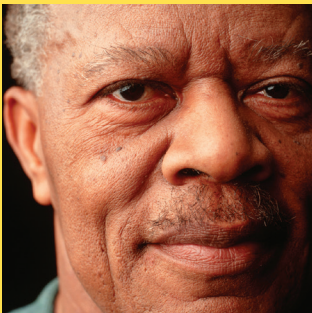




THE BOOK OF ALZHEIMER'S



**For African-American
Churches**



**SANDERS-BROWN
CENTER ON AGING**

African-American Dementia
Outreach Partnership



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Acknowledgements

Introduction

The Book of Alzheimer's is written for church leaders interested in helping families cope with dementia. Its development was sponsored by the African-American Dementia Outreach Partnership (AADOP) at the University of Kentucky's Sanders-Brown Center on Aging. This manual is designed to share what we have learned during our work in the community to build awareness and support related to Alzheimer's disease in the Lexington/Bluegrass area of Kentucky.

Studies suggest that African Americans have an increased risk for developing Alzheimer's disease. This manual shares ideas on how congregations can provide sensitive and appropriate support to families as they struggle with this devastating disorder. Educating churches about Alzheimer's disease is important because African-American families look to their churches and ministers for guidance in their times of need. Even when those with disease and their caregivers cut off others, they strive to stay connected with their church. Historically, the African-American church has provided strength to assist church members in maintaining their sense of well being, and Alzheimer's disease is a new threat. Fortunately, churches in Lexington have begun to ready themselves for this challenge. As Pastor Gaines from Consolidated Baptist describes, "The good news is we have a history of reaching out and embracing one another in the community, so here is another opportunity to do that."

This is the sixth printing of the Book of Alzheimer's. Copies from the original printing were distributed throughout the country to groups that included Alzheimer's Disease Centers, churches, senior centers, and area agencies on aging. This reprinting will allow us to continue to share what we have learned through our work with our local African-American faith community.

The Book of Alzheimer's for African-American Churches

- Explains the basics of Alzheimer's disease and dementia
- Describes the impact of Alzheimer's on the African-American community.
- Teaches how to provide quality care for people with memory loss.
- Discusses how to build a support network through the church.

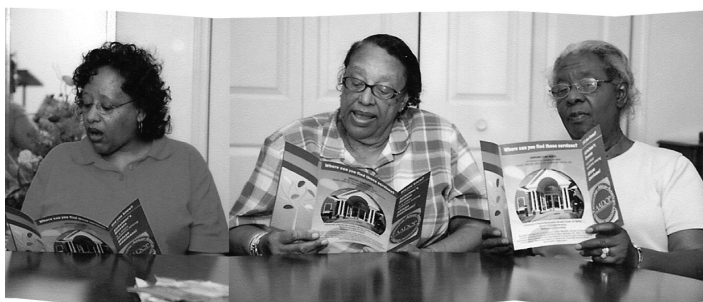
Lela Knox Shanks, a prominent African-American leader in Lincoln, Nebraska who cared for her husband with Alzheimer's disease, said that her best advice to fellow caregivers was to "connect faith to everyday life." This manual will help church members reach out to caregivers like Ms. Shanks and let them know that they are traveling the caregiving journey not only with their personal faith, but also with a supportive community.

Deborah D. Danner, Ph.D.

*Project Director, African-American Dementia Outreach Partnership/Sanders-Brown Center on Aging
University of Kentucky, Lexington, KY*



The African-American Dementia Outreach Partnership includes the University of Kentucky's Alzheimer's Disease Center, local African-American churches, community leaders and representatives of agencies serving local underserved populations.





THE SERENITY PRAYER

*God grant me the serenity
to accept the things I cannot change;
The courage to change the things I can;
And the wisdom to know the difference.*

*Living one day at a time;
Enjoying one moment at a time;
Accepting hardships as the pathway to peace;*

*Taking as He did, this sinful world
as it is, not as I would have it;
Trusting that He will make all things right
if I surrender to His Will;
That I may be reasonably happy in this life
and supremely happy with Him
forever in the next. Amen.*

—Reinhold Neibuhr—

This non-denominational prayer may be helpful for caregivers and newly diagnosed patients. The message is very appropriate to the challenge of the disease, and repetition of the prayer may reinforce the meaning of the message.



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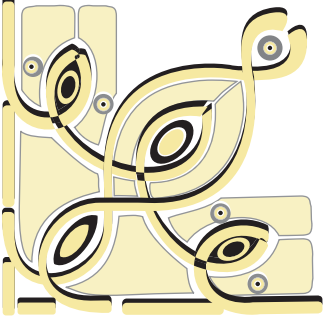


CHAPTER 1

Alzheimer's Disease *and* Dementia

"Alzheimer's disease does not discriminate between rich and poor, African-American and white. All individuals touched by this disease deserve our love and the best care available."

*William R. Markesbery, MD, Sanders-Brown
Center on Aging and Alzheimer's Disease Center,
University of Kentucky*





INTRODUCTION

This section briefly describes Alzheimer's disease and dementia, discusses symptoms and treatment, and provides valuable information about research participation. Church leaders and members reading this section will walk away much better informed about Alzheimer's disease, the sixth leading cause of death in the United States.

Dementia affects one in four American families. By reading and using this manual, your church can be a leader in supporting families. To fight this disease, knowledge gives power!

About Dementia

Dementia is a medical condition that affects the brain and its symptoms include: memory loss, confusion, problems with speech and language, anxiety, paranoia, personality changes, lack of initiative, and difficulty learning new skills.

A person with dementia may get lost in a familiar neighborhood, have trouble paying bills and managing money, lose the ability to do simple tasks, and become suspicious of those close to him or her.

There are different kinds of dementia, including a dementia caused by small strokes. Some people with Parkinson's disease also show signs of dementia.

ALZHEIMER'S DISEASE

Alzheimer's (*AHLZ-high-merz*) disease (AD) is the leading cause of dementia in the elderly. The most striking symptom is memory loss, especially the loss of recently learned information. Other symptoms include a decline in the ability to learn, reason, make judgments, communicate and carry out daily activities. As the disease progresses, the person may also experience changes in personality and behavior, such as anxiety, suspiciousness or agitation. Even though the person may look fine, he or she may begin to have problems with his or her daily routine.

Confusion is common, and people with Alzheimer's disease may mix up appointments, think they are a different age than they are, or believe that they are late for work when they have been retired for years.

Delusions (fixed, false ideas) may also occur. The affected person may accuse others of stealing money or be sure something has happened that has not.

Alzheimer's is a growing problem - 13% of people over age 65 are affected, and 43% of those over age 85. While much less common, Alzheimer's disease can occur in younger people as well.

Although there is currently no cure for Alzheimer's, researchers are working to develop new treatments. Research has also shown that effective care and support can improve the quality of life for both patients and their caregivers.

The Difference between Dementia and Alzheimer's Disease

Think of the word "dementia" as a classification like "soup." Soup is a general category of food and "dementia" is a general classification of illness. When we go to a restaurant, we don't just order soup; we want to know what kind of soup the restaurant is serving.

Similarly, when we go to the doctor, we should not accept the word "dementia" as a diagnosis. That's too general. We want to know, "What type of dementia does mother or father have?" A good medical workup will tell us the answer.

See **BOX 1A**

£ BOX 1A

Understanding the Meaning of Dementia and Alzheimer's Disease

True or False

1. You can have **dementia** and not have **Alzheimer's disease**.

[TRUE; there are different kinds of dementia besides AD, including dementia caused by small strokes.]

2. You can have **Alzheimer's disease** but not **dementia**.

[FALSE; Alzheimer's disease is a type of dementia. By definition everyone with AD has dementia.]

3. Most older people with **dementia** have **Alzheimer's disease**.

[TRUE; AD is the leading cause of dementia in the elderly.]

4. A good medical exam will help figure out what is causing a person's confusion or memory loss.

[TRUE; a good medical work-up is recommended and will usually result in a specific diagnosis. Also, a good medical exam is important because some problems with memory, such as those caused by vitamin deficiencies or depression, may be reversible.]

5. A person can have more than one **dementia** at the same time (for example, **Alzheimer's disease** and dementia caused by small strokes).

[TRUE; multiple problems are possible.]

Progression of the Disease

Alzheimer's disease advances at very different rates. The length of the illness can vary from 3 to 20 years. The areas of the brain that control memory and thinking skills are affected first, but as the disease progresses, cells die in other parts of the brain. Eventually, the person with Alzheimer's may require complete care.

Alzheimer's disease shortens life, and people with AD are vulnerable to pneumonia, serious falls, infection and other related problems. As the health of a person with Alzheimer's disease begins to fail, Hospice services can be called for necessary support and important end of life care.

Warning Signs and Symptoms



My family and I knew something was going on with my mother because she wasn't acting like she used to. For example, my mother, who usually loves to eat and fix meals, became uninterested in food.

