“LISTEN TO ME, I AM STILL SOMEBODY”

UNDERSTANDING THE ALZHEIMER’S DISEASE SUFFERER

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"Listen to Me, I'm Still Somebody":
Understanding the Alzheimer's Disease Sufferer

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ACKNOWLEDGMENTS

This book is the culmination of 35 years of caring for and learning from all the professionals in Alzheimer's disease research and education and the sufferers of this dreaded disease and their families.

It could not have been accomplished without the loving friendship of my colleagues, Brenda Carr and Fran Floersheimer who have remained with the Alzheimer's Association, Houston and Southeast Texas Chapter. With their support and our collective expertise, the work of learning about the special needs of the Alzheimer's Disease sufferer and their families was begun.

We simply studied the needs of the Alzheimer's Disease sufferer by observing their behaviors and discussing the difficulties encountered by the families taking care of them. The knowledge gained enabled us to design environments and plans of care that would assure the best quality of life. We listened and we learned.

We were hoping as a group that these special environments would spread throughout all areas of care, since actually it is patient oriented care. This in itself was a leap of faith since traditionally, at that time, we "the medical community" would create the environment that we decided was the best one and attempt to put people in it without truly understanding their special needs. We were trying to put square pegs in round holes.

Ultimately this collective knowledge was used in developing comprehensive workshops to train professionals and help family care givers create these specialized living environments. This knowledge has

helped the Long Term Care Industry, Assisted Living Industry, Day Care Industry and families create these Alzheimer's friendly areas. They now understand that these areas are not purely structural in nature. Understanding the nuances of the disease process is necessary to successfully manage the behaviors of the person with Alzheimer's Disease.

Armed with this knowledge and the help of community professionals, the Alzheimer's Disease sufferer can be managed at home for a longer period of time, if the family dynamics permit.

This book has been a dream of mine for several years. I must thank my family and friends for their encouragement and my dear friend and fellow Rotarian, Bill Sikes, for his countless hours of computer work in helping me make my dream a reality.

Sandy

PROLOGUE

I have been fortunate to receive very positive reaction to my lectures. I seem to be able to put the information about the Alzheimer's Disease process and its effects on the sufferers and their families in a very understandable, personal way. These occasions are as meaningful to me as they are to the participants. I know that what they learn from me will be used to help themselves and others survive the life-shattering effects of this disease.

This book is my attempt to put the information I present during my lectures and workshops in written form. I am attempting to write it in a conversational way. I want those who read my book to *hear* me.

Instead of talking to a group, I found myself talking to my computer. A strange thing happened to me, though; I was crying. It seemed that all of the times I had maintained my composure, while the many families I met told me of the horrors they were experiencing, had a lasting effect. Apparently that composure was not needed when I was alone with my computer. This reaction surprised me.

Mercifully, I have had no one in my family suffer with this disease. I was introduced to this devastating disease in 1983. We had moved to Texas and I was working in a nursing home as a Community Relation Representative. The nursing home, along with several in the area, was attempting to develop Alzheimer's and Related Dementia units. I knew very little about this disease, so I contacted the Alzheimer's Association to find out about any workshops that were available in the community. I read all that I could find about this strange disease, and I also attended family support

groups. I would sit there and listen in awe to the families talk about the frightening things that have happened to their families because of this disease. They were desperate for any information and support they could find to help them survive this nightmare.

The pain and sadness expressed by the care givers at these meetings left a lasting impression on me. I knew at that time that I must do something, anything, to help ease this pain. I learned as much as I could and began to volunteer with the Alzheimer's Assoc. in Houston. I joined with other professionals and began lecturing, facilitating support groups and setting up workshops for other professionals and helping facilities like ours to set up specialized environments.

One would expect that the staffs of competitor facilities and companies would find it difficult to work together. We didn't. The needs of the Alzheimer's Disease sufferers and their families brought us together for a greater purpose. We became the members of the Advisory committee, Education Committee and the Family Support Committee of our local chapter. This time was the most amazing time in my life and was the best example of what a group of like-minded individuals can do when they combine their expertise to benefit the community.

Actually, I learned that this is how the National Alzheimer's and Related Dementia Association came to be in the first place. Families were desperate for information, as this disease was becoming more visible. Alzheimer's Disease had been around for years as a no-named mental and physical deterioration that was not spoken about in polite society. It was seen as a mental illness and families kept its existence a secret due to the social disgrace it implied. It was a few

brave families that sought out other families suffering with this disease in an attempt to disseminate the few bits of information they had and offer support. They would take donations during these meetings in order to get the money to mail out the meeting notices and information to any and all families who needed it.

If anyone doubts that a small group of people can move mountains, just remember this. These very families, meeting for support and information, began meeting all over the country. These were the beginnings of The National Alzheimer's and Related Disease Association we know today. Impressive, huh?

I hope the readers of this book can feel the love and concern I have for the Alzheimer's Disease sufferer and their families and for professionals who are gathering information in order to relieve some of the sadness and suffering associated with this disease process. I humbly pray that my book will bring some peace to the families and encouragement to these professionals.

Sandy

DEDICATION

This book is dedicated to my son, Mike, who inspired me to pursue the education that has allowed me to help so many Alzheimer's Disease sufferers and their families.

FOREWARD

I will begin this book as I do my lectures, with a poem. I believe that hearing, or in this case reading, this poem prepares the participant for and makes them receptive to the information about caring for the Alzheimer's Disease sufferer.

I have had this poem for the last thirty- five years. It was relevant then and it is relevant today. As I understand it, the poem was written by a Alzheimer's Disease sufferer who lived in California.

ADVICE ON CARING FOR ALZHEIMER PATIENTS

By
Joy Glenner
San Diego, CA

Dear family and friends:
Please try to understand
What I am now, not think of me
As I was.
I am alone, shut in
With my fears,
My frustration,
My forgetfulness.
Forgive me if I strike out at you.
Why do I do that?
What has happened to me?
I cannot cope with this alien world.
I feel threatened. I am frightened.
Speak softly, approach slowly.
Repeat again and again what you want of me.
Those twisted tangles in my brain
Have messed up my world.
Be patient, for I do love you,
And I need your help and love
So very , very much.
Your Alzheimer Patient.

CONTENTS

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MEMORY LOSS

It is not always Alzheimer's Disease

Educating the community about the Alzheimer's Disease process and the specialized treatment required has been the most rewarding aspect of my professional career.

My colleagues and I have worked tirelessly for years to educate the community, so the Alzheimer's Disease sufferers and their families would be able to receive more help.

With the help of increased visibility in the me- dia and the disclosure that our late president Ronald Reagan suffered from this dreaded disease, Alzheimer's Disease is more clearly understood. Funding for care and research has increased significantly.

So, apparently, has the fear of having the disease. An understandable reaction, