes that the counselor should make the child aware that they are not alone in dealing with this situation. Not only do health professionals, educators, and parents understand the difficulties of the situation, but other children they know are experiencing the same thing and share the same feelings. This article encourages school counselors to work in collaboration with the Alzheimer's Association to bring an awareness program to their schools in order to encourage more students to speak up about their situations and to gain comfort and support from one another (Magnuson, 1999).

Two other articles are directed to and helpful for parents who need guidance in talking to their children about Alzheimer's disease. The first one is in *Children Today* and is called "Questions Children Ask". It is written by Rachel Shields Scott, a support

group coordinator who was asked to help teach elementary school students about Alzheimer's disease. She gives a general overview of the types of questions her students asked and how she structured her teaching sessions with those students. Her article is valuable and reassuring to concerned parents. A parent who is intimidated by the prospect of educating their child about this sensitive subject may be surprised to learn, for example, that the children ask questions like, "Can you catch it like a cold?", and "Do children get Alzheimer's disease?", and "If we forget something, does that mean that we are getting Alzheimer's?" (Scott, 1989) This article reminds the parent to approach the subject with a child's eyes and emphasizes that parents need to be reassuring and loving when explaining Alzheimer's disease to their child.

Another useful source is a recent article by Brooke Adams in the *Salt Lake Tribune*. Adams encourages the reader to make the most of the time that can be spent with a grandparent with Alzheimer's disease, since the disease gets progressively worse. She emphasizes that kids can be especially open to the quirky things that an Alzheimer's disease patient may do, like wanting ice cream for breakfast (Adams, 12 July 04). The article underscores the importance of educating your children's friends as well so that the child will feel more comfortable about the situation. This author encourages the parent to involve the children as much as possible in helping their grandparent and to be sure to set aside special time for the children as well. She also emphasizes the important point that the grandparent can still feel love in spite of memory loss. This article also includes a reading list from the local chapter of the Alzheimer's Association that is especially helpful.

I will turn now to recent research about Alzheimer's disease in general, focusing on issues that would be of interest to adults. It is important to note that although there are many articles that reflect hope and optimism, there are also a considerable number that focus on the difficulty and hopelessness of caring for a loved one with Alzheimer's disease. For instance, an article about a recent White House Conference on Aging discussed mixed feeling of hope and frustration. It says that a crisis looms because by 2025, Alzheimer's disease is expected to strike up to 16 million Americans. Delegates advocated for plans to be made now to respond to this crisis, but felt that there is not enough government recognition of these problems ("Crisis in Elder Care Foreseen" by Janet Kornblum in *USA Today*, 12 December 2005, p. 9D).

Another particularly pessimistic viewpoint discusses how difficult caregiving can be on a marriage and family. "Experts talk about a 'loss of intimacy' between couples when one member (and studies show it's usually the woman) is caught up in caring for an older, usually ailing, parent" ("Caregivers Redefining Family" by Melissa Fletcher Stoeltje in *San Antonio Express-News*, 5 March 2006, p. 13). A spouse of a caregiver discusses how he "finds himself resenting the time his spouse devotes to her caregiving role" (Stoeltje, p. 13). The article emphasizes about eldercare that "we're really going to learn how to love unconditionally, and we're going to teach it to our own children" (Stoeltje, p. 13). Thus, although mostly pessimistic, this article offers a small amount of optimism at the end of the article.

On a more hopeful note, one article that mentions former Senator William Proxmire discusses recent trends in Alzheimer's disease care. For instance, depression is being diagnosed and treated more often in Alzheimer's disease patients, a sign that

medical professionals are becoming more committed to the patient's quality of life. Further, questions are being asked about quality of life. A researcher at Johns Hopkins University has recently developed an assessment scale that measures quality of life in Alzheimer's disease patient. Another discovery mentioned in the article is the fact that research shows that Alzheimer's disease patients who spend time each week engaged in a one-on-one activity with a caregiver showed a significant reduction in apathy, which is a common symptom of Alzheimer's disease ("Research That Hits Home" by Beth Baker in *The Washington Post*, 1 November 2005, p. F01).

On a certainly positive note, a LexisNexis search found an article in a trade journal, *Kitchen and Bath Business*, that focuses on how to design the kitchen and bathroom in a way to make daily tasks easier for an Alzheimer's disease patient ("Details Count" in *Kitchen and Bath Business*, 1 April 2005). This article illustrates that more writers are looking at the long period during which a patient suffers from Alzheimer's disease can still be a period of enjoyment and productivity, even though some changes may need to be made to facilitate quality of life.