I also noticed that she was not as social as she used to be. Instead of hanging out with and talking to adults and being right in the middle of conversation, she would isolate herself from groups or hang out with the children. When we would talk, she would be more guarded in her conversation, almost as if she was carefully watching her words to make sure she said nothing wrong.

—Anna Mason, Caregiver—

To help family and church members recognize the warning signs of Alzheimer's disease, the Alzheimer's Association has developed a checklist of common symptoms.



1. **Memory changes that disrupt daily life.** One of the most common signs of Alzheimer's, especially in the early stages, is forgetting recently learned information. Others include forgetting important dates or events; asking for the same information over and over; relying on memory aides (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own. What's normal with age? Sometimes forgetting names or appointments, but remembering them later.

2. **Challenges in planning or solving problems.** Some people may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before. What's normal with age? Making occasional errors when balancing a checkbook.

3. **Difficulty completing familiar tasks at home, at work or at leisure.** People with Alzheimer's often find it hard to complete daily tasks. Sometimes, they may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game. What's normal with age? Occasionally needing help to use the settings on a microwave or to record a television show.

4. **Confusion with time or place.** People with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there. What's normal with age? Getting confused about the day of the week but figuring it out later.

5. **Trouble understanding visual images and spatial relationships.** For some people, having vision problems may be a sign of Alzheimer's. They may have difficulty reading, judging distance and determining color or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not recognize their own reflection. What's normal with age? Vision changes related to cataracts.

6. **New problems with words in speaking or writing.** People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation

and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name (e.g., calling a “watch” a “hand-clock”). What’s normal with age? Sometimes having trouble finding the right word.

7. Misplacing things and losing the ability to retrace steps. A person with Alzheimer’s disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time. What’s normal with age? Misplacing things from time to time, such as a pair of glasses or the remote control.

8. Decreased or poor judgment. People with Alzheimer’s may experience changes in judgment or decision-making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or to keeping themselves clean. What’s normal with age? Making a bad decision once in a while.

9. Withdrawal from work or social activities. A person with Alzheimer’s may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid social situations because of the changes they have experienced. What’s normal with age? Sometimes feeling weary of work, family and social obligations.

10. Changes in mood and personality. The mood and personalities of people with Alzheimer’s can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone. What’s normal with age? Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

If you recognize any of these warning signs in yourself or those in your church family, make sure concerns are brought to the attention of a medical professional. Early diagnosis is an important first step to getting appropriate treatment, care and support.



Diagnosis and Treatment

For persons with dementia, an early diagnosis has many advantages including:

- Relief from anxiety about the unknown problem.
- A better chance to benefit from treatment.
- Time to plan for the future and get legal and financial affairs in order.
- Information to help improve his or her quality of life.

Alzheimer's disease is not the only cause of memory loss or other dementia-like symptoms. **Some problems can be reversed if they are caused by treatable conditions** like depression, drug interaction, thyroid problems, vitamin deficiencies, or excess use of alcohol. Symptoms caused by Alzheimer's disease cannot be cured, but medications are available that may slow the course of the illness. Most current drugs work best when they are taken early in the disease. New drugs are under development; there is always reason to have hope.

Families should be encouraged to get a specific diagnosis. Unless the family and doctor know what is causing the symptoms, the development of an appropriate treatment can be difficult.

Even after the work-up and diagnosis, patients and families may need time to adjust to the news as one patient in Lexington describes:

The hardest thing for me to deal with was in the beginning, I didn't believe I had anything. I was putting it all on old age. After I saw what you all represented and I come and had tests and everything, and then I was sent and had a "CAT" scan and you all told me the results and that I had the disease. It has been a problem in a way because when you are thinking one thing and it is something else, it keeps you kind of confused. Patient, Polk-Dalton Clinic, Lexington.

NOTE: The above patient later expressed relief that his problem had a name. His family rallied around him to help.

PREPARING FOR THE DOCTOR'S VISIT

The following tips may help when advising families about talking with their doctor:

1. Encourage the family member to go with their loved one into the examination room so that they can describe their concerns and hear what the doctor says.
2. If the family is uncomfortable speaking about their concerns in front of the patient, have them write out a list of problems and drop it off or fax to the office before the visit.
3. Have the family bring all medications, over-the-counter and prescription, to the visit.
4. The family should ask the doctor about medications that may help with memory and behavioral problems. New medications are being developed every day.

A complete medical evaluation for memory loss should include:

1. A complete and accurate medical history. The family should be honest about past or current use of alcohol.
2. A neurological and physical exam, which may include brain imaging techniques such as CT scan, MRI, or PET scan.
3. Lab tests (blood and urine) to look for infection or vitamin deficiencies.
4. An evaluation of the patient's ability to perform common daily activities, such as balancing a checkbook or taking medications.
5. Testing to measure the patient's thinking and memory.
6. An interview with the patient's caregivers to hear their story. Some patients are aware of what is happening to them. Be sure to respect their dignity by giving them time to ask questions and express their concerns. The exam can be stressful. The family member can help by taking the person's hand, offering encouragement, and maintaining hope.

TREATMENT

Unfortunately, no cure for Alzheimer's disease has been discovered. However, researchers have developed several medications that may slow the course of the illness. Medications are also available to relieve problems with depression, anxiety, agitation, paranoia, and sleep disturbances.

The best treatment is loving care. The old saying, "to know someone, you must walk a mile in his or her shoes" applies to dementia care. Caregivers must learn to accept that the memory loss is real and that the person is not trying to make life difficult for them. As discussed in Chapter 3 of this manual, it will be helpful for the caregiver to create a positive caregiving environment, follow a routine, and help the person feel safe, secure and valued. Long-held rituals such as favorite songs and hymns, religious readings and prayers may also be comforting.

Those providing care should try to keep the person physically active and busy with activities the person enjoys. Even later in the illness, many people can help fold laundry, assist with light yard work, or sweep the back porch. Remember to remind families that Alzheimer's disease is not a punishment for sins they have committed and that God is not angry with them. Reassure families that help is available and you will help them find it.

The following story describes one caregiver's efforts and summarizes this loving approach:

At first it wasn't easy dealing with the personality changes in my uncle. I would get frustrated when I spoke to him because he wouldn't give the right answer to a question I would ask or to things I would say. So I learned to play make believe with him to get things done and make living with him easier. When I would come home from work, I would ask, "Did you go to Louisville today?" and he would say, "Yeah, I went to see my girlfriend." Well, he didn't go anywhere and he doesn't have a girlfriend, but I've learned to have fun with him that way.—George Ellis, Lexington Caregiver—

NOTE: Caregivers who can maintain a sense of humor find that their journey is much easier!

Research

Through faith in God and my years of ministry, I have learned that it takes patience and understanding to forget about self and do what you can to help others. My work as a research participant affords me the opportunity to exercise the power of that faith to continue in the battle to eradicate Alzheimer's disease for all humankind. We know more about this disease than ever before, and I don't believe God brought us this far to leave us.

—Rev. Reynolds, Research Participant—

PARTICIPATION IN RESEARCH

Many people dealing with Alzheimer's disease want to do something to help find a better treatment or a cure. They want to help others. One way to help is to participate in research.

Not only does research help future generations, but it may help those participating in the study as well. Study participants may receive new medications or free check-ups as a part of participation.

Due to a mistrust of the healthcare system, historical barriers, and a lack of awareness of research opportunities, African Americans have not been represented in research studies. This lack of representation has meant that knowledge related to how Alzheimer's disease affects African Americans differently than whites is lacking. Participation in research is necessary to improve drug therapies, patient care, and enhance knowledge related to Alzheimer's disease and other forms of dementia.

African Americans should be reassured that safeguards to ensure the protection of all participants in research are now in place to prevent earlier abuses from occurring again. For example, all researchers must now obtain Institutional Review Board approval before they can ask anyone to be a



part of their research. This approval requires that potential risks and benefits along with specific study requirements are clearly explained to all participants. Participants give their voluntary consent to participate and know that they can withdraw at any time. These protections benefit all research participants.

If individuals with dementia or their families are interested in participating in research, they will want to seek answers to the following kinds of questions.

1. Is there any risk to the person with dementia? If so, how much?
2. Does the potential benefit outweigh the risk to the patient or the family? For example, if a new drug could help the mother now, and the only potential side effect is a stomach-ache, the family may decide that the risk is acceptable.
3. Does the family know the group doing the research? Are they a respected in the community? Do they ask, not require, participation and explain exactly what will be involved including how much time is required?
4. Are the researchers' explanations provided in language that is easy to understand?
5. Will researchers report their findings to you?
6. Is the program free of charge?
7. Will out-of-pocket expenses (like transportation) be reimbursed?





THE PARTICIPANT'S PERSPECTIVE

The following interview between an AADOP staff member and one of our committed research volunteers, Rev. Reynolds, describes his attitude and feelings towards research and his experiences as a research volunteer. Rev. Reynolds' dialogue captures many of the important issues involved in research participation.

