

# **WELCOME STRANGER**

**Alzheimer's Caregivers Guide  
by  
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## ACKNOWLEDGEMENTS

After my dear Kendall's passing several caregiver friends suggested I compose a much needed list of do's and don'ts which would help reduce Alzheimer's caregiver stress and frustration. As a result of our commiserating over our lengthy ordeals, we gathered sufficient information to aid caregivers. Their perseverance and tenacity is much appreciated.

Were it not for my lifelong friend and mentor, Merton M. Minter Jr., this manual would have never been written. His journey as an Alzheimer's caregiver began over a year before mine and his sharing of experiences proved of enormous help and reassurance. The periodic phone calls we shared enabled me to both better handle my responsibilities as a caregiver and deal with the ever present stress. His recognizing the need to fervently seek God's help was a profound gift and lessened the stress I otherwise would have experienced.

Walt McFadden had a more lengthy role as caregiver and faced more aggressive behavior than I. His stories and experiences broadened my perspective of Alzheimer's conduct and the range of patient behavior. He had a multitude of stories, all of which were different, except for the perpetrator. His keen awareness of Alzheimer's patient frustrations makes a significant contribution to this manual...a subject I have not seen discussed in existing caregiver material.

A great “Thank You” goes to Sally H. McNeal, whose many years of teaching high school English enabled my composition to pass muster. She found multiple corrections in punctuation and grammar that saved me enormous embarrassment and chagrin. She had numerous suggestions that hopefully make your reading more lucid. Though she has had no experience with Alzheimer’s, her experience with inept authors was truly invaluable!

Louis H. Zbinden was most kind and generous of his time to review my original manual after grammatical corrections were made. He made several helpful and important suggestions, which were subsequently implemented. His support and affirmation is deeply appreciated and welcomed.

There are several others who have been most helpful and informative in the past, though they not only wished to remain anonymous but chose to defer contribution because of the anguish that it would restore. I give thanks to them and respect their desire to not turn back the pages of history to the darkest period of their lives. They choose to let some memories remain dormant. Bless Them!

## BACKGROUND

According to a 2016 American Alzheimer's Association report, Alzheimer's disease represents 60-80% of the dementia patients in the United States and the numbers are growing rapidly. While much has been and is being written on the disease, little focuses on the huge cadre of non paid spouses, children, relatives and friends who represent the bulk of dementia caregivers. The report estimates that 15.9 million persons are serving as caregivers: a huge number of unrecognized heroes! Specifically, children represent 55% of those caregivers, spouses and partners 15%, other relatives 23% and friends 7%. Seldom is anything written about the great trials and sacrifices of those caring for Alzheimer's and dementia patients. In addition to the mental and emotional stress, caregivers incur financial loss, some due to costs incurred such as transportation. The report further indicates that 48% of caregivers cut back on personal spending, 43% reported a reduction in savings, 30% tapped their savings account, 20% spent retirement savings, 15% borrowed money, 13% sold assets and 5% had to borrow money to serve their patients. What a remarkable commitment of self and one's finances! Many of these servants had no choice, there were no options, no alternatives. You may be included in this group of caregivers, a large universe of committed patrons willing to help others for no compensation and under the most onerous of conditions. You will need assistance of various means, and hopefully, this manual will be a major contribution to your efforts and make your service more tolerable.

## FOREWORD

For most of us, there is little or no preparation for the profound confrontation with dementia and Alzheimer's disease. Whether in a spouse or parent, it progresses slowly and all too often friends and family members are late in noticing the subtle changes in behavior that finally results in the patient being diagnosed. That reality is a major contribution in my desire to help those who are facing the problem, either as a spouse, child or caregiver. Regardless of the circumstances, caring for a dementia patient is an overwhelming challenge and obligation. To many of us who have served as a caregiver to a dementia patient, it is the most difficult and stressful undertaking ever experienced. Unfortunately, there are no shortcuts or easy solutions. Caregivers are "put to the test" of their limits. Hopefully you will find herein a few suggestions that will be helpful and a few things to avoid to make your task less difficult. A serene caregiver will greatly contribute to a calmer patient. Support groups, current books available and occasional articles are helpful, but I found them inadequate in helping me reduce stress and the emotional pressures encountered. My experience exposed several topics never discussed in support groups and never was there the mention of anything spiritual.

Little has been written specifically focused on how to lessen the stress suffered by the dementia caregiver. This guide is not intended to be a primer to understanding Alzheimer's disease but rather to provide a few meaningful ways to make the job of care

giving less onerous and life more pleasant for both parties. The title of this manual is purposeful. An Alzheimer's patient becomes a stranger in that their behavior, likes, dislikes and actions change from what we have previously known and lived with in prior years. Regrettably, we cannot predict nor anticipate patient behavior, which implies we are now dealing with a stranger; a person we do not know. Yes, the appearance may be familiar, perhaps some habits and routines continue in the beginning, but as time goes on the patient eventually will become a complete stranger! The caregiver must embrace an attitude of warmth and hospitality toward the patient, much as they would do in welcoming a new acquaintance. Hence.....“Welcome Stranger”.

Concurrently, we the caregiver becomes a stranger to the patient! This transformation is one of the most subtle and difficult adjustments confronting the caregiver. No longer does the patient express warmth, gratitude or appreciation for assistance and eventually the patient may actually become belligerent and hostile. Intimacy will evaporate and the caregiver is performing chores for which there is little or no gratitude expressed. Thank you will disappear. This is a wrenching experience and environment in which to serve. It can quickly lead to resentment and hostility by the helper. The caregiver must make changes in order to respond to the stark changes in the behavior of the patient.

The inter relationship that worked well for years disappears and in its place is behavioral change that becomes impossible to foretell or anticipate. The

caregiver must realize that the patient's unreasonable actions and behavior are not deliberate, nor discretionary, but due entirely to the disease. This realization must not be overlooked as it otherwise contributes to the frustration and stress of caregiving.

Most anyone experienced in boating is familiar with the phrase "man overboard." The universal response to the yell is to immediately locate a life preserver and toss it to the person in distress. The preserver may not alter the duration the individual is in the water, but it will certainly add comfort, security and relief to the stranded person! It is hoped that this manual will do for the dementia caregiver what a life preserver does for a person possibly struggling for his or her life. Hopefully this manual will be used often for that purpose.