Many articles are available that shed light on the everyday issues facing caregivers and focus on how to face them with a positive attitude, offering insight that will make that possible. For instance, a recent article in *The Seattle Times* discusses what the Alzheimer's disease patient might be thinking and how a caregiver can take that into account. This article states that the brain of somebody with dementia becomes shriveled and therefore less able to think and reason. It says that there are periods when the person is probably not interacting with the world and that this is not good or bad, but rather is just how it is. It explains, further, that people with Alzheimer's disease vary in their

ability to be introspective and to think deeply (“Loving Caregiver wonders: What is She Thinking?” by Liz Taylor in *The Seattle Times*, 30 January 2006, p. E6). This type of information is very helpful to caregivers, yet until recently it has not been readily available. This article does an excellent job of giving insight into the mind of an Alzheimer’s disease patient.

Finally, it is interesting to note that many recent journal articles focus on taking a more optimistic view when caring for an Alzheimer’s disease patient. For instance, an article in the *Journal of Aging and Identity* “examines the process of how caregivers can shape the frustrations and exasperations of caring for a family member with Alzheimer’s disease into blessings” (“Exasperations as Blessings’ Meaning-Making and the Caregiving Experience” by H.K. Butcher and K.C. Buckwalter in *Journal of Aging and Identity*, June 2002, 7:2, p. 113).

Another journal discusses a creative way to provide respite for Alzheimer’s disease caregivers. It describes Baluchon Alzheimer’s, which is a program where somebody goes into the home of a patient with Alzheimer’s disease and takes over the daily care of the patient so that the family member can go on a vacation yet keep the patient in his or her daily schedule. This is an exciting concept because one of the most difficult situations for a caregiver is to try to figure out how to keep their patient in their schedule even when other obligations present themselves. The Baluchon Alzheimer’s program understands this issue well and addresses it skillfully. This article is written primarily for experts in the field, to introduce them to the possibility of introducing such a program in their geographical area and to provide the scholarly background to support it (Baluchon Alzheimer[c]: an innovative respite and support service in the home of the

family caregiver of a person with Alzheimer's in *Alzheimer's Care Quarterly*, July-Sept 2005, 6:3, p. 249).

Showing another recent trend in scholarly writing, that of taking into account the spirituality that drives some people, one recent article discusses how some female Alzheimer's patient caregivers get their strength from their spirituality and from their religion. It discusses how they rely on prayer and church attendance and how their religious beliefs buoy them through difficult times. This article treats caring for elderly loved ones as a usual part of life, rather than as a recently looming crisis. This point of view, although common in other cultures, is somewhat unusual in our culture. Therefore, seeing both a look at spirituality and the point of view that caring for the old ones is a normal part of life, is particularly refreshing and hopefully reflects a trend that will continue ("Female Alzheimer's patient caregivers share their strength" in *Holistic Nursing Practice*, Jan-Feb 2004, 8:1, p. 11).

In a book review covered by *Newsweek*, the author states that "in a warm, loving family, taking care of parents can actually be an exercise in reciprocity and promote a new level of intimacy between generations. Even when family dynamics have been fraught with tension, caregiving can become a learning experience" ("Doing the right thing" by Peg Tyre in *Newsweek*, 5 April 2005). She believes that the benefits include: seeing your parents more objectively, understanding and accepting your parents' limitations, and ultimately understanding and accepting your own limitations (Tyre, *Newsweek*, 5 April 2005). Like the previous article, this one, too, calls caregiving a normal part of life and, while not pretending that it is easy, it does not treat it as an unusual crisis. It advocates embracing this stage in life, learning from it, and doing it well.

The *Harvard Women's Health Watch* also treats the caregiving stage of life as a normal one. In an article about caregiving, this publication offers some creative strategies for dealing with caring for an Alzheimer's disease patient at home. It says that there are ways to deal creatively with common problems that make many people put their loved one into a nursing home. For instance, for dealing with a patient who wanders, the article suggests a backyard with a lock on the fence so that the person can go out of doors and feels a sense of freedom, yet not get lost. It also recommends adult day care. Most importantly, it emphasizes the importance of focusing on the process rather than the end result in dealing with everyday tasks ("Caregiving – strategies for caring for someone with Alzheimer's disease" in *Harvard Women's Health Watch*, Dec 2003, p. 0). This article offers hope, yet is very realistic in its approach to dealing with day-to-day issues. It, too, makes the reader feel that this is a normal stage in life, which can be encouraging. It is much easier to cope with daily issues when feeling like they are normal issues that many other people face as well. This article reflects that point of view well.