When I say the word research, what does that mean to you?

Research gives an opportunity to learn more about diseases such as Alzheimer's disease. When research findings are published it enables us to learn more,

and it makes me proud to be a research volunteer. My eyes have been opened to the necessity of knowing more about the devastation that can happen to the human brain and ways that we can prevent or at least delay that devastation. Continued research gives me hope for a cure.

Some people have mixed feelings towards research participation as they fear it may be harmful to them. How do you feel about that statement?

I know about the research at Tuskegee, but I also know that there are safeguards in place that prevent that from happening again. The information I have received from research has been extremely helpful, and I continue to read and learn. I think research is beneficial because without research what little knowledge we have about diseases that exist in our world today, these diseases would continue to be unknown factors in human lives. Research provides more information and more possibilities for treatments and solutions to eliminate these diseases.

What would you say motivates you to participate in research and is trust in the researchers a big factor?

I suppose it is my belief that my participation could be positive enough to help somebody else as well as myself. Trust is not as important because something as serious as this disease should not be limited or curtailed by my personal mistrust alone. My skepticism might cause me to be vigilant, but when I balance



my personal discomfort against the help that could be provided, I want to be a part of the help that is provided. It takes everyone, and I must do my part.

Some African Americans don't want to be involved in research. Why do you think that is?

African Americans are often a suspicious people, and that is understandable—given the history of discrimination in our country. Today things are better, but racial discrimination still exists and is often more subtle. Because the possibility of unfair treatment always looms, we need reassurance and definite proof that researchers are treating us fairly and are working to produce positive results that will benefit not just the majority but African Americans as well.

Do you think it is important for African Americans to participate in research?

I KNOW it is important! If positive progress is to be made, we need to know how this disease affects all races and genders. Alzheimer's disease can be far too devastating to limit studies to one race or one gender and to make assumptions about the others. Our studies must be thorough and inclusive so that we will know what it takes to find appropriate medications and an eventual cure that will benefit everyone.

Have you told other people that you're involved in research?

Yes, I use every chance I get to tell others about research and its importance. I believe that those who are recruiting, treating patients, and doing the research need encouragement, cooperation, respect, guidance, and the love of Almighty God as well as the support of research participants. Those of us who are already involved in research participation can be ambassadors for the cause. Even though it must always be a personal choice to participate, sometimes we can lead by example.

CLINICAL TRIALS

Clinical trials look at new drugs or vaccines that may help prevent disease, look at ways of detecting or finding out more about a disease, and monitor new drugs or evaluate new combinations of established treatments. The main goal of clinical trials is to see if these new drugs or technologies are safe and work to cure or treat the illness being

studied. Clinical trials at our Center are usually related to Alzheimer's disease and possible treatments or prevention.

Why should minorities participate?

In the past, most drugs were tested on white men. Groups such as African Americans, Hispanic Americans, Native Indians, Asian Americans, and women, were usually not a part of drug clinical trials. Studies have shown that sometimes drugs work differently in people in these groups. It is important to make sure we understand how to use drugs to get the best results in all people.

Phases of Clinical Trials

A new drug must travel a long path before it becomes available to consumers.

Phase I: To enter phase I, a new drug must go through extensive laboratory testing which shows that it is safe for human consumption and use. This could involve anything from animal testing to testing on actual human cells, but is never consumed directly by an individual. Once proven safe, researchers are then able to observe the drug's effects on the human population. Phase I studies how the drug interacts with our bodies and what potential side effects it has with use. About 70% of drugs move on to Phase II.

Phase II: The drugs that reach phase II are then studied for their treatment efficacy (how well they work to fight the disease). One group of research participants will get the study drug and another group will get a placebo pill; this is a pill that closely resembles the study drug but is not active medication (it is often a sugar pill). The group getting the placebo pill serves as a comparison group when treatment results are evaluated to fully understand the effects of the new drug on the person with the disease. About 1 in 3 drugs will continue to Phase III.

Phase III: Phase III is similar to Phase II but expands the study to include many more research participants. This provides a more thorough understanding of the drug's effects in the general population and determines if it is a safe and appropriate treatment for a certain disease. About 70%

to 90% of drugs will pass Phase III and continue to the final phase of testing, Phase IV. At the conclusion of Phase III, most drugs can be put on the national market for use.

Phase IV: After drugs are put on the market, pharmaceutical companies complete a post marketing trial that makes up Phase IV. The new drug is compared to similar drugs on the market to see if it is more beneficial or if it has fewer side effects. These drugs are also monitored for long-term effectiveness and impact on the individual's quality of life. Cost effectiveness is also evaluated. At the conclusion of this phase, depending on the results, the drug will remain on the shelves or be taken off.

All drugs on your pharmacy's shelves have gone through all four phases before they become available to you!

Benefits of Participating in Clinical Trials

- Opportunity to get a new drug before it's available to the general population.
- Possibility of being among the first to benefit from a new treatment or new information about a current treatment.
- Special care and close oversight by trial doctors.
- Possibility of free health screenings and exams.
- Opportunity to contribute to medical and scientific knowledge, possibly for your good and/or the good of future generations.
- For some trials, participants are paid for travel to the research site and to undergo certain medical procedures.



Risks of Participating in Clinical Trials

- The new treatment may not work well for you.
- It might be less effective than the standard treatment.
- The new drug may have known and unknown side effects.
- Sometimes side effects can occur after the trial stops.
- You may receive a placebo—(an inactive pill) that has no treatment value. **However, placebos are not used when doctors already have treatments that work or getting no treatment could put you at harm.**
- For some trials, there may be expenses such as medical tests, which may not be covered by your insurance or by a trial sponsor.

For information on clinical trials in your area, please visit:

- University of Kentucky Clinical Trials
(www.mc.uky.edu/research/clinicaltrials.htm)
- Clinical Trials.Gov (www.clinicaltrials.gov)
- Clinical Connection Clinical Trials
(www.clinicalconnection.com)

If you are in Lexington Kentucky and would like information about current research, please call our Alzheimer's Disease Center at 859-323-5550.



CHAPTER 2

Caring for the Person
with
Dementia





INTRODUCTION

This chapter will make the case that there is a “right way” and a “wrong way” to help a person with Alzheimer’s disease. When caregivers learn some of the tips in this chapter, life will become easier.

One simple example is “not arguing.” When a caregiver can learn to let go of the little things and be “in the moment” with the person with dementia, the day will go better.

The chapter offers some basic tips for quality dementia care. For information contact your local Alzheimer’s Association.

About The Person with Dementia

Persons with dementia have a disease or disorder that is gradually robbing them of the ability to do the things they’ve always done. This can sometimes cause loneliness, sadness, anger and frustration. On a positive note, it can also cause a person to become happy-go-lucky since he or she may not be aware of his or her losses.

The following sections describe how to create a positive environment for the person and the strategies that a caregiver can employ to reduce challenging behaviors and protect personal dignity.

Common Causes of Behavior Changes

Coping with challenging or difficult behaviors requires patience, creativity, and the ability to live in the moment. There is not a magic answer, but there are steps that might help, whether you are offering advice to church members or providing care to a family member in the home.

First, keep in mind that the person with dementia will probably not be able to understand reason and logic. The following are some likely causes for behavior changes in the person with dementia.

- Physical discomfort caused by illness, pain or medications.
- Too much noise or activity.



- Not able to recognize familiar places, faces, or things.
- Difficulty completing simple tasks or activities.
- Not able to communicate effectively – to find the right word, answer a question or communicate needs and want.
- Fatigue.
- Depression.
- Constipation.
- Boredom.

EXPLORING CAUSES AND SOLUTIONS

It is important to try to identify the cause or causes of the problem behavior and consider possible solutions.

Identify and examine the behavior

- What was the behavior? Was it harmful to the individual or others?
- What happened before the behavior occurred? Did something cause the behavior?

Explore potential solutions

- Is there something the person needs or wants?
- Can you change the surroundings? Is the area noisy or crowded? Is the room well-lighted?
- Are you responding in a calm, supportive way?

Consider different responses in the future

- Did your response help?
- Do you need to explore other potential causes and solutions? If so, what can you do differently?

RESPONDING TO PROBLEM BEHAVIORS

- Stay calm and be understanding.
- Be patient and flexible.
- Don't argue or try to change the person's mind.
- Acknowledge requests and respond to them.
- Don't take behaviors personally.
- Accept the behavior as a reality of the disease and try to work through it.

Best Friends Approach

In the last decade, a new phrase has evolved to describe the



most effective approach to Alzheimer's care – “person-centered care.” The phrase was originally used by British researcher Tom Kitwood and has become the “Golden Rule” for dementia care.