1 Cor. 15:58 Remain steadfast... **"Because you know that your labor is not in vain."**

## DISCLAIMER

My tenure as an Alzheimer's caregiver lasted just under five years. It abruptly terminated on March 10, 2014, just six days following my dear wife being diagnosed with colon cancer. Interestingly, Kendall never complained of pain or feeling ill prior to her diagnosis. In the preceding several months I noted Kendall resting and sleeping longer and a decline in her mobility. She was much more deliberate and cautious in her walking, especially at night in low light conditions.

As a result of her unexpected demise, I was spared the burden of placing her in a rest home and the accompanying difficulties and emotional problems it creates. My several friends who did place their spouse in a nursing facility did so with great remorse and difficulty. That is a decision that most caregivers forgo too long as acknowledged frequently by physicians. It is a "damned if you do and damned if you don't" decision.

I was blessed not having to make such decision. Consequently, I am not able by experience to comment on the difficulties associated with placing a mate or parent in a facility. Those who have all remarked on the enormous stress of visiting a loved one in a nursing home and being greeted with a *who are you?* question. This perennial conflict lasts I am told to death of the patient.

Additionally, as a caregiver to my wife, I did not experience the multiple issues often faced among

siblings as they focus on caring for a parent. This subject is among the most frequently discussed in Alzheimer's support groups and is mentioned in a subsequent topic.

In no way does this manual purport to include all issues and difficulties that you may encounter. Every patient is different, as is every caregiver. You will experience different circumstances and with different outcomes, but there are similarities and this manual attempts to respond accordingly. Things to do and things not to do.

Though no research, study or survey was conducted, it is the opinion of the author that those spouses, children and other family members who spent years and decades with the patient in pleasant, harmonious and tranquil conditions will experience more challenges and find the role of care giving more difficult than other caregivers. They have not experienced the wild, unpredictable and sometimes explosive behavior so frequently accompanied by some Alzheimer's patients. This publication is especially directed to those new, inexperienced caregivers.

## PURPOSE

The foremost purpose of this publication is to help reduce the stress and tension encountered by the unpaid dementia caregiver. It is hoped that the suggestions found herein will contribute to that goal. While this manual focuses predominately on spouses caring for another spouse, or child caring for a parent, it is applicable for other situations. Recent studies have reported that roughly 2/3 of Alzheimer's caregivers die before their patient dies, which is stark confirmation and testimony to the enormous stress imposed on the Alzheimer's caregiver, especially if a family member.

This guide is intended to supplement books on Alzheimer's such as **The 36 Hour Day** and others. They offer helpful information on the disease and patient but frequently without much helpful emphasis on what to expect emotionally and how the caregiver should respond to unexpected behavior. It is hoped that this manual will strengthen the caregiver and spare him or her from some of the stress and rejection we all experience. There are a few actions a caregiver can do to alleviate conflict and several to avoid which will make a material reduction in stress and tension. They will be beneficial to both parties. All too often the caregiver may be a contributing factor to distasteful behavior by the patient. Alzheimer's patients cannot be dealt with in a rational manner, as they lose cognitive thinking ability.

# DENIAL

It is frequently said that Alzheimer's is one of the most insidious of all diseases because it typically progresses slowly and is also difficult to diagnose. Family members are most often the last to recognize or notice its symptoms. Spouses are generally the last to perceive behavioral changes and when the formal diagnosis is rendered, a spouse is the last in recognizing and accepting the decision.

Consequently, it is common for spouses to both question the validity of the doctor's decision and or accept the realization that their mate now has a dreaded illness. The action frequently is denial by the spouse. Some may ask why me? Others may be embarrassed, protective or reluctant to disclose to others that their mate is inflicted with the foreboding disease.

What to do?

Since a mate is so often the last to see the changes, it behooves them to accept reality sooner than later. Friends and acquaintances are most likely to have earlier recognized behavioral changes and may even anticipate confirmation of some form of dementia. Little if anything is gained if the caregiver denies the diagnosis. The disease does not go away, and the sooner the caregiver accepts the decision the better. Also, acceptance is good for the soul.

Informing family members may be the most difficult task. Children can be the most skeptical of all. My

good friend Harold (pseudonym) had a very tumultuous experience with his adult daughter, who could not believe her mother had dementia. Daughter lived hundreds of miles away. In an attempt to convince her of her mother's dilemma, Harold invited her to come home to Florida to visit firsthand. The first two days were remarkably blissful and pleasant. So much so, that Harold thought his wife was actually improving and worried his daughter would not observe any hostile or belligerent behavior. On day three Harold and his daughter were sitting side by side on the living room couch when wife, walking downstairs, saw Harold and daughter together. She accused Harold of hosting a floozy and went into a rage, failing to recognize her own child. Daughter returned upstairs and called the village police. Coincidentally, Harold downstairs did likewise, fearing imminent violence. It took the police to restore peace. Daughter returned home, having observed several subsequent outbursts. She finally accepted the fact that her mother had Alzheimer's and for the first time appreciated the difficult conditions in which Harold was living.

Many Alzheimer's patients are able, while in early stages, to hide their illness when meeting other people. An example happened to a dear friend. His wife was the youngest of three children and when in her early seventies, was diagnosed with Alzheimer's. Her siblings questioned the diagnosis and claimed they saw no evidence of dementia in their letters and phone conversations. My friend was unable to convince them otherwise. Eventually one of her older brothers made a visit and after a lengthy lunch at a popular restaurant, reaffirmed that his sister was just fine. As the three

were driving home together and after a pause in the conversation, wife turned to her brother in the back seat and inquired: “Are you my father?” My friend nearly wrecked his car but suddenly regained creditability with his in-laws!

## WHAT TO EXPECT

One word can describe what to expect with an Alzheimer's patient.....CHANGE! Change brings surprises, most of which are stressful and some may be volcanic! The period from diagnosis to eventual death is one of constant change, mostly for the worst with some possibly brief periods of stability or modest improvement. The decline in mental acuity is inherent with the disease. Memory constantly declines. Rational thinking is replaced by irrational and strange behavior. During much of that period of time, the caregiver must also change in order to best adapt to the new and unpredictable behavior. This is not only a challenge but a necessity. If the caregiver is a family member, it becomes a difficult task to respond to constantly changing new demeanor and habits. The spouse essentially becomes a stranger, requiring new responses from you, the new caregiver.