Finally, an article that focuses on the caregiver emphasizes that the caregiver must take care of herself (or himself) as well. It acknowledges that caregiving can be very difficult and that caregivers must reward themselves with frequent respite breaks, must accept help when it is offered and seek help when it is not offered, and must educate themselves about their loved one's condition as well as about the latest technology. Further, the article tells caregivers to trust their own instincts and not feel guilty ("Caregivers need some TLC, too" by Harry Jackson, Jr. in *St. Louis Post-Dispatch* on 29 November 2005). This article also treats caregiving as a part of life, but speaks to the caregiver in a nurturing way that affirms the difficulty of caregiving, yet helps the

caregiver do better at it by taking care of themselves. That tone reflects hope, which is a very encouraging attitude for a caregiver to hear.

These articles illustrate that the tone of the literature is changing; more articles are now available that focus on quality of life during a disease whose patients tend to live a long time after diagnosis. These articles look at life with Alzheimer's disease in a new way that is very helpful to a caregiver. To help the caregiver reframe the situation is to increase the quality of life for both the patient and the caregiving family. That sense of hope belongs in a public library collection and should be accessible to the caregiver who relies on the library for information about their situation.

Methodology

In order to provide a guide for librarians to prepare to serve caregivers of Alzheimer's patients, I will first review the existing resources for librarians. What guides librarians today? Do they have easy access to such materials? Is caregiver support seen as a major service at Triangle area public libraries? Do librarians expect caregivers to look to their collections for information?

Next I will look at themes and trends on works being written about Alzheimer's disease and the role of the caretaker. It is interesting to note that when a cancer patient looks for information, there are many sources that give them hope. Conversely, caregivers of Alzheimer's patients are given advice about coping and are told that what they are doing is extremely difficult, but until recently, hope has not usually part of the conversation. One trend that I will look for in my research is the conveyance of hope in the literature. I expect to find that there is a new trend toward a positive outlook in the literature.

In the next chapter, I will discuss the best sources available for adults and children. I will introduce them and explain why I believe they are core sources in a collection that reflects the latest trends in research and in care.

Finally, I will examine the collections at the Chapel Hill Public Library, the Durham County Library, and the Wake County Library System. Do they provide adequate resources for their patrons? I will choose the sources that I believe are essential

in a collection for caregivers and their children and then I will see if they are in the collections of the local public libraries.

Annotated Bibliography

What sources are most helpful for caregivers and therefore should be evaluated by a librarian who is building a collection for Sandwich Generation caregivers? The two components of this collection will be the adult sources and the sources especially for young adults. This chapter will evaluate selected sources for inclusion in such a collection, beginning with the resources for adults.

The most important sources for caregivers can be divided into two major categories. The first is the body of literature that helps a caregiver cope with day-to-day issues associated with caring for their loved one. This category also includes the works that discuss the caregiver's attitude and emotions as well as taking care of the caregiver. Second would be literature that brings insight to the caregiver about what is going on in the mind of their aging parent. These two types of literature are important in a collection designed to meet the needs of a caregiver to an Alzheimer's disease patient. I will now discuss the seminal works and articles that I believe should be in a collection for caregivers at a public library.

Caregiving: Seven Essential Titles

1. One essential volumes in the first category of this collection is the volume entitled *The 36-Hour Day* by Nancy L. Mace and Peter V. Rabins (Baltimore: Johns Hopkins University Press, 1999). This book is a handbook that provides structure for the caregiver in many ways. It deals in simple language with the day-to-day issues

associated with caregiving and it is written in a very supportive tone, acknowledging how difficult it can be to be a caregiver. As the title implies, days can be very long for both the caregiver and the patient. This book does a good job of explaining why an Alzheimer's disease patient might repetitively engage in an annoying behavior. The authors believe that if caregivers understand better what is going on in the patient's mind, it might be easier to manage a difficult behavior. It talks, too, about getting medical help and managing medical issues at home, current research issues in Alzheimer's disease, and transitions that will have to be made as the disease progresses. Making this volume essential, also, is the fact that it includes a chapter on children as well as a chapter on the care of the caregiver. This book would be an essential part of any collection.

2. Another essential volume in the first category of this collection is *There's Still a Person in There: The Complete Guide to Treating and Coping with Alzheimer's* by Michael Castleman, Dolores Gallagher-Thompson, and Matthew Naythons (New York: Perigee Books, 2000). This book is particularly good for the adult who is just realizing that they are going to become a caregiver. It discusses the warning signs of Alzheimer's disease and talks about taking steps toward a diagnosis in the first third of the book. Then it shifts to practical matters about taking care of an elderly parent as well as taking care of the caregiver as well. One thing that is particularly thought-provoking in this book is the "Experts' Ten-Step Program" for coping with Alzheimer's disease. The ten steps are 1) be confident of the diagnosis, 2) be realistic, 3) enjoy pleasant surprises, 4) treat everything, 5) combine medication with psychological and complementary therapies, 6) assemble an extensive support network, 7) take good care of yourself, 8) take good care of the person with Alzheimer's disease, 9) plan for the future early, and,

10) stay informed (Castleman, *There's Still a Person in There*, p. 101-106). Also useful is the section about whether to tell your loved one that they have Alzheimer's disease.