As Virginia Bell, a nationally known social worker and writer in Lexington, Kentucky has said, “Person-centered care suggests that a person with dementia is still just like you and me, with all the same feelings. They want to be heard and valued, loved and cared for. Treat them as you would want to be treated if you had Alzheimer's.”

Virginia Bell and her colleague David Troxel have developed a philosophy of care called “Best Friends” that is designed to bring out the best in the person with dementia. This approach to Alzheimer's care reflects the growing belief that much can be done to improve the lives of dementia patients.

The premise of the Best Friends approach is that what a person with Alzheimer's disease really needs is a good friend –a best friend. When the elements of friendship are incorporated into Alzheimer's care, the caregiving relationship becomes less stressful for both the caregiver and the patient.

The Best Friends approach maintains that each person with memory loss:

- Is an adult with infinite value apart from loss of memory.
- Has needs of the spirit that must be nurtured with help from others.
- Has feelings about the losses from Alzheimer's disease.
- Has a unique life story.
- Needs something meaningful to “do” and ways to “be.”
- Can be helped to experience more positive feelings through quality care.

The following techniques can be used to bring out the best in the person with Alzheimer's disease.

USING THE LIFE STORY TO PROVIDE CARE

As Alzheimer's disease or dementia begins to affect a person's memory, it becomes important that the people involved in his or her care know the person's Life Story. The Life Story involves knowing more than a person's family or occupation. The Life

Story is who we are: our hobbies, likes/dislikes, values, roles, faith/spirituality, and experiences.

It can be very helpful to create the person's Life Story for future use. Assisting the caregiver in writing the Life Story of their loved one, not only can be an enjoyable process for the caregiver, but also results in a useful tool for the person's care in the future. This written Life Story can be shared with visitors, adult day staff, home care aides, long-term care staff, and even physicians to assist in caring for the person. Perhaps you have volunteers in your church who would like to help by compiling a life story.

PARTS OF A LIFE STORY

To compose a Life Story, you will need to find out about the person's past. The parts of the Life Story are listed in chronological order for your convenience, but the events are not necessarily only related to those years. For example, someone may have been in military service throughout his or her working life [Bell & Troxel, *Best Friends*, p. 68].

Childhood

- Birth date and birthplace
- Parents and grandparents
- Brothers and sisters
- Early education
- Pets

Middle Age

- Grandchildren
- Hobbies
- Work/family role
- Clubs and organizations
- Community involvement

Adolescence

- Name of high school
- Favorite classes
- Friends and interests
- Hobbies and sports
- First job

Later Years

- Life achievements and accomplishments
- Hobbies
- Travel
- Family

Young Adulthood

- College and work
- Marriage(s)/relationship(s)
- Family
- Clubs and/or community involvement
- First home
- Military service

Other Major Ingredients

- Ethnicity
- Religious background
- Awards
- Special skills



Collecting the Life Story can be a wonderful project for a Church youth group. The story honors a person's past and can be helpful for the family in the future.

Communication

How Alzheimer's Disease and Dementia Change Communication

A caregiver from Lexington described communication with her Mother and her approach:

Well, with my Mom, she is very sensitive about being wrong and things of that nature. So one thing that I try to do is to be sure that I give some credibility to things that she is telling me. I just try to always make sure that I listen to what she is saying.

–Wanda, Lexington Caregiver–

The way that Alzheimer's disease affects communication varies from person to person.

Early in the disease, people with AD are often aware of differences in their communication. When aware of their language changes, they may try to cover up. They may make up all or part of a story, become indignant, nervous or anxious. They may use humor to cope with their difficulties or they may admit that they are having a problem.

Alzheimer's disease may have the following effects on a person's communication:

- Increasing difficulty expressing ideas and thoughts in words.
- Trouble understanding what has been said.
- Difficulty finding the right words.
- Using familiar words repeatedly.
- Inventing new words to describe familiar objects.
- Difficulty translating thought into action.
- Easily losing train of thought.
- Difficulty organizing words logically.

- Reverting to speaking in a native language.
- Using curse words more often.
- Speaking less often.
- Relying more on nonverbal gestures.

Unfortunately, many people with AD withdraw from social situations because they don't want others to know about their problems.

One caregiver described the change in her sister:

She didn't want to visit or see her friends anymore. She just did not want to be bothered. And then I would try to get her to play cards and she would say, "I don't want to play cards, what am I going to play cards for?" She loved to play cards. And, of course, it got to the place where she did not want to go to the grocery store. She did not want to go out. Socially she just did not want to be bothered; it was too hard for her.

–Juanita, Lexington Caregiver–

NOTE: Juanita's sister's withdrawal from society could be caused by her awareness of her losses or by depression. In these situations, caregivers should keep trying creative ideas to keep the person involved in the community. An adult day program can help.

Caregivers may need to develop different ways of communicating with people with dementia. By changing communication strategies, the person may feel more comfortable and in turn, have more effective interactions.



£ BOX 2A

Ø Communication How To

Do not:

- Argue, confront, correct.
- Give orders, make demands.
- Talk down to a person.
- Talk about a person in his or her presence.
- Ask questions that require too many facts.
- Try to explain or prepare too far in advance.
- Take negative comments personally.
- Be insincere by asking questions when you are not offering a choice.
- Give too many choices.
- Take anything for granted.

Do:

- Listen carefully.
- Help the person fill in the blanks.
- Read facial expressions and body language and try to respond appropriately.
- Give compliments.
- Ask opinions.
- Ask open-ended questions.
- Give generous praise.
- Use common sense.
- Enjoy the person.
- Take the blame, apologize.
- Be sincere.
- Use the person's Life Story.
- Use positive language.

[Bell & Troxel, pp. 115-126.]



£ BOX 2B

🔗 Repetitive Phrases or Questions

People with Alzheimer’s disease sometimes ask the same question or make the same statement over and over. For example, “What time is it? What time is it?” or “I want to go home. . . I want to go home.”

For caregivers, this repetition can be maddening!

What does not work is to argue, get angry or try to correct the person.

What can work?

Gently answer the person the first time or help him or her with needed information.

Draw the person out by trying to find out what is bothering them:

Person with
AD

“I want to go home”

Caregiver Response

Mom, tell me about your home.
Was it in the country or city?
Did you enjoy living there?

“What time is it”

What do you need?
Tell me how you are feeling today.

“Where’s Mama?”

Tell me about your mother.
Was she a good cook like you?
Was she very strict when you
were growing up?

Using this method will often break the repetitive cycle and demonstrate care and concern for the person.



AGGRESSION

When a person with Alzheimer's disease is frustrated, scared or unable to communicate, he or she may become aggressive and may even physically strike out. Aggressive behaviors can be caused by many things, including physical discomfort and the inability to understand. If the person is showing signs that he or she may become physically aggressive, review the following list of tips.

TIPS FOR DEALING WITH AGGRESSIVENESS:

- Identify signs of frustration - Look for early signs of frustration during activities such as bathing, dressing or eating and respond in a calm and reassuring tone.
- Don't take the behavior personally - The person isn't necessarily angry with you. He or she may have misunderstood the situation or be frustrated with lost abilities caused by the disease.
- Don't lecture - Avoid long explanations and arguments. Be encouraging and don't expect the person to do more than he or she can.
- Use distractions - If the person is frustrated because he or she can't unbutton a shirt, distract the person with another activity. Later, you can return to helping the person unbutton the shirt.
- Communicate directly with the person - Avoid expressing anger or impatience in your voice or physical action. Instead use positive, accepting expressions, such as "don't worry" or "thank you." Also use touch to reassure and comfort the person.
- Decrease level of danger - Assess the level of danger—for yourself and the person with Alzheimer's. You can often avoid harm by simply stepping back and standing away from the person. If the person is headed out of the house and onto the street, more assertive action may be necessary.
- Avoid using restraint or force - Unless the situation is serious, avoid physically holding or restraining the person. He or she may become more frustrated and may cause personal harm.

An example of how to handle agitation was provided by one of our caregivers:

Well I've seen, I guess in the last couple of years, I've seen her become more agitated, like if there is a project that she is working on trying to complete. She gets agitated, just like when she loses her train of thought she becomes very agitated...I notice this more so recently, she will get her words mixed up, or if a word doesn't come out exactly correct it bothers her, but I try to make her realize that it doesn't bother me or anyone else. We just help her finish the sentence.

—Anna, Lexington Caregiver—

NOTE: Anna's calm and supportive approach calms her mother.

Sleep Problems are Common

Sleeping problems experienced by those with Alzheimer's disease and caregiver exhaustion are two of the most common reasons for placement in nursing homes. While experts are not certain how or why sleeping problems occur, many professionals attribute them to late-day confusion or "sundowning." When sleep problems occur, try to plan more active days, restrict sugar and caffeine late in the day and consult your physician.

Wandering

A person with Alzheimer's is likely to wander at some point during the disease. Identifying the cause of the behavior can help reduce its occurrence. One reason wandering is common is that persons get confused about time and place. They head out the door since they think they're late for work or have to get home.