Irrespective of your relationship to the patient, the caregiver recognizing a role reversal is mandatory. Whether the patient is a spouse or parent, it is incumbent on the caregiver to recognize that he or she must become the decision maker. It is especially difficult for a child, who for the first time must tell the parent what to do, for an only child this is particularly difficult! Parents likewise, are most likely to resist the role reversal as well. Even spouses find it difficult to deal with this issue as they are continually challenged to make all of the decisions, oftentimes with opposition and resistance.

This role reversal may be one of the first events testing the caregiver's patience and authority. It will not be the last! The caregiver must recognize that a long period of mental decline lies ahead. It will become evident that the dementia patient loses the ability to think rationally. For couples who have happily lived their lives together and shared decision making, this proves to be a difficult transition. One can no longer anticipate the patient's actions because they are unpredictable. They will get angry or perhaps hostile on a moment's notice to something they previously took for granted or accepted. An Alzheimer's patient becomes childlike in many respects. Being unable to anticipate sudden outbreaks is most stressful for the caregiver.

The caregiver must realize that two major behavioral changes by the patient will take place. The foremost change is that of rejection. Count on the fact that much of what you, the caregiver, does is done without receiving signs of thanks or appreciation. The absence of a familiar "Thank You" will be quickly noticed. This is a formidable behavioral change in most cases and is increasingly stressful for the caregiver. It is helpful to always remember that your patient is not able to render appreciation or act in a logical or coherent manner because of the Alzheimer's disease or dementia. The second and perhaps less likely change is the evaporation of intimacy. My caregiver friends concur that their afflicted spouses lose their capacity and interest in most all expressions of intimacy: touching, hugging, or kissing. For happily married couples this is a major adjustment, to which the caregiver must adapt. One must not show irritation or disappointment

with a failure to respond to a kind gesture or hug. Loss of libido may also occur and the patient may show no interest in sex or actually rebuff any attempts. This adds to the caregivers feeling of isolation and rejection.

The American Alzheimer's Association claims that 6 in 10 persons with dementia will wander. This obviously becomes a serious issue if the patient possesses this tendency, especially if inclined to do so at night. If so, it requires close supervision during the daytime and some means of security to prevent wandering during the night, when the caregiver is asleep. Locking doors and safekeeping the keys is mandatory in such situations. This condition adds to the stress of caregivers and expands the caregiver's responsibilities. It may result in being unable to leave the patient alone in the house, even for brief periods of time.

An example of change occurred with my mother-in-law, Louise, a deacon and elder in her church for many years. For some period of time prior to her diagnosis with Alzheimer's and when dining in public, she would frequently compliment the parents of children if they displayed good behavior and etiquette. Over the years she made many parents quite pleased. Not long after her diagnosis a noticeable and embarrassing change took place. When at a restaurant if she observed an unruly, loud, undisciplined child, on the way out she would stop by the table and tell the parents what a well mannered, charming child they had! The worse the behavior the more praise given and given in a sincere manner. She could not distinguish good from bad. This happened so often that on occasion I would hand the

derelict parents a tab of paper which said, "Louise has Alzheimer's. Thank you for your understanding." This at least made me feel better.

One of the most difficult adjustments required of a caregiver is the need to tell "white lies" to the patient. Happy marriages and relationships are built on truth and honesty. However, it behooves the caregiver to depart from this doctrine in order to maintain harmony with the patient. Truth is not always a virtue with Alzheimer's patients. This will be discussed in greater detail in subsequent pages.

Lastly, CHANGE brings STRESS to the caregiver. You must be prepared to be confronted frequently with stress. Constant stress of one type or another, most likely more stress than ever before experienced. It comes unannounced and unexpected. Much of the caregiver stress is the result of not being able to predict when, what and why. What generates a furious reaction today may not do so tomorrow. It comes and comes without a clue or inkling. Be prepared!

A classic example occurred with my lifelong friend Bob (pseudonym). He and his wife Ann lived in an exclusive community. Ann was a most refined, genteel and gracious lady. Several years after Ann was diagnosed with Alzheimer's, Bob was in their dining room and noticed water running down the chandelier. Ann was bathing upstairs. He dashed upstairs to find Ann, stark naked, standing by the bathtub, mesmerized by the profuse waterfall cascading over the tub! Gallons of water going everywhere, causing the plaster ceiling in the dining room to crash, damaging rugs, carpets and the upholstered dining room chairs and table.

Thousands of dollars were spent correcting the damage. Not more than several months later the same situation occurred again, but this time no restoration was performed. The dining room was essentially declared “off limits”. Between the two events Bob began receiving notices in the mail of unpaid bills. How could this happen? He now was paying all family bills. His mail was delivered through a mail drop by his front door on to the floor of his entryway. Upon investigating he fortuitously discovered unopened bills in Ann’s cereal boxes! He had to surreptitiously relocate the mailbox outside and change the lock on the front door to keep Ann from intercepting the mail. You may not experience similar examples of unpredictable behavior but be prepared for surprises.

At some point during your journey of care and possibly on numerous occasions, expect to feel “ground down”. There will be moments when you think there is no solution to your problem(s), or no relief or help in sight. You will feel hopeless, as though there is no way out nor means to change your situation. No door to exit your circumstances. It may be the constant rejection, or incessant questions or repeated refusals to do something. You must remind yourself that the patient is not purposely trying to make your job stressful, it comes with the affliction; including doors slammed, things thrown or oaths uttered. Yes, on occasion you will feel “ground down”!

Fortunately the patient does not exhibit deteriorating behavior every day. There will be periods, if not several days, when the patient seems to improve with perhaps better memory and normal behavior. It could

easily manifest itself when a child or grandchild appears. It could occur at a party or meeting with others. If the occasion is to celebrate a birthday or anniversary or a wedding, it is likely the caregiver will hear several comments suggesting the patient has made progress or seems like his or her old self. Somehow and with really no prior indications, the patient may occasionally rise to the occasion and exhibit few signs of Alzheimer's. Of course, be pleased but be prepared for a change, for it will be forthcoming. But when?

1 Cor. 15:58... Stand firm... **“because you know that your labor in the Lord is not in vain.”**

## ROLE REVERSAL

Irrespective of your relationship to the patient, recognizing a role change is mandatory. This is perhaps the single most important issue to confront early in the onset of dementia and Alzheimer's. Even if the patient is a spouse or parent of many years, it is incumbent of the caregiver to recognize that they must accept the need to become the decision maker: i.e. "the parent". This will be particularly difficult for a child to accept or even a spouse, who has shared decision making with their partner, sometimes for decades.

This new responsibility requires intervention or control over such important issues as driving, writing checks, credit cards, cell phone, computer, shopping and ultimately cooking and usage of stoves and microwaves. It is especially true in administering drugs and medicines.

It is generally accepted that curtailing the use of an automobile is the most formidable and continuous single issue faced. The auto is a vehicle of independence and a symbol of one's freedom. Taking vehicle keys away from a parent or spouse is probably the biggest of issues confronting the caregiver. Once a person is diagnosed by a doctor as having dementia or Alzheimer's, it becomes a priority of the highest importance to restrict the patient from driving. The potential financial liability becomes too serious to disregard. The caregiver should request the physician to write a letter to the patient informing him or her to

refrain from driving. Anticipate rebellion, anger and hostility because it will be forthcoming. This is a major burden for the caregiver or other family member. You must expect the patient to accuse you of collusion and conspiracy! You must repeat over and over that it was not your idea or doing. This is one example of where the caregiver must cast aside their code of ethics and tell a “white lie” in order to maintain harmony and pleasantness! There will be other occasions. Once keys are taken away or hidden, be sure to remove the patient from the auto insurance policy, but only when they no longer have access to a vehicle.

## LITTLE WHITE LIES

For generations parents, schools and churches have told us at an early age to always be honest and tell the truth. George Washington and his cutting of the cherry tree was a story we heard many times and throughout life most of us have attempted to abide by the good advice. Alzheimer's caregivers are challenged to depart from this high principled conduct, though with stunning results. The payoff however, is not without stress...especially at the outset. Telling white lies is one of the several significant challenges one must make as a caregiver. Telling a little white lie is not intended to harm or mislead the patient, but purposeful in avoiding a likely incident or explosive reaction. It is stressful to fabricate a falsehood to protect harmony and calm. The good news is that the benefits are quickly realized and appreciated by the caregiver, and the patient is enabled to remain calm. One quickly realizes that much is gained by discretely telling white lies.

Leaving the house together is a common source of major difficulty. The caregiver will be asked *why are you just now telling me?* or *Why did you not tell me earlier?* You cannot say that you have told them earlier, which is the truth, for it will spark a hostile reaction, if not explosion. One must tell a little white lie to maintain tranquility. You, the caregiver, must be the party at fault at all costs. A little white lie will save you! Telling your patient *I failed to tell you earlier, I am so sorry*, is a most difficult and troubling assignment, but it must be done to maintain harmony. To tell your

patient that you have reminded them several times yesterday and twice this morning that a therapist is coming to the house at 10:30 may be akin to holding a live hand grenade. Do not make that mistake!

Expect to be asked multiple times... *Where are my glasses* or *Where is my book?* Of course the first instinct is to say *You had them last*, but that is NOT the thing to do! It places blame on the patient and reminds them that their memory is failing. The response should be... *I saw them just moments ago*, or *I do not know, but will help you locate them*. The caregiver will quickly realize the value of white lies and fortunately the apprehension associated with telling a white lie will quickly disappear. The benefits are enormous and one of the most productive things a caregiver can do. Expect to do it often.

## PATIENCE

The most formidable change imposed on an Alzheimer's or dementia caregiver is the need to materially increase his or her patience. Webster's defines patient as....*able to remain calm and not become annoyed when waiting for a long time or when dealing with problems or difficult people.* Patience is defined as..... *the capacity, habit or fact of being patient.* The caregiver must both become patient and constantly practice patience. He must constantly practice patience as never before! One's patience will be tested and retested in a multitude of ways.

One of the most common areas of patient resistance is preparing to leave for an appointment. Suddenly the patient may refuse to leave and the excuses can run the gamut. It might be the inability to find the proper attire and the need to try on multiple items of clothing for the occasion. It might well be that the patient complains of an ache or pain that precludes their departing from the house. Or it could be a simple ....*I don't want to go* or an emphatic .....*I am not going!* Even if there is no formal resistance in leaving, doing so under the very best of conditions will take considerably more time preparing to leave than in previous months and years! To some this is perhaps the most stressful of all the events a caregiver must confront.

Another common issue is that of taking medicine. The caregiver must be prepared to hear *I don't want to take those pills!* It will surely occur and without any notice.

It is quite likely that no amount of explaining will shake or alter the refusal. If so, the caregiver must accept temporary defeat and try again later. It is better to step backward than push the patient into a period of combativeness. My Kendall was one of those people who had a great dislike for taking pills of any description, which may have been a carryover from childhood. She only occasionally tolerated an aspirin or Buferin for a headache. When the neurologist first prescribed Namenda for her Alzheimer's it started a daily battle that we both found most undesirable. After several months of conflict, I mentioned the issue to the doctor and fortunately a patch was prescribed to replace the pills. That did not solve the matter completely, as other pills were periodically needed, but it was a big help.

In retrospect, one of the early indications of Kendall's Alzheimer's went unnoticed. She was a consummate cook and for years enjoyed hosting dinner parties. Some years before her diagnosis she suggested we go out for dinner or bring in food for dinner, which fortunately our budget allowed. Our kitchen was closing when we were told of her dementia. She participated in the decisions as to where to get dinner. Her last several years were a different story. Invariably when I asked her choice for dinner she would reply ....*anything is fine with me*. The more pressed to get a suggestion, the more resolute the answer, so I would make a suggestion, to which she would say....*that sounds good*. Frequently when we arrived at the restaurant, she would say....*I do not want to eat here!* My question: *where do you want to go?* Her response: *anywhere*. So, dinner rather quickly became a chore

and a source of irritation to me. Again, my patience was being tested. I did get some relief when I discovered that when I told her that Geraldo, the owner of one of her long favorite restaurants was expecting her, she agreed to enter. So I got to know the managers of several other favorites, but occasionally she would say no deal. Food to go became our main source of dinner meals during the last year of her life.