This book is an integral part of a public library collection.

3. A more recent volume is *The Best Friends Approach to Alzheimer's Care* by Virginia Bell and David Troxel (Baltimore: Health Professions Press, 2002). This book, newly revised in 2002, presents a very optimistic view for caregivers and focuses on daily tasks and how to make them easier for both the patient and the caregiver. It is written as a workbook as well as a guidebook and it includes much detail about day-to-day life. These authors introduce the Alzheimer's Disease Bill of Rights and use that concept as the underlying philosophy of the entire book. The Alzheimer's disease Bill of Rights states that "every person diagnosed with Alzheimer's disease or a related disorder deserves the following rights:"

- To be informed of one's diagnosis
- To have appropriate, ongoing medical care
- To be productive in work and play for as long as possible
- To be treated as an adult, not like a child
- To have expressed feelings taken seriously
- To be free from psychotropic medications, if possible
- To live in a safe, structured, and predictable environment
- To enjoy meaningful activities that fill each day
- To be outdoors on a regular basis
- To have physical contact, including hugging, caressing, and hand-holding
- To be with individuals who know one's life story, including cultural and religious traditions
- To be cared for by individuals who are well trained in dementia care. (Bell & Troxel, p. 39)

This book also includes an excellent section on caring for the caregiver. The tone of this book is nurturing and the authors do an excellent job at dealing with day-to-day issues that caregivers face.

4. Another book that should be in every collection is less mainstream, and very valuable. In *Creating Moments of Joy* (West Lafayette, IN: Purdue University Press, 2003), Jolene Brackey takes an unusual approach to day-to-day care. She writes frankly of the reality of Alzheimer's disease care and offers creative solutions to common problems. Her writing is nurturing, too, and her suggestions will take many caregivers by surprise. This book offers unique suggestions for everyday problems and calls for a loving, humor-laden approach to caregiving. Her premise is that if the caregiver can figure out how to create moments of joy, even difficult tasks can be made easier. Brackey wants the reader to "look beyond the challenges of Alzheimer's disease and focus more of our energy on creating moments of joy..."(Brackey, p. 11.)

5. Another essential book focuses on how to talk to a person with Alzheimer's disease. Entitled *Talking to Alzheimer's* (Oakland, CA: New Harbinger Publications, 2001) it talks about how important it is to connect with an Alzheimer's patient and it offers examples of how to do so. It tells the reader, in a practical manner, how to carry on a successful conversation with an Alzheimer's patient. The conversational skills that it suggests are invaluable in such conversations and might not be known by a person who is not trained in the care of Alzheimer's. Like Brackey's book, *Talking to Alzheimer's* emphasizes the importance of daily enjoyment in both the patient's and the caregiver's lives, and states that knowing how to have a successful conversation is an integral part of feeling joy and connection.

6. An older, yet helpful book, *Doing Things: A Guide to Programming Activities for Persons with Alzheimer's Disease and Related Disorders* (Baltimore: Johns Hopkins University Press, 1987), gives excellent suggestions on essential and enriching activities

and how to present them and execute them with an Alzheimer's disease patient. The author, Jitka M. Zgola, provides practical information for professional caregivers that are very helpful to family caregivers. Written from a more academic standpoint, Zgola discusses attention span, distractions, judgment, and inability to stop repeating a behavior and shows ways to work with each challenge in a constructive way. This book is not as nurturing as the books presented so far, but the insights and suggestions that it gives make it an invaluable part of the collection.

7. Finally, another book written for professionals is also an important monograph to include in a public library collection. *Caring for People with Alzheimer's Disease: A Manual for Facility Staff* (Washington D.C.: American Health Care Association, 2001) offers practical suggestions for common experiences. For instance, it talks about how to prevent outbursts and how to respond to challenging behaviors. This book allows the patron to learn from the experts, and for that reason I would include it here. Some of the situations are not applicable, but most of them ring true in either a home or an institutional setting, and therefore I think it is valuable to be able to see how the other setting handles a particular situation.

Insights: Seven Essential Titles

The second set of books for the adult caregiver focuses on gaining insight into their situation and into the situation of their parent. These books are not necessarily guidebooks, as were the books in the first category. Rather, they are in different formats.

1. The first one, entitled *Making an Exit: A Mother-Daughter Drama with Alzheimer's, Machine Tools, and Laughter* (New York: Henry Holt and Company, 2005) is a memoir that describes very effectively the ups and downs of dealing with a parent

with Alzheimer's disease. The author, Elinor Fuchs, injects humor into her writing which juxtaposes well the issues related to Alzheimer's disease with the opportunity for day-to-day joy and understanding. This book is encouraging as well as realistic, which makes it an important part of the collection. It is also the only memoir in these lists.

2. Another essential volume in this collection is John Kotre's *White Gloves: How We Create Ourselves through Memory* (New York: W.W. Norton & Company, 1996). This book is written in the tone of a memoir, but the author is using that tone to give scientific information to the lay person, so the book is not strictly a memoir. Kotre, a professor of psychology, talks about memory and the role that it plays in our lives. He also discusses how our memories are subjective and how they change over time. While not always directly related to Alzheimer's disease, I believe that this book is a valuable part of the collection because it helps the caregiver to understand and appreciate the memories of his or her parent, both their current memories and the memories that they had before getting Alzheimer's disease. It can sometimes be difficult to witness how the parent's memories change, and this book puts it into perspective and makes the entire concept of memory make sense. The insight provided here is very helpful to an adult who is watching the memories of his childhood through his or her parent's eyes change and become distorted.

Next I would include several sources that discuss memory from a more scientific standpoint. I believe that it is very important for the caregiver to understand some of the scientific facts behind Alzheimer's disease. Therefore, I have included books that give scientific explanations in a layperson's language.

3. The best book in this category, I believe, is Daniel L. Schacter's *Searching for Memory: The Brain, the Mind, and the Past* (New York: BasicBooks, 1996). This book takes scholarly research and makes it accessible to the layperson. It gives insight into how the memory works, how the field of memory research has evolved, and how scientists approach questions about how our memory works, or does not work. Schacter uses examples from his scholarly work and that of others to illustrate his points, but he writes at the level of the layperson so that the information is accessible to the average caregiver.

4. Additionally, Schacter's newer volume, entitled *The Seven Sins of Memory: How the Mind Forgets and Remembers* (New York: Houghton Mifflin Company, 2001) gives more recent scientific work, also in layperson's terms. Schacter frames his memory study in terms of seven sins: transience, absent-mindedness, blocking, misattribution, suggestibility, bias, and persistence. He uses this construct to bring the reader up-to-date on memory research. After reading these two Schacter volumes, the caregiver will have a much more nuanced understanding of memory. This will provide new insight into the memories that their parent still has, since as Schacter says, "memory's errors are as fascinating as they are important" (Schacter, *Seven Sins of Memory*, p. 3).

5. Another very valuable part of the collection would be the volume entitled *The Moral Challenge of Alzheimer's disease* (Baltimore: Johns Hopkins University Press, 1996). This book talks about how our society is extremely impatient with forgetfulness and about how that prejudice has a big effect on how persons with Alzheimer's disease are treated. This book is one of the oldest in the collection, but the points it raises about our cultural predisposition to the dislike of forgetful people make it a very important

addition to this collection. This book makes the reader realize that the very presentation of Alzheimer's disease symptoms (i.e. forgetfulness) makes it particularly challenging to deal with in our society that is focused on accuracy, on-time performance, truth, and efficiency. The book emphasizes that the Alzheimer's patient must be treated with the respect and dignity that we afford to patients of diseases, like cancer, where the patient's symptoms coincide with our traditional ideas of illness.

6. To continue with the theme of treating an Alzheimer's patient with respect, the monograph edited by Phyllis Braudy Harris, entitled *The Person With Alzheimer's Disease: Pathways to Understanding the Experience* (Baltimore: Johns Hopkins University Press, 2002) talks about living with Alzheimer's disease. This book describes well the new trends in caring for persons with Alzheimer's disease. It states that "phrases such as person-centered care, culture of dementia, and quality of life are the new buzzwords in the field of dementia research and care" (Harris, p. xi). Further, the book is written from the perspective of a person with Alzheimer's disease in an effort to help us understand what that person experiences. This book explores what it calls the journey of Alzheimer's disease from a Western perspective, ending with the nursing home experience. It also includes information about spirituality in the face of Alzheimer's disease and also an excellent chapter on what happens to the concept of self. It is a scholarly book, yet it is understandable to the layperson. I believe that it is an important part of this collection because it covers the latest research trends, includes spirituality, and gives hope from the academic perspective. It also has endnotes so that the reader can find other sources.

7. Another book that gives voice to the experience of Alzheimer's disease is Steven R. Sabat's *The Experience of Alzheimer's Disease: Life Through a Tangled Veil* (Malden, MA: Blackwell Press, 2001). This book is written primarily for professional caregivers, but I believe that it is an important addition to the public library collection because of its section on the maintenance of self-esteem. It uses examples of real situations to illustrate how the self-esteem of the Alzheimer's patient can be profoundly affected by how we treat them. It talks about strategies for maintaining the patient's self-esteem, which is an important skill for any caregiver to develop. This book's style is somewhat more accessible than the Braudy book, and even though both books present different information (i.e. spirituality vs. self esteem) that leads to the same goals, I believe that both of them are valuable part of this collection because they approach similar goals in different ways.

Titles for Children and Youth

I will switch now to books for children, focusing particularly on children in grades 4-7. I have chosen this age group because they are independent readers, yet they might not be ready for the books that focus on adult care giving issues. Additionally, I have chosen novels. This is a conscious choice, because the voice of a young person who has a loved one with Alzheimer's disease speaks more clearly than the voice of an adult describing the situation. Even though these books are fiction, they capture the sting of the Alzheimer's disease behavior better than any other type of source that I evaluated. These children can be quite traumatized by their grandparents' behavior and it can be difficult for them to find support because their parents are also coping with Alzheimer's disease issues. It can also be embarrassing to admit to another adult that one's

grandparent is saying mean things. I have chosen four novels as possible resources for these children. A novel is another useful tool to help a child cope with this situation because it allows the child to identify with a character in the book who is experiencing a similar situation.

1. I most highly recommend *The Graduation of Jake Moon* by Barbara Park.

This story is told by a boy named Jake who has just graduated from the eighth grade. He recounts the past four years, telling about when his grandfather becomes afflicted with Alzheimer's disease and how it changes his life. He talks about how embarrassed he gets when he has a friend over after school and they find a sign on the freezer that says "This is not a hamper." Next, they find wet sheets in the oven, put there by his grandfather. Jake is embarrassed and does not want to tell his friend that his grandfather has Alzheimer's disease, so he tells his friend that the oven's owner's manual says that it can also be used to dry clothes. After awhile, Jake does not have friends over anymore; he is too embarrassed. As Jake's grandfather gets worse, it becomes harder and harder for his mother to find a caretaker for him while she is at work, so Jake has to come straight home from school to care for him, which he not only resents, but also prevents him from participating in after-school activities. As the book progresses, Jake works through his resentment for his grandfather, to whom he used to feel very close. As the book draws to a close, Jake has come to terms with his grandfather's condition and he learns to treat him tenderly and patiently, like his grandfather used to treat him when he was a little boy. This reversal of roles is an especially poignant part of this book. This book is valuable because it spends a lot of time examining what Jake is thinking. It does not criticize Jake's embarrassment and guilt, but, rather, it examines them and describes how he learns

to overcome both feelings. These feelings can be hard for a child to recognize and articulate, and a fictional character “discusses” the subject with the child-reader in a more meaningful, immediate way than would a parent.

2. I also recommend *An Early Winter*, by Marion Dane Bauer. This book is about an eleven year old boy, Timothy, whose family returns to his grandparent’s house where they used to live because the grandmother is worried about changes in the grandfather. After they arrive, Timothy overhears his parents and grandmother talking in low voices about his grandfather. Timothy cannot believe that the things they are saying are true. He cannot understand why his grandfather cannot drive anymore or why he gave up his veterinary practice. He thinks that if people would only treat his grandfather better, he would be just fine. Timothy proposes a fishing trip with his grandfather, and the grandfather agrees, in spite of the fact that he is not supposed to drive. Timothy and his grandfather leave on their fishing trip without his parents’ and grandmother’s knowledge. As the fishing trip progresses, Timothy realizes that his grandfather is different. Early on, Grandpa calls Timothy by his estranged father’s name. Grandpa then gets very angry with Timothy and tells him he is useless. Timothy is hurt and dismayed. He also realizes that his grandfather no longer has the fishing skills that he once had and that he cannot remember how to make a sandwich. About halfway through the trip, Timothy realizes that he must help and lead his grandfather, rather than the other way around. This frightens him and makes him angry-- then sad. As the book progresses, Timothy learns to be patient with his grandfather and help him. He learns to hug him and reassure him and to be tender with him. He also learns to listen to his grandfather when he calls him by his estranged father’s name, and, in doing so, Timothy learns the truth

about why his father left the family and about why his mother never mentions him. As the story ends, Timothy has even learned how to enjoy hearing the same story over and over again, realizing that his grandfather enjoys telling it. He also comes to realize that his grandfather's telling of the story is a sign of his love for his grandson. This book teaches huge lessons while telling an exciting story. This book would probably be more appealing to boys than girls, but this would not interfere with a girl identifying with Timothy's feelings and getting a lot out of the book, too.

3. The best book that would appeal to a girl is called *If I Forget, You Remember*, by Carol Lynch Williams. This book is not as well written as the other two books because the author tries to cover too much ground while not addressing the feelings of a child about Alzheimer's disease well enough. The story is centered on the dynamics of a difficult relationship that the protagonist, Elyse, has with her sister. This tension is exacerbated when their grandmother with Alzheimer's disease comes to live with them for the summer. The resulting challenges, however, bring them closer together. Elyse's single mother begins dating during the same summer. Focus on the Alzheimer's disease issues became obscured by issues related to Elyse's mother dating for the first time while also taking care of her mother. Similarly, a story line of Elyse getting bullied by two neighborhood boys seems superfluous, obscures the Alzheimer's disease issues, and is not resolved satisfactorily. Such story lines, addressed without reference to Alzheimer's disease issues, cause the reader's attention to wander. Nevertheless, this was still the best book that I could find, at a reading level similar to the other books, which had a girl as the main character. The tension of the Alzheimer's disease story lines does, however, resolve, with Elyse coming to terms with her frustration about her grandmother, learning

to love her grandmother under the new circumstances, and also learning to do activities with her which they both enjoy. It does not, however, deal well with issues like how to learn patience when her grandmother repeats herself and how to overcome her embarrassment about her grandmother's condition. It mentions that Elyse's mother is tired, but does not deal effectively with her mother's range of emotions, thereby making the adult's situation more understandable to the reader. Additionally, the final solution to the grandmother's care is to move her into an assisted living home, which in this case leaves the impression that the family could not effectively manage their loved one's disease at home and thus decided to take a different approach.

Unlike the other books, this book addresses the family's difficult decision to place the grandmother in a nursing home. This is yet another difficult reality which some caregiver families must eventually face and address. In this way, *If I Forget, You Remember* covers yet one more nuance of Alzheimer's disease that is not addressed in the other books. Although institutional care is another option for Alzheimer's disease patients, most families care for their loved one at home during the early and middle stages of Alzheimer's disease. In response to this fact, more home-based options are becoming available such as adult day care facilities, enabling more families to be able to have their loved one at home.

The Graduation of Jake Moon and *An Early Winter* are on the cutting edge of the latest research done on families caring for a loved one with Alzheimer's disease at home. They support the concept of caring for the grandparent at home and encourage the child to learn patience, to pitch in and help, and to confront and deal with feelings like embarrassment and guilt. These books are creative, tender, and engaging as well. *If I*

Forget, You Remember is not quite as engaging, but it does address issues faced by families who eventually choose to place their loved one in an assisted living or nursing facility. Even though it might be more appealing to girls, I believe that the other two books would be most useful to girls or boys whose parents are choosing to care for their loved one at home.

Alzheimer's disease is becoming part of more families' daily lives. These books all put Alzheimer's disease right into the middle of their child-protagonists' lives in an engaging, personal way. Used in conjunction with succinct brochures and thorough discussions, these books will enhance the child's coping skills and make them feel less alone as they confront their feelings and learn to deal lovingly with their sick grandparent. With well targeted education using materials such as these, a child can enjoy more good days with their grandparent and can learn to be empathetic and loving in a difficult situation while giving the child poignant memories and wonderful skills for living the life they have ahead of them.

Three Library Searches

The sources mentioned about represent the ones that I believe present the most positive, useful, and hopeful evaluation of life with Alzheimer's disease for the daughters, sons, and grandchildren of persons with the disease. Are these sources readily available in public libraries in the Triangle area of North Carolina?

A search on the local public library's catalogs showed that many of these sources are not available at local libraries, as shown in the chart on the next page. Out of 13 sources that I chose as the best, there are 7 that no local library has in their current collection. Interestingly, 4 of them are practical books that help a caregiver be creative in

their daily tasks and offer interesting ways to maintain a positive attitude during a difficult situation and possibly even manage to create a loving, memorable moment. Two of the other books that our local libraries do not have are books that offer insight into the patient's experiences. These books help the caregiver understand what the patient experiences as the disease progresses and also what the patient experiences in various situations. These books can be very helpful to children who care for their parents with Alzheimer's disease. Giving insight can often help the caregiver to handle a situation well. These books provoke explore the patient as a person who still has sensitive feelings even if he or she cannot think so well anymore, and that can be very valuable insight for a caregiver. The other unavailable book discusses the moral issues that arise when dealing with an Alzheimer's patient. It provokes thought that can help a caregiver look at the situation from a macro viewpoint, helping the caregiver gain valuable insight into the cultural norms that inform care giving in our society today.