Recommend that church members join the Safe Return program of the Alzheimer's Association for an identity bracelet and other materials. The program has a 24 hour Hotline that can be called to report a wanderer or for law enforcement to call if they find someone.

People with Dementia Benefit from Activities

Life is an activity. Throughout the day, we spend our time working and playing with friends and family or by ourselves. People with Alzheimer's disease often need help to continue to participate in their favorite activities. Participation in activities, including those offered by your faith community, can improve mood and enhance the caregiving relationship.

As one caregiver in Lexington shared: "I think many of my problems with my husband stem from his boredom – he doesn't have enough to do." This caregiver worked hard to plan more for him to do at church, and enrolled him in an adult day center program. "I didn't think he'd like it but now he looks forward to it."

PURPOSE OF ACTIVITIES

- To socialize and feel physically close to others.
- To be productive.
- To feel successful.
- To play.
- To build and retain skills.
- To have a sense of control.
- To fill a religious or spiritual need.
- To experience growth and learning.

Some simple activities to do around the home include: folding laundry, drying dishes, setting the table, sweeping the floor, brushing the dog, scrap booking, sorting socks, or watering plants.

In the community, examples could include: taking walks, sitting on a park bench and watching the world go by, going to church, attending a short concert, or even volunteering to do some simple tasks for a local non-profit group.

"I think many of my problems with my husband stem from his boredom – he doesn't have enough to do."



£ BOX 3A

PLANNING ACTIVITIES

When planning activities and daily tasks to help the person with Alzheimer's disease organize the day, think about:

- What skills and abilities does the person have?
- What does the person enjoy doing?
- Does the person need help beginning activities?
- Does the person have physical problems?

APPROACH

- Make the activities part of the daily routine.
- Focus on enjoyment, not achievement.
- Determine what time of day is best for the activity.
- Offer support and supervision.
- Be flexible and patient and stress involvement.
- Help the person remain as independent as possible.
- Simplify instructions.
- Establish a familiar routine.

ENVIRONMENT

- Make activities safe.
- Change your surroundings to encourage involvement.
- Minimize distractions that can frighten or confuse the person.

Personal Care

People with Alzheimer's disease may need help with routine activities related to grooming and hygiene. This assistance can be a problem because it signifies a loss of independence and privacy. Providing such care is also difficult for caregivers, especially when they assist with activities that interfere with the individual's privacy.

When it's time for my mother to bathe or take her medications, she can be resistant to doing these things, and sometimes just be mean. So I've come up with things to say when she doesn't want to do something in particular. If she says something like, "You're not my momma or daddy," I try to put some humor in it and I tell her that I've been reincarnated as them, you have to do it. Or, if she tells my sister the same thing, she'll tell my mother that her mother and father were in her dreams the night before and told my sister to tell my mother to do what she says. Taking this approach makes us all laugh and takes the edge off of difficult moments.

—Tim, Caregiver—



BATHING

Bathing is often the most difficult personal care activity that caregivers face. Because it is such an intimate experience, the person with Alzheimer's may perceive it as unpleasant, threatening or painful and, in turn, scream, resist and hit. These behaviors often occur because the person doesn't know what bathing is for or doesn't have the patience to endure the unpleasantness associated with a lack of modesty, being cold or experiencing discomfort. Try the following:

- Simplify - Do as much as possible to make the process easier, such as increasing the room temperature and having bath towels nearby.
- Help the person feel in control - Involve and coach him or her through each step of the process. You may need to experiment to find out if the person prefers showers or tub baths and what time of day is best.

- Create a safe and pleasing atmosphere - Place nonskid adhesives on the floor surface and grab bars in the bathtub to prevent falls. Test water temperatures in advance to prevent burns.

A recommended resource for more help on this topic is *Barrick (editor), et al, Bathing Without a Battle, 2001.*

TOILETING

People with Alzheimer's disease often experience a loss of bladder and/or bowel control. This loss can be caused by many factors, including medications, stress, a physical condition, the environment or even the person's clothing. If incontinence is a new problem, consult a doctor to rule out potential causes such as a urinary tract infection, weak pelvic muscles or medications.

DENTAL CARE

Good oral hygiene can be a problem for people with Alzheimer's disease. Brushing is sometimes difficult due to the person's inability to understand and accept assistance from others. In order to help:

- Provide short, simple instructions - "Brush your teeth" may be too complex. Instead try: "Hold your tooth brush," "put paste on the brush" and "brush your top teeth."
- Use a mirroring technique - Hold a brush and show the person how to brush his or her teeth.
- Monitor daily oral care - Brush teeth or dentures after each meal and floss daily. Remove and clean dentures every night and brush the person's gums and the roof of the mouth. If the person refuses to open his or her mouth, try using oral hygiene aids available from your dentist to prop the mouth open. Strained facial expressions during dinner or refusal to eat may indicate oral discomfort.

Caregivers are essential in helping the person maintain oral hygiene, noticing any problems and seeking help from a dentist. Notify the dentist in advance that the person has Alzheimer's disease, so that an oral care routine can be developed.

Safety

A confused person should not be left unattended. However, it is often difficult or impossible to watch the person all of the time. Thus, home-based caregivers need to make their homes as safe as possible. Here are some tips.

SAFETY CHECKLIST:

Kitchen:

- ✓ Lock up cleaning supplies.
- ✓ Turn off the electricity to the garbage disposal.
- ✓ Hide knives and other utensils.
- ✓ Put away the toaster, blender and other small appliances.
- ✓ Unplug larger appliances such as microwaves.
- ✓ Remove the knobs from the stove, or hook up the stove to a hidden gas valve or electric switch.
- ✓ Keep a fire extinguisher nearby.
- ✓ Clean out the refrigerator regularly.

Bathroom:

- ✓ Set the water temperature at 120 degrees.
- ✓ Install grab bars.
- ✓ Apply textured decals on slippery surfaces.
- ✓ Supervise the use of hairdryers, razors and curling irons.
- ✓ Remove any locks from the bathroom door.
- ✓ Remove any dangerous items from the medicine chest.

Bedroom:

- ✓ Avoid using electric blankets.
- ✓ Monitor the use of heating pads.
- ✓ Install night lights between the bedroom and bathroom.

Garage:

- ✓ Put away hand and power tools such as drills, axes, saws and picks.
- ✓ Limit access to large equipment such as lawnmowers, weedwackers and snowblowers.
- ✓ Lock up poisonous products such as fertilizers.

Throughout the House:

- ✓ Disguise outdoor locks or install deadbolts.
- ✓ Remove or tape down throw rugs and carpeting.



- ✓ Apply colored decals to large windows and sliding glass doors.
- ✓ Remove poisonous plants.
- ✓ Create an even level of lighting near doorways and stairways and between rooms.
- ✓ Remove objects that block walking paths.

Outside:

- ✓ Disconnect gas grills.
- ✓ Lock gates to fences.
- ✓ Supervise the person in areas that are not enclosed.

Other tips:

- ✓ Remove guns from the home.
- ✓ Consider some kind of confusion lock or buzzer to alert you if the person leaves the home unattended.

A good resource is Mark and Ellen Warner's book: *The Complete Guide to Alzheimer's Proofing Your Home: purdue Univ. Press, 2000.*

DRIVING

Safe driving habits require quick reactions, alert senses and split-second decision making. For a person with Alzheimer's disease, driving inevitably becomes difficult.

For most of us, the restriction of driving privileges means a loss of independence. People with dementia may refuse to give up their car keys because they have similar feelings and do not want to depend on others for transportation. They also may not have the insight and judgment to realize that they should not drive.

A diagnosis of Alzheimer's disease does not necessarily mean that a person has lost the ability to drive. Caregivers should evaluate the person regularly to determine if it is safe for him or her to continue driving.

Tips on stopping the person with Alzheimer's disease from driving:

- Ask a doctor to write a "do not drive" prescription.
- Control access to the car keys.





- Disable the car by removing the distributor cap or battery.
- Park the car on another block or in a neighbor's driveway.
- Arrange for alternate transportation.

Be sensitive and supportive during this no-driving period, as the person may feel angry and depressed. A winning strategy can be to turn the matter over to the Department of Motor Vehicles. A member of the public or the person's doctor can report the person to DMV who will be an independent decision maker about an individual's ability to drive safely.

CONCLUSION

Utilize the ideas in this chapter to coach friends and family members, or members of your church on the dos and don'ts of providing quality care. When you protect a person's dignity, help him or her feel safe, secure and valued, life becomes easier. Sometimes it just takes 30 seconds to build a relationship and reassure the person that you still care. This is a spiritual act as well as an act that will help prevent problem behaviors.





C H A P T E R 3

Helping Caregivers
with
Their Journey



INTRODUCTION

Alzheimer's is slow and progressive, and caregivers often have a difficult journey. In many ways, they too are "patients." The following material offers ways to help family caregivers in your church and the community.

About Caregivers

Caring for someone with Alzheimer's disease can take a toll on the caregiver's physical, emotional, and financial health. As the disease progresses, caregivers need to devote more attention to their loved ones. At the same time, they should not forget their own needs.

The most important needs caregivers say that they have are:

1. Information about caregiving.
2. Social support from friends and family.
3. A break from caregiving responsibilities.
4. Help in planning for the future.

African Americans are more likely to take care of their family members in the home without the use of outside help. These caregivers benefit from education and increased awareness of the disease. They also need special encouragement to overcome disease stigma and to utilize services early and often. The caregiving demands may be perceived differently depending on who is providing the primary care as one of our patient's describes:

My wife has been more affected by the disease than our children. The children they've got the wrong concept about it. Every time they're here, they're like – how are you feeling? Dad, can I do this? They're going to make me an invalid.

–Patient, Lexington–

NOTE: *A family meeting facilitated by a trusted party, perhaps a clergy member, can help families clarify roles and successfully travel the caregiving journey.*

Stress

More than 80 percent of people who care for Alzheimer's patients report that they frequently experience high levels of stress, and nearly half say they suffer from depression. Many caregivers don't recognize their needs, fail to do anything about them, or simply don't know where to turn for help. Too much stress can be damaging to both caregivers and the people for whom they provide care. Recognizing the signs and learning how to reduce stress can help.

A TIP FROM AADOP

One technique for encouraging African American caregivers to utilize services is to focus on the benefits to their loved one. For example: discuss how learning more will help provide better care; how day center care can provide socialization and fun; how getting a good diagnosis will help the doctor figure out the best medications. If you focus on the caregivers needs, "You are so tired," "You need the help," it can backfire and feed the guilt that a caregiver has somehow failed by accepting help.

One of our Lexington family members described how she dealt with her stress:

Sometimes I get tired and I think, "Oh, I cannot do this anymore". I go see my Mom every day, but usually if I take a few minutes to reflect and pray and so forth, I feel better about it. It kind of seems like well maybe this is what I'm supposed to be doing. Maybe this is what God has chosen me to do, to help a person who really needs my help.

—Wanda, Lexington Caregiver—

NOTE: Wanda's faith has given her comfort and purpose.

WARNING SIGNS OF CAREGIVER STRESS:

- Denial.
- Anger.
- Social withdrawal.
- Anxiety.

- Depression.
- Exhaustion.
- Sleeplessness.
- Irritability.
- Lack of concentration.
- Health problems.

SUGGESTIONS FOR REDUCING STRESS:

- Identify and use community resources.
- Become educated about Alzheimer's disease and caregiving techniques.
- Ask for help from family, friends, and the community.
- Watch your diet, exercise, and get plenty of rest.
- Talk with your physician and learn to use relaxation techniques.
- Accept changes as they occur.
- Plan for the future – legal and financial.
- Be realistic about what you can do.
- Don't feel guilty if you lose your patience or can't do everything.

GRIEF AND LOSS

Family caregivers can expect to experience feelings of loss, especially as their lives and the people they love are changed by disease. The natural phases of grieving usually involve denial, anger, guilt, physical symptoms and eventually acceptance. However, it is important to know that everyone grieves differently.

To cope with the grieving process, those providing care should consider the following:

- Confront their feelings.
- Accept guilt as a common part of loss and grief.
- Find ways to forgive themselves and others.
- Share their feelings with a friend, support group, therapist or spiritual leader.
- Learn to feel comfortable accepting and celebrating good things in their life. It is okay to feel happy at times even though a family member is sick.

Churches can help families by reinforcing the importance of faith.

Legal and Financial Issues

Alzheimer's disease brings with it important legal concerns. Individuals diagnosed with Alzheimer's and their families should plan for the future. Legal planning should begin soon after a diagnosis is made and should include documents that authorize another person to make health care and financial decisions and identifies appropriate plans for long-term care.

If the person with Alzheimer's disease has legal capacity—the level of thinking necessary to sign official documents—he or she should be a part of the legal planning process.

LEGAL DOCUMENTS THAT SHOULD BE CONSIDERED

Commonly used documents in legal planning for individuals with dementia include:

Durable Power of Attorney

A durable power of attorney document gives the person with Alzheimer's disease the opportunity to authorize another person, usually a trusted family member or friend, to make decisions when he or she is no longer competent.

Power of Attorney for Health Care or Health Care Surrogate

These documents appoint someone the person trusts to make all decisions about health care, including choices about health care providers, medical treatment and facilities. For people in the later stages of Alzheimer's, the health care surrogate will choose care services and make end-of-life decisions.

Living Will

In a living will, the person with Alzheimer's disease expresses his or her decision on the use of artificial life support systems.

Finding An Attorney

It can be important to find an attorney who is familiar with "Elder Law." Elder Law covers those legal issues that affect older people. In the past, attorneys serving the legal needs of the elderly tended to focus on estate planning. They dealt with the financial needs of the healthy retiree and focused on the distribution of estates at death.

As America's older population has grown, the field of Elder



Law also has grown. Elder Law encompasses aspects of planning for aging, illness and incapacity, including:

- Disability Benefit Applications and Appeals.
- Estate Planning.
- Guardianship/Conservatorship.
- Long Term Care Planning.
- Medicaid and Planning.
- Powers of Attorney/Advanced Directives.
- Social Security and Retirement Benefits.

There are a number of additional fields which apply to Elder Law. However, most Elder Law attorneys do not specialize in every field. It is important to hire an attorney who understands those matters of greatest concern to the patient and caregiver. It is also important to consider the attorney's level of experience and the amount of time devoted to Elder Law issues.

If one's affairs are simple, internet resources and self help legal offices may save the family money. Many senior centers or area agencies on aging offer low-cost or free legal services.

NO MAN (OR WOMAN) IS AN ISLAND

Many caregivers make the mistake of isolating themselves and waiting until they are exhausted to take advantage of available community services.

A faith community should encourage members to be open about aging issues and elder care. Caregivers may benefit from support groups and adult day care for their family members. Day centers get the person out of the house for supervised activity. Many day centers are low cost or have fees based on a sliding scale, so caregivers should be encouraged to try these programs without being discouraged by potential costs.

Another way churches can help is by writing about caregiving issues in the church bulletin or newsletter. Personal testimonials make those suffering aware that they are not alone. If a son or daughter, husband or wife, writes about their caregiving experiences and their needs, it may encourage others to come forward and ask for help.



CHAPTER 4

Dementia
and the
African-American
Community

We're all precious in God's sight.

Reverend Jesse Jackson





INTRODUCTION

This section describes the impact of Alzheimer's disease on African Americans and provides information on ways African-American churches can help.

The Alzheimer's Association has identified a growing public health crisis among African Americans calling it "the Silent Epidemic of Alzheimer's Disease." Data from long-term studies suggest that high cholesterol, high blood pressure, lack of exercise and diabetes may be important risk factors for Alzheimer's. The consequences of these discoveries are enormous for African Americans because high blood pressure, high cholesterol, and diabetes occur at greater rates among Blacks. The number of African Americans entering the age of risk (age 65 and over) will more than double to 6.9 million over the next 30 years. There is no time to waste.

One hero in the African-American community who took her despair and turned it into a positive mission to help others is Lela Knox Shanks. She found herself traveling the caregiving journey when her husband was diagnosed with Alzheimer's disease.

Among the lessons she learned were:

- Attitude determines outcome.
- Refuse to be a victim.
- The AD experience is part of a "Grand Design."
- Tap into your inner strengths.
- Creativity is infinite.
- Connect faith to your daily life.

She cared for her husband Hughes until his death in 2000 and wrote a best-selling book about her experiences. Her final recommendation to caregivers like herself is that "acceptance takes away the burden," and "in the end, only Love matters."

Alzheimer's and African-Americans — Sobering Facts

According to the National Alzheimer's Association, African Americans are two times more likely than whites to develop dementia. Researchers do not yet understand why this is the case.

"Acceptance takes away the burden," and "in the end, only Love matters."
—Lela Knox Shanks



Among the theories are that individuals with a history of either high blood pressure or high cholesterol are twice as likely to develop Alzheimer's disease. Those with both risk factors are four times as likely to develop the disease. Sadly, these conditions are common in the African-American community.

Other health factors that may contribute to the risk of Alzheimer's disease are hypertension and diabetes. Sixty-five percent of African-American Medicare beneficiaries have hypertension, compared to 51% of White beneficiaries.

Stroke is also an enemy of the brain and can lead to dementia. Because of the higher rates of hypertension, again, African Americans are more likely to develop Alzheimer's disease.

These sobering facts suggest that there is an important link between life style and the risk of developing Alzheimer's disease. Many African-American churches are introducing health education programs including physical fitness and dieting programs. It seems clear that there are now more reasons than ever for the African-American community to embrace these healthy lifestyle efforts and churches are aware of this need as described below.