There are countless issues most every day that test one's patience and those above are but just a few of the many. Your major areas of conflict may well be different but no less taxing. We must ask God many times daily for His support and strength to accommodate the patient.

**Eph. 4:2... “be patient, bearing with one another in love.”**

## DO NOT SHOW EMOTIONS OR ANGER

It is impossible to anticipate when and what will cause an outburst of anger. It is important for the caregiver to remember to refrain from correcting the patient or disputing something said, done or not done. It is best to say, *"I am sorry. I forgot to tell you or I was just called or It just happened.* Be patient! At all costs do not appear angry, surprised or agitated for it will be transmitted to the patient and become fuel for an explosion.

The caregiver most generally holds the key as to whether the patient is content or whether the patient is agitated. An agitated caregiver will produce an agitated patient! At all costs do not show displeasure with something said or done by the patient. The caregiver must not react to any act of rejection by the patient. This is admittedly difficult but so important. The patient does not want to make mistakes and mistakes should not be recognized.

Rejection is frequent and should not be responded to by the caregiver. A gasp or any expression of frustration is all that is required for an outburst by the patient. Admittedly not all outbursts are caused by the caregiver, but it is incumbent to not respond to flare-ups. Patience is again being tested!

Patients generally become more at ease with current surroundings and routines as time goes on. Changes in either are likely to become increasingly difficult for the

patient and for the caregiver. This is particularly true when making arrangements to make an appointment or prepare for a visit. It is events like this that the caregiver must be prepared for the worst.

## TRAVEL

Traveling may well be the most difficult and potentially exasperating activity a caregiver encounters while caring for a dementia patient. Travel is change and change is what so often ignites explosive behavior. Change in location and surroundings are more formidable than change in routine or other changes. Preparing for a trip is in itself a stressful experience. The selection of clothing, footwear, pills and personal items contribute to a stressful event. One major concern revolves around food and bathroom facilities en route, especially if traveling by air. A change of planes may become a serious issue. Not all airports provide personal bathroom facilities, thereby forcing one to use the large public facilities. On a trip from Newark, NJ to Florida, Bob and his wife Ann had a change of planes in Atlanta. While in Atlanta and before departure to Florida, Ann went to the ladies room and due to her propensity to roam, Bob kept a sharp eye for her emerging. A strike out! After an extraordinary period of time, Bob went to the entrance and attempted to engage a lady to assist in Ann's return. No one offered. The flight was being called and after approximately 30 minutes Ann emerged and their flight departed without them! There is not much one can do to prevent this. Some airports have individual facilities, primarily designed for wheel chair passengers that accommodate two people, though many airports do not offer this facility. How the patient will react at the final destination is another issue. Much will have changed and is different and it is quite possible the patient will want to return home and return

home now! One must be prepared for repeated requests to return home.

Traveling with a wanderer, and that is roughly 60% of Alzheimer's patients, is especially precarious. One dear friend whose wife wandered, especially at night, when away from home, had to place a chair in front of the bedroom exit door and on top place any object that would make noise if disturbed. One cannot leave a wanderer unattended, whether at the grocery store, Wal-Mart or airport. They have excelled in disappearing and some even thrive on doing so.

My dear Kendall would drive me crazy as we took our 2 hour drive to Fayetteville, requesting we stop en route to buy groceries, even though our SUV was loaded with food for the weekend. Repeatedly she would insist that she needed to buy several quiches, though our freezer was loaded with quiches and there was not room for another. It was incessant diatribe and always difficult to deflect. What in earlier years was an enjoyable opportunity to visit turned into an incubator of great stress and friction.

In later years of Ann's illness, Bob fortuitously bought her a small child's teddy bear, which became a treasured friend. He made sure it went with Ann any time they traveled or went to a restaurant. It served two valuable purposes. One, it became Ann's best friend and gave her immense comfort, especially when away from home. Bob would say *don't upset Teddy* and she would settle down. Secondly, it served to indicate to others that Ann had an infirmity and perhaps unusual behavior. It was most helpful and it would

mollify her quickly. On occasions Bob also treasured  
Teddy Bear!

## IMPORTANT DETAILS

Caregiver behavior and communication with their patient plays an enormous role in influencing patient demeanor. The principal component of both successful salesmanship and patient care is to maintain eye contact with the respondent while speaking. Many of us have a habit of multitasking, such as reading the newspaper and simultaneously conversing with someone. Much of our conversation with family members is subjected to this practice. Regrettably it does not work well when caring for an Alzheimer's patient. In fact, it has a deleterious effect on the patient. Constant eye contact when conversing is a helpful elixir to the patient. The caregiver must avoid any signs of being hurried and constant eye contact when speaking signals attentiveness. Ann, Bob's wife, was a masterful wanderer. When Bob realized that he no longer could leave his wife at home when he went to the nearby barber, he decided to go to Ann's hair dresser for haircuts, thinking the surroundings would be helpful for her. As soon as Bob was in the barber chair and his back facing Ann, she would bolt for the door. The only solution they found was to have Ann sit in the adjoining barber's chair, turned so that she could see Bob's face. Additionally, they could occasionally converse, which contributed to Ann's staying put.

Body language is also critical. The caregiver must avoid distancing himself/herself from the patient when speaking. To make any gesture to step away from the patient during a conversation will likely be interpreted as rejection or disinterest. Any action by the caregiver

suggesting disapproval of something said or done will likely provoke the patient. To stand in a position suggesting impatience or a desire to move on will not be well received. It is well for the caregiver to remember that the patient has a declining sense of time and a body movement that suggests impatience will agitate the patient. Stepping closer to the patient also gives the caregiver the opportunity to say *I love you or what may I do to help you*; both pleasing to the patient.

## A MUST DO LIST

The caregiver must recognize he or she will increasingly be dealing with a stranger! A person whose behavior and conduct is foreign and unexpected. Habits, priorities, likes and dislikes will always be changing, without the ability to predict responses. The more the patient is treated as a guest, the more calm and contented that patient will be. A tranquil patient will materially contribute to a calm caregiver and a calm caregiver will equally contribute to a tranquil patient! Consequently the caregiver must adapt to new needs and wants. A spouse or child caring for a dementia patient needs to change as much as the patient changes, although in different respects. The caregiver must remain cordial and understanding at all times, regardless of the circumstances. This is asking a lot, when books are thrown, doors slammed, oaths uttered and defiance expressed. The caregiver must remain above the fray!