Thus, the caregiver can get help at our local public libraries, but he or she would not gain the insight available from the latest sources that do an excellent job at giving hope to their situation and offer creative solutions to daily issues.

The Triangle-area public libraries' children's collections have most or all of the books recommended for their collection. These collections are well equipped to serve children who go to the public library for help with their grandparent's Alzheimer's disease. These libraries would serve their adult patrons better, however, if they were better equipped with titles that reflect current research trends in caregiving for patients with Alzheimer's disease.

Conclusion

Alzheimer's disease is an unusual end-of life disease in that the patient might live 8-10 years after diagnosis. Life changes with Alzheimer's disease, but it does not end at the point of the diagnosis. The situation is also unusual in that, unlike diseases such as cancer where the patient remains aware of their situation and maintains their mental acuity, the Alzheimer's disease patient is eventually not aware that they have the disease and they are not in control of their quality of life. Therefore, the caregiver holds an unusual amount of power in that they are largely responsible for the quality of life of the patient. This makes the need for helpful and hopeful caregiver information especially acute. A good caregiver needs to be able to go from merely coping with day-to-day tasks to putting joy and quality into the days of their loved one. This can be particularly difficult without the understanding of the situation that comes from being familiar with the latest literature on the topic of caregiving for an Alzheimer's patient.

Over the past ten years, a significant body of literature has developed that gives hope to the caregiver and patient and also that looks at the Alzheimer's patient as a person who is still very capable of living a happy life. Yes, their life will be different and yes, they might not act the way they did before the disease took over, but they still have the capacity for enjoying life.

There exists also a significant body of literature that talks about how sad Alzheimer's disease is and about how it is a long, sad period of watching your loved one slip away. However, with some flexibility and a sense of humor, there are still moments

of joy to be had and good memories to be made with the person that the caregiver's loved one has become.

The sources introduced in this paper reflect the hopeful point of view. They tell the caregiver how to handle the day-to-day tasks in a way that will bring joyful moments to both the patient and the caregiver. In these sources, the caregiver is taught to let go of truth and convention and to simply enjoy the moment with their loved one. The caregiver is also taught about what happens in the brain of an Alzheimer's patient and how our society collectively regards negatively a person who forgets. Recent scholarly literature states that even though there is no cure for Alzheimer's disease right now, there is still much of life to be lived after it is diagnosed. The caregiver is the one who can make that possible by overcoming societal prejudices and by looking at this disease in a new way.

My collection therefore will give the caregiver insight into the big picture, which is the fact that a now-forgetful person is living in a society that values very highly being on time, remembering details, being self-sufficient, and being truthful. It can be very difficult to let go of these time-honored values that we are taught by American culture. It is also very difficult to watch a loved one change into somebody that you do not know and to realize that they will not return to being who they were. However, it is not a hopeless situation.

Caregivers of Alzheimer's patients desperately need informative, readily-available information. They need hope, coping skills, and reassurance. A strong library collection can meet all of those needs.

Unfortunately, the local public library adult collections have not kept up with the changing nature of the point of view in the scholarly literature about Alzheimer's disease.

The sources in the local public libraries do not convey the hope that the caregivers need and that recent scholarly literature conveys. More guidance needs to be available to librarians who collect materials about Alzheimer's disease so that they can select appropriate, up-to-date materials for their collection.

Note, however, that the children's collections were excellent. They provide supportive materials for children who have a grandparent or friend with Alzheimer's disease. The Alzheimer's Association also has an excellent collection of resources.

I recommend an improvement in the sources available to librarians so that they will be able to build their collection based on the latest scholarly research. I also recommend that the librarians look to the Alzheimer's Association when developing their collection so that they can take advantage of the current information that they offer.

In conclusion, I believe that there is much useful and hopeful information that can inform a caregiver in regard to quality of life for the caregiver and patient. As baby boomers age, the number of Alzheimer's disease patients will continue to rise. Not only will better information improve quality of life on a case-by-case basis, but it will also improve our perception of living with Alzheimer's disease in our society as a whole. As we continue to integrate our elderly relatives into our daily lives, much can be gained by having a hopeful, positive outlook. Recent literature abounds with that help. It is my hope that the public library can be a source for such learning.

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