Black folks enjoy certain kinds of foods, fried foods, greasy foods, traditional foods, and ethnic foods. Many times these things are very, very harmful to people and they don't know it because it has been such a tradition. These are things that they grew up with, foods they grew up with. Education becomes very important in trying to re-educate people to understand that you need to be concerned about the kinds of foods you eat – fried foods and that kind of thing. And that is not an easy thing, because traveling around as I do, church related, one of the first things that people want to do is feed you! You have to be very selective about what you do in terms of the food that you take in.

–Bishop Richard Clark, House of God #1, Lexington, Kentucky–

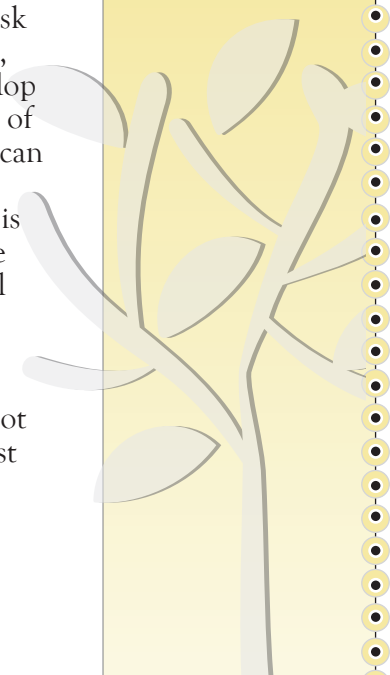


Over and above life style factors, advancing age is the greatest risk factor for developing Alzheimer's disease. Currently, an estimated 5.4 million Americans have Alzheimer's disease. Every 69 seconds, someone in America develops Alzheimer's disease. By year 2050, the time of every 69 seconds is expected to decrease to every 33 seconds. Over coming decades, the baby boom population is projected to add 10 million people to these numbers. In 2050, the incidence of Alzheimer's disease is expected to approach nearly a million people per year, with a total estimated prevalence of 11-16 million people. Dramatic increases in the numbers of "oldest old" (aged 85 years and older) across all racial and ethnic groups will also significantly affect the numbers of people living with Alzheimer's disease.

Because old age happens to all of us, Alzheimer's disease is ultimately a problem for everyone - whatever their ethnic or racial background.

Alzheimer's Disease and Heredity

While the greatest known risk factor for Alzheimer's disease is advancing age, there are other factors that may increase one's chance of developing the illness. Another strong risk factor is family history. Those who have a parent, sibling, or child with Alzheimer's disease are more likely to develop the disease themselves. The risk increases as the number of family members who have the disease increases. For African Americans, the cumulative risk of dementia among first degree relatives of a person who has Alzheimer's disease is 43.7%. For spouses of someone with Alzheimer's disease the cumulative risk is 18%. Heredity and environmental factors may both play a role in this cumulative risk. However, just because someone in your family has the disease does not mean you will too. Just as if there is no family history of the disease, it does not mean you will not get Alzheimer's disease. A family history of the illness just increases your overall risk.



Lessons from the African-American Dementia Outreach Partnership (AADOP):

Based on the experience of staff and faculty of AADOP, individuals working with African-American families coping with Alzheimer's disease should consider the following:

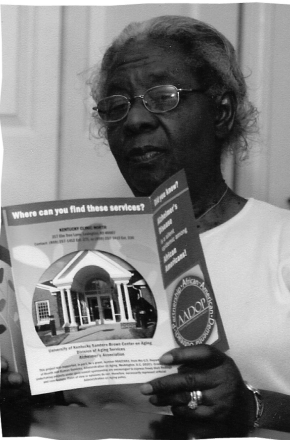
Old wounds can be slow to heal - Many African Americans remember times in the past when doors in the health community were shut to them. Churches will need to help their families identify trusted health care providers including well trained neurologists who can assist in the dementia diagnosis. Don't forget to check with the Alzheimer's Association for physician listings. When working with families, be good listeners and keep your promises.

Family is important - African-American families often include multi-generational households, and **respect for elders is strong**. Family meetings can be a good idea, but remember that there are often multiple decision makers in a family. Identify decision makers, and work to educate them about Alzheimer's disease and the decisions that they will need to make.

Faith is a part of daily life - African Americans continue to be active in faith communities. Churches can play an essential role in identifying people struggling with symptoms of dementia and encouraging the use of services. Also, caregivers often need the kind of informal support that can be best provided by religious congregations. Such support, if adequate and timely, has the potential to reduce stress and related health problems for the caregiver. Encourage your church elders to develop a pro-active approach to helping members travel their journey with dementia. **Be a source of strength!**

Additional copies of this book are available for your church members. Contact the Sanders-Brown Center on Aging at the University of Kentucky at 859-323-6040.

Remember to stay personal - Tell stories - Many caregivers are willing to share stories about their experiences. Encourage





person-to-person exchange; it's the best way to share information and possible solutions to specific problems.

Offer church based services - If support groups that are offered through your Alzheimer's Association are not well attended by your church members, the church may need to sponsor a group with help from the Alzheimer's Association.

Address the stigma of Alzheimer's - Many in the African-American community have untrue ideas about Alzheimer's disease and dementia. Recognition that Alzheimer's disease is a medical problem requires education. One way AADOP has encouraged the use of services is to offer free memory check-ups. These screenings stress the importance of "enhancing brain power." Many in the African-American community have responded in a positive way to this approach and have then shared concerns about older family members. Check to see if free memory check-ups are available through trained professionals in your community and consider offering the service through the church just as you do with blood pressure screenings. Also, families who may be unable to deal directly with dementia will usually respond to an emphasis on the importance of keeping their loved one safe in the home.

Keep it social - Even when talking about the serious topic of caring for a family member with Alzheimer's disease, the best meetings usually include social time with coffee and refreshments or other ways to "break bread." Meetings with food allow people to talk informally and create a comfortable, non-judgmental setting to discuss changes in memory.



“What happens to my mother’s faith if she forgets it? Does that mean she has lost her relationship to God?”

Keeping the Faith

In support groups, caregivers often ask: “What happens to my mother’s faith if she forgets it? Does that mean she has lost her relationship to God?” Most religious leaders and experts on Alzheimer’s disease would answer “No.” Alzheimer’s disease may take away the person’s ability to think and reason, but the spirit of the person remains and is shown in other ways, including their experience of the present moment. Some experts have suggested that Alzheimer’s disease may put the person in a more spiritual space, as they are no longer distracted by TV news, cell phones, news of the day, or problems of the world.

Research has found that those patients with Alzheimer’s disease with higher levels of religiosity and spirituality had a slower progression of the disease as shown by their scores on tests of memory and thinking (Kaufman, Freedman & Koenig, 2005). Such research suggests that families should support the patient’s remaining abilities and help them to keep religion in their lives.

Families may need to be reminded that God is not angry with them and is not punishing their family, and that He has not forgotten them. They should be encouraged to keep God as a part of their family and help their family member in the expression of faith and hope.

Some suggestions for keeping the person with dementia connected to his or her faith include:

1. Singing and listening to familiar hymns and other religious music
2. Reading from the Bible or other sacred texts
3. Praying or participating in prayers given by others
4. Sharing in religious rituals such as the cross, or saying the rosary
5. Seeing and feeling the love of God in the actions of their caregivers and others who love them

[Bell & Troxel, *A Dignified Life*, p. 212]



One family member described her Mom's faith as follows:

I noticed that Mom's faith was still very high even though there might be things that she has forgotten. She taught Sunday school for 32 years and she is always talking to people wherever we go about the Lord.

—Ms. Marie Allen, Lexington—

NOTE: Faith is one way patients can feel connected with others and maintain their dignity.

Giving Spiritual Care

Caregivers should understand that nurturing the spiritual being is not limited to church activities. God's presence in nature can be shared through walks or drives in the country with the patient.

Spiritual life can be enhanced through:

1. Participating in the arts including music, painting, or poetry.
2. Being outside on a beautiful spring day.
3. Enjoying a rainbow.
4. Walking along a river, lake or ocean to experience the majesty of nature.

Virginia Bell has written that while *many* people have a religious background and are members of a faith community, *all of us* have a spirit.

A church community can nurture both!

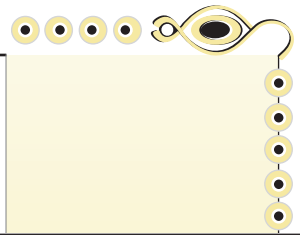
Help with Prayer

A continued fellowship with God may be essential for maintaining dignity and quality of life for the person with dementia. For the person for whom religion and prayer have been an important part of life, efforts should be made to allow the continued practice of faith in a manner as similar as possible to what brought comfort to the person before the illness. Attendance at church services may become difficult as the disease progresses and crowds become a distraction that interferes with communion with God.

Individuals with dementia move through the disease at different speeds and with different symptoms. They may suffer from losses that affect vision and hearing as well as the ability to think and understand the written word. Early in the disease attendance at church services and other religious events may provide a welcome sense of being normal. As the disease progresses, attendance at shorter services or Bible studies may be an option as the length of a regular service may be too tiring for the person and large groups of people may be upsetting. Visits to the sanctuary when there is no service may also allow the person with dementia to continue to connect with their earlier training.

For those persons, who cannot put words together to form a prayer and whose mind may not recall how to pray, praying with them, reciting old prayers, or singing hymns may help the person to recapture the peace that praying brought earlier in life. Long elaborate prayers are unlikely to provide comfort and may even create anxiety when the words or meaning are not understood. Identifying the person's favorite Bible verses and observing the person's reactions when different scripture and prayers are read will help to determine the words and situations that create the most positive spiritual experience. Try to determine whether a particular physical time, location, or position makes the person feel closer to God. If at home, the person may have had a special chair or place in which he or she prayed or may have always prayed at a particular time of day. A simple prayer before meals said with the person is usually easy to include in the day's activities and may provide important continuity to the person's spiritual existence. When assisting with prayer, it may be helpful to remind the person to close his or her eyes, bow the head, or kneel if that was a part of how they prayed before the disease. These rituals are also helpful for blocking out distractions during the time for prayer and may allow the person to recapture the experience of prayer.

It is important to remember that persons with dementia continue to experience emotion, and their moods may change from day to day. Just as with anyone else, a prayer may be appropriate one day but not appropriate the next. However, prayers of praise to God as well as prayers of hope and gratitude for life are likely to be spiritually uplifting.



The Lord's Prayer is not only familiar, but is an excellent example of praising God in the humility of our humanity and asking God's forgiveness, guidance, and protection.

Simple Prayer Before Meals:

Bless us, O Lord! And these Thy gifts, which we are about to receive from Thy bounty, through Christ our Lord. Amen.

Simple Prayer After Meals:

We give Thee thanks for all Thy benefits, O Almighty God, who lives and reigns world without end. Amen. May the souls of the faithful departed, through the mercy of God, rest in peace. Amen.

NOTE: Saying familiar prayers or being part of a ritual is comforting to many persons with dementia.

Churches and Caregiver Support

Churches play a major role in American society, particularly in the African-American community.

In general, congregations are getting older, described as the "graying of the congregation," thus churches will be facing more and more issues related to caring for increased numbers of older members in the near future. (Pieper and Garrison, 1992).

Caregivers tend to continue their participation in religious communities, while decreasing participation in most other activities (George and Gwyther, 1986). This finding provides church leaders with an important message: families are turning to the church in their greatest time of need – even while giving up other activities. Sensitive church leaders will return this confidence with support and concern.

The church is a place for community support for African Americans of all ages (Taylor and Chatters, 1993). Again, church leaders and volunteers play an essential role in



African-American life and can be “earth angels” to their congregation members by offering education and support for caregivers.

Unfortunately, many congregations are unaware of the needs of dementia caregivers or lack the information necessary to provide assistance.

BOX 4A offers positive suggestions and easy steps to get your church more involved.





£ BOX 4A

🕒 Ten Ways Churches Can Help

1. Be informed! Host educational events about aging, Alzheimer's disease and caregiving and remember that education is an on-going process. Information and resources change over time. Stay connected with your Center on Aging and local Alzheimer's Association.
2. Host a support group for family caregivers, or inform your members where groups are being held. Provide a listing of support groups and other dementia activities in your church bulletin.
3. Encourage your church volunteers and leaders to learn about Alzheimer's disease and dementia and to be a resource for families in need.
4. Offer alternative shorter services or home-visits for persons who find larger crowds upsetting. Try to prevent patient and caregiver isolation.
5. Develop a Church Respite program, where friendly visitors help out in the home or provide companionship a few hours a week. Don't forget those church members in nursing homes.
6. If needed, develop an adult day program perhaps in cooperation with other churches or community groups.
7. Invite early-stage persons to continue to volunteer for tasks that may bring them satisfaction such as folding a church newsletter or light housekeeping/gardening.
8. Build a relationship with the University Alzheimer's Center or Center on Aging and the local Alzheimer's Association.
9. Encourage retired nurses to develop a church wellness program.
10. Encourage congregation members to adopt a healthier lifestyle to reduce the risk of stroke and Alzheimer's disease.

£ BOX 4B

Church Youth Programs

A church youth program can take on elder and Alzheimer's care as an important project. Often one or two members may show concern about their grandparents. Their enthusiasm and interest can get a whole congregation involved.

Encourage church youth to sponsor educational programs, volunteer to make visits to church members at home or in assisted living/nursing home settings, or to volunteer at a day center.

Channel enthusiasm for a project at school into broader community service. Keep young people educated and involved with issues that effect their family and community.

If your church's youth ministry is interested in including a lesson on Alzheimer's disease, AADOP has produced a film and educational toolkit designed specifically for youth to learn about how aging and Alzheimer's disease affects African American families. Both the video and toolkit are free of charge. Please contact the AADOP staff for more information at 859.323.6040



£ BOX 4C

Do you have a Sister Jones in your Congregation?

Sister Jones is an 84-year old woman. She and her husband were active members of St. Matthew's Church for over forty years. Brother Jones was diagnosed with Alzheimer's disease five years ago. Since then, his wife has been the primary caregiver and they have not been as involved in their church community. Sister Jones attends services almost every week, but does not participate in volunteer projects as much as she used to. Sometimes her husband accompanies her to church but he just sits—smiling and looking around. Sister Jones' health is declining and she told her pastor that she feels ill and tired.

Sister Jones has not used formal services such as adult day care or home-delivered meals because she does not think she can afford them and she is not involved in a support group because she cannot leave Brother Jones alone. She would greatly benefit from informal support.

If a few church members would alternate providing respite a few hours per week, Sister Jones could attend church activities or meetings of others caring for a person with AD (fellowship group) and she would have the needed break she requires, knowing that her husband is in good hands. Members of the congregation could deliver meals to the couple a few times per week, relieving Sister Jones of the responsibility of preparing dinner, and giving her a break. These simple tasks require only a small time commitment on the part of the congregation, yet would have a positive impact on Sister Jones' sense of well being. Do you have a Sister Jones in your congregation? What do you have in place to help her?

If you need help with planning programs through your church, contact the Center on Aging at the University of Kentucky at 859-323-6040. We can help you reach out to Sister Jones and others.

When asked whether his faith had helped him cope with his disease, one of our participants provided a beautiful summary for this manual:

Oh, it has, because my faith has kept me calling on God and asking him to give me more faith and more understanding to help me in crises like these. He said, "I'll never leave you, nor will I forsake you." ...So, this made me call on Him.

—Pastor, Lexington—

Additional Information

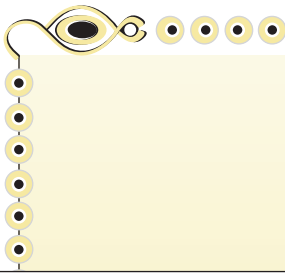
For further information or recommended readings on any of the topics mentioned in this manual, please contact the Alzheimer's Association. Local chapters are available in communities nationwide. To find your local chapter call 800.272.3900 or visit the Alzheimer's Association web site at www.alz.org.

The Alzheimer's Disease Center at the University of Kentucky also has listings of resources and readings. To contact AADOP staff at the University of Kentucky call 859.323.6040.

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Index



The following prayer, written from the patient's perspective, reminds us that the person with the disease retains his life history and spiritual essence and above all requires love and respect.

Alzheimer Patient's Prayer



*Pray for me, I was once like you.
Be kind and loving to me,
That's how I would have treated you.
Remember I was once someone's parent or spouse,
I had a life and a dream for the future.
Speak to me, I can hear you even if I don't understand
what you are saying.
Speak to me of things in my past of which I can still relate.
Be considerate of me, my days are such a struggle.
Think of my feelings because I still have them and can feel pain.
Treat me with respect because I would have treated you that way.
Think of how I was before I got Alzheimer's; I was full of life,
I had a life, laughed and loved you.
Think of how I am now, my disease distorts my thinking,
my feelings, and my ability to respond, but I still love you
even if I can't tell you.
Think about my future because I used too.
Remember I was full of hope for the future just like you are now.
Think how it would be to have things locked in your mind and
can't let them out. I need you to understand and not blame me,
but Alzheimer's.
I still need the compassion and the touching and most of all
I still need you to love me.
Keep me in your prayers because I am between life and death.
The love you give will be a blessing from God and both of
us will live forever.
How you live and what you do today will always be remembered
in the heart of the Alzheimer's Patient.
—Carolyn Haynali ©3/10/2000—*



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