One of the most important “must do” is to tell the patient that you love him or her and do so often! Not only does the patient generally appreciate and welcome the affirmation, inevitably those caregivers who lose a family member to Alzheimer’s regret not telling them more frequently that they love him or her. This admittedly is difficult to do when so much of the time is fraught with frustration and irritation. Once gone, the caregiver is most likely to forget the many instances of stress and focus on the loss, wishing that more had been done to support and appreciate the lost patient. Regardless of how often “I love you” is told to

the patient, the caregiver will forever wish that he had been more understanding and expressed his love more often. This is needed therapy for both the caregiver and the patient. This is something that cannot be overdone! Even those who have lost some or all of their intimacy seem to appreciate an “I love you” and a hug. I love you serves both the caregiver and the patient and should be said multiple times a day.

Care giving spouses or children must at some point take control or monitor family finances. This may result in closing savings or checking accounts, canceling or limiting credit card activity, and limiting access to securities accounts and ATM machines. At age 77 the wife of a dear ex-banker friend was diagnosed with Alzheimer's. He shared with me an unfortunate story that occurred soon after his wife was diagnosed. For many years they each had separate property and individual brokerage and bank accounts. For all of their nearly 50 years of marriage, they had been prudent in their spending habits. The husband only occasionally reviewed his wife's bank and brokerage statements. Suddenly one month he noticed several \$2,000 - \$8,000 withdrawals in his wife's bank statement. Before questioning his wife, husband reviewed several previous bank statements and discovered similar activity in those months also. When questioned, wife became immediately hostile and angry, rebelling to the intrusion into her affairs. Turns out wife was the victim of several major scams. Wife had been transferring money overseas to help stranded U.S. vacationers, who needed funds to return home and she also provided good faith deposits

needed to repatriate funds to the U.S. Well over \$50,000 had disappeared in a matter of just several months. Wife resented husband's efforts to halt the activity and before he could cancel her cell phone, comply with necessary paperwork required by the financial institutions, another \$50,000 disappeared. Over \$100,000 of dearly needed retirement funds had evaporated, accompanied by numerous hostile confrontations. In earlier years wife would have been the very last person to have spent many thousands of dollars of retirement funds for anything! Oh, how some people with dementia can change! Caregivers must closely monitor family financial activities and statements, even if it brings resistance and criticism.

Another "must do" is to NEVER suggest or imply that the patient forgot something! When asked by the patient *why did you not tell me before now*, you should reply..... *I forgot to tell you. I am sorry.* NEVER say *I told you yesterday* or *I handed it to you 30 minutes ago*. Never make the patient feel guilty, irresponsible or forgetful!!

It is strongly suggested that as a new caregiver you make contact with one or more acquaintances who likewise are caring or have cared for an Alzheimer's patient. Should this prove a difficulty, one should contact their church or synagogue for assistance in locating another church member involved with dementia care giving. Every caregiver experiences difficult obstacles and issues and each can be of immense help to one another, the more contacts the better.

## WHAT CAN GO WRONG

Two resources are required in care giving for an Alzheimer's patient... Time and Money. The patient will require an increasing amount of caregiver's time as they decline and lose their independence. This may be a slow process and will likely catch the caregiver "off guard". Suddenly the caregiver feels overwhelmed, not knowing what to do next. It is likely to be accompanied by more patient rejection and resistance. For those who have few alternatives, it becomes incumbent that they both seek and receive relief. One's patience begins being tested and that challenge becomes an overwhelming task. The need for spiritual support arrives! Prayer and a closer relationship with God will be of immense benefit. As with many of one's needs, our Lord will provide comfort and strength if we pray and seek God's intervention. He will always enable us to rise to the challenge if we petition in sincerity and faith in Him.

All too frequently and for a myriad of reasons, one finds himself or herself providing an overwhelming amount of time devoted to a patient. Other family members may not be physically available or financially able to contribute to the patient care. In cases where other family members are able to make contributions and do not do so, it invariably adds enormous stress to the caregiver. Much of the time and dialogue at Alzheimer's Support groups is devoted to this very issue. All too often siblings will choose to remain passive and indolent, while one sibling provides the overwhelming care and attention.

What can go wrong? ..... YOU!

You can make several mistakes. The foremost mistake is to fail to acknowledge that you need to alter the manner in which you relate to the patient. It is disastrous to believe that constructive criticism of the patient is helpful. It helps not the patient and in turn backfires on the caregiver if criticism or corrections are rendered. Nothing is more destructive than asking the patient *Why did you do this or that?* or *Did you forget that we were to have dinner with the Smiths?* You must compromise honesty sometimes in order to maintain tranquility. One must never say that something was given to the patient and the patient is the one that lost or misplaced the item!

Dementia patients lose the concept of time. Preparations for leaving home for a doctor appointment must begin much earlier than previously, and if the caregiver shows any sign of anxiety over leaving on time or being late it only backfires and leads to explosion.

Departures are almost always stressful for the patient. If the caregiver adds to the stress by hurrying the patient, it spells TROUBLE! Start departures early and if successful, arrive at your destination early. The best of alternatives!!

# RULES

When interacting and caring for your Alzheimer's patient, there are three basic, but often difficult, rules to remember:

## Rule #1

NEVER put the blame on the patient. The most important of all rules is to never tell the patient, *I told you yesterday and again at breakfast today that we had a doctor's appointment at 11:00 today*. This is an invitation to a hostile and rebellious response! As previously mentioned, "white lies" become necessary and helpful in caring for a dementia patient. A truthful statement is not what the patient wants to hear and will likely create a firestorm of reaction. It behooves the caregiver to say, *Honey, I forgot to tell you earlier that we have a doctor's appointment at 11:00 and I am so sorry. I made a mistake. I will try harder to remember next time*. This initially will be difficult for many caregivers to accept but it is immensely helpful and effective

## Rule #2

NEVER raise your voice, criticize, or express anger. Be gentle! Refrain from showing displeasure or irritation. This will only agitate your patient and create a corresponding reaction in return. At all costs do not appear impatient or surprised as it could be the fuel for an explosion. Your outward emotions must remain suppressed. Alzheimer's patients have little awareness of time. When preparing to leave for an

appointment, one must allot an extra amount of time to avoid such a confrontation.

### Rule #3

REFRAIN from correcting the patient or disputing something said, done or not done, and never argue! The caregiver must accept the fact that it is impossible to anticipate when and what will cause an explosion of hostility. It is best to say, *I am sorry I forgot to tell you* or *I was just called* or *It just happened*. When asked, *Where are my glasses?*, it is intuitive to want to say *I handed them to you 20 minutes ago*, but the response should be *I will help you find them* or *I misplaced them, so I will go find them for you*.

## THE THREE NEEDED P's

### PATIENCE

The most compelling behavioral change required of the caregiver is to vastly increase one's patience. Patience is the antidote to bizarre, stressful and unexpected behavior! The caregiver must constantly remind himself to exercise patience, to refrain from any criticism, correction or expression of disapproval. A cool, collected caregiver will contribute greatly to a calm patient. When focusing on patience, the caregiver will experience an element of much needed relief and less stress.

### PERSEVERANCE

Merriam-Webster defines perseverance as: *the quality that allows someone to continue trying to do something even though it is difficult.* It will be the rare caregiver that on one or more occasions will not have the desire to throw in the towel and wish to quit. In fact many, if not most caregivers will experience the feeling frequently. The stress can be overwhelming and on occasion relentless. One should once again tell one's self that the patient is infirm and not in control of his or her behavior. During those periods of persevering, it is important to seek God's support, which leads us to the third **P** the **P** that is omitted from most everything written to assist caregivers.

## PRAYER

Virtually all caregivers will at one time or another feel the need for support and help. Some may be fortunate to have family members who can participate and bring relief. Regardless of the circumstances help and support is needed and needed badly. It is incumbent of caregivers to strive for a closer and stronger relationship with his or her God. Sincere and frequent prayer to God will bring much needed relief and comfort to those who petition in good faith. God's assurance, love and care will be extended to those who truly seek his presence and intervention. Since there is no medication that currently halts dementia, Alzheimer's caregivers experience a greater burden and there is relief to be found by prayerfully seeking God's intervention and care. He brings relief and support to those who place their faith and trust in him. He may not eliminate problems and stress, but He does enable us to better handle and respond to our assignment. We can pray. . . *please make me willing to be willing*. Praise the Lord!

## GOOD INTENTIONS GONE ASTRAY

As pressure builds on caregivers, which is inevitable, we try to cope and help the patient. Not every effort helps to satisfy the patient or make life better for either party. Often good intentions are rejected or rebuffed. An early example of this involved my wife and my mother-in-law, Louise. When Louise was no longer capable of living at home with assistance, my wife, Kendall, with great reluctance placed her in an assisted living facility near us in Houston. It was considered the best such location in the community. Needless to say, Kendall felt enormous guilt and remorse and thought it would be hospitable to bring Louise to our home several times a week for lunch and a visit. However, when it was time to return Louise to her new home, all hell broke loose. Louise would ask: *Why are you taking me home, I want to stay with you! Why can't I stay here?* Kendall felt she was rejecting her mother, and it was devastating. When they arrived at the facility, Louise would become mildly belligerent and state: *I do not like this place! Why can't I live with you? Why are you leaving me?* This routine occurred each time Louise came to visit and it took a very noticeable toll on Kendall's demeanor. It would take a day or two for Kendall to restore her equanimity. Then, it would be time to repeat the visits. Fortunately caregivers at the facility acknowledged to Kendall that not only did her mother quickly forget her visits, but she was noticeably restive after returning. I helped Kendall decide to stop the home visits and instead to visit Louise at her facility. It soon appeared that a weekly visit was optimal and Kendall was able to release an

enormous load of stress and guilt. A clear example of good intentions gone astray!

A major contributor to this manual, Harold, had a more humorous story. Soon after his wife was diagnosed with Alzheimer's, she began misplacing and losing her house key. Harold made duplicates but that did not solve the problem. So he decided it propitious to do away with keys and install a five button combination lock on their primary door of entrance. It was done at considerable expense and with high expectation. The five keys had to be punched in precise order to function. ALAS, wife was never able to remember the correct buttons and sequence, so his helpful idea proved a failure to both parties! Yes, it is possible for caregivers to try too hard to please and satisfy!

## SUPPORT GROUPS

Soon after my dear wife was diagnosed with Alzheimer's, many friends suggested I seek a support group. The American Alzheimer's Assn. was helpful and I located a longstanding group located conveniently nearby. Having no previous information or experience regarding such organizations, I did not know what to expect. Accordingly I anticipated that I would gather some good suggestions and ideas which would make my job of care giving easier and more pleasant. I left the first meeting with nothing of substance but continued to attend most monthly meetings for the next 18 or more months. After several meetings, I realized that the primary purpose was to give caregivers an opportunity to vent their frustrations and discuss their particular problems. Over the 18 months we had three different leaders from the local AAA, all professionally trained and all following a similar format. After several months it became patently clear to me that my problems seemed mild compared to most everyone else. Oftentimes the leader had to console sobbing members. I left all subsequent meetings feeling fortunate in that my problems seemed minor ...no physically belligerent events (though occasionally something was thrown at me), no problem with wandering at night, no destruction.

As I reflect on the monthly Alzheimer's support group meetings I attended, considerable time was spent on siblings caring for a parent. One frequent attendee was a middle aged woman with multiple siblings, some

residing in town and others living elsewhere. The lady was by default the chosen caregiver to her mother. Papa had died some years before and mother was living in her modest home alone. Mother had been diagnosed with Alzheimer's for a year or so and increasingly committed to the house. Mother also had a boyfriend neighbor who had been helpful and gradually interceded into caring for mother. Mother still retained her bank checking account as boyfriend performed more assistance in grocery shopping, bringing in fast food for dinner, etc. Relations between boyfriend and daughter became strained. Mother seemed to favor boyfriend and denied that he was taking advantage of her. Finances worsened, and daughter every month elaborated on the lack of consensus among her siblings. Daughter was in tears and obviously feeling great stress, frustration and anger. This continued month after month until mother was finally placed in a rest home.

The meetings were in retrospect quite sterile. During my experience I do not recall one instance of spirituality being discussed. No mention of prayer was spoken. No call or suggestion to seek God's help was offered or suggested. It did expose me to the multitude of problems confronting Alzheimer's and dementia caregivers, but I took home very little other than I was fortunate compared to so many others. If you need to expel frustrations a support group is of some benefit, but do not expect any silver bullets. Grief support groups at numerous churches do provide a much more productive service, though they focus on death and typically very little specifically related to dementia and Alzheimer's during a period of care.

Several months after the passing of Kendall, I decided to return to the AAA support group to give brief testimony to the need for prayer seeking God's intervention and help. It was well received. I returned for several subsequent sessions and while the leader supported my message, it was not within AAA protocol to engage in sensitive or possibly controversial subjects. So I stopped attending, realizing the need for a helpful manual for caregivers might be more helpful. That experience was much of my inspiration to help those besieged with a grueling task. My dear friend Bob, became a caregiver a year before me and was of immense help in directing me to God for guidance and support which was invaluable. A friend who has or has had experience with Alzheimer's may be helpful and should be sought.

## DEMENTIA DRUG TRIALS

World wide it is estimated that 47 million people have dementia and 9.9 million new cases occur annually. Alzheimer's patients contribute 60-70 % of those new cases. Longer life spans are contributing to the problem, and by 2030 the numbers are expected to double! The National Institute on Aging states that as of June 2017 there are over 150 Alzheimer's and dementia clinical drug trials underway in the United States and 70,000 Alzheimer's patients are needed currently to fill the trials. There is no "break through" drug more needed than that for Alzheimer's. Drug trial results have so far proven most elusive, and the several approved drugs currently available at best just slow the degenerative process for some of those patients.

At the time Kendall was diagnosed with Alzheimer's, the neurologist was participating in the clinical trial of Bapineuzumab, sponsored by two of the largest US pharmaceutical companies. She indicated that she thought some of those patients were responding, even though it was a double blind trial. The paperwork required to apply was daunting. When finally accepted, Kendall had strong second thoughts. But I encouraged her to continue. She was in the trial for 18 months, which consisted of a three hour infusion, MRI and cognitive tests every 90 days. Over the period of time there were multiple indications that suggested her disease had stabilized. Just short of 18 months in the trial, Kendall fell, bumped her head and broke her glasses. Soon afterwards her MRI indicated

a small hematoma and due to trial protocol, she was discharged from the program. That was a disappointment to both of us, though Kendall was quite relieved to dismiss the MRI, which she claimed was claustrophobic. Some eight months later the trial prematurely terminated because of missing its end points. In visiting with the drug trial neurologist, I was told there were numerous observations suggesting that Kendall had experienced noticeable benefits from the drug. We were grateful that she had been permitted to participate but sorry how things ended.

From this experience, I would encourage any caregiver to inquire of their neurologist if any drug trials are available and investigate accordingly. Drug trials are monitored assiduously for adverse events and any harm to the patient is quite unlikely. In retrospect, I think Kendall on occasion, found some satisfaction from both participating in the drug trial and in complaining about the MRI. Drug trial participants are sorely needed and positive results may possibly be attained.

## BEWARE

This topic is written especially for one who is caring for a spouse. It is particularly addressed to those of you who feel they have had a relatively stress free, happy and harmonious marriage, with love and boundaries; a marriage filled with politeness, respect and care for one another; a marriage which rarely experienced anger or rejection. If this description fits, you have been richly blessed and accepted. Life has been filled with joy and comfort but change is coming. You are likely to become a caregiver with stress and frustration. You will quickly perceive great changes in your spouse that you have not previously experienced. You will be among the first to recognize that you will be dealing with a stranger. The quicker you are able to adopt the “do’s and don’ts” of care giving, the more control you will have over your new situation. The **3 P’s** will become a source of strength and comfort to you, and both you and your loved one will benefit.

## THE UNSOLVED MYSTERY

There is so much we do not know about the Alzheimer's patient. We do know that the five senses (sight, taste, touch, hear, and smell) do not decline as rapidly as does acuity and cognitive thinking. The patients are able to convey problems with their senses, but not so with their feelings and emotions. Not in a manner that we understand. Feelings and emotions play a large part in the patient's behavior and disposition. Consequently, it is most important for the caregiver to be mindful and sensitive to the fact that the Alzheimer's patient is dealing with a great deal of frustration, the cause of which, we are so frequently unable to discern or identify.

What causes the patient to do the things they do?

We really do not know. We do know that the caregiver can be responsible for a good portion of the patient's behavior, but there is much we cannot explain. It matters greatly if the caregiver is always aware that the patient senses their abilities have changed, causing anxiety and frustration. The patient is fraught with both. We must do whatever we can to not exacerbate relations with our patient. Caregiver actions and reactions are so important! We must always put the patient and his interests ahead of our own. The patient comes first, much as we would welcome a stranger in need.

## CONCLUSION

As a caregiver you are on a sacred journey you have probably not chosen but have inherited. Perhaps even inherited against your will. It may well be due to other family members renouncing any responsibility. Additionally, you most likely have had no prior experience or familiarity with your new role in life and new responsibilities. My heart goes out to you for surely at times you will experience enormous stress, so severe you will wish for extreme solutions to your situation. At times you will feel there is no help or answer to your situation. You will give thought to giving up; there seems to be no relief. The rejection and isolation reigns supreme, and there is no end in sight.

If and when this condition appears, it is incumbent to seek comfort and guidance from God. We must ask for peace and guidance and grace from Him. He will provide your needs if prayer is sincere and with faith in Him. He may not give immediate relief or solve issues as requested, but He will not burden us beyond what we can sustain.

Once you are in His presence, He will provide strength and calm to enable you to continue. The journey may be designed to purposefully bring us closer to Him and His kingdom. The greater the trust in Him, the more acceptable your role becomes. At some later point in time there will be a realization of having fulfilled a mission of love and care to someone who was not able to care for him or herself. Satisfaction and thanks will

manifest itself and one can claim mission accomplished! Job well done! God has answered our prayers!

1 Peter 5:7.....***Cast all of your cares on Him, because He cares about you.***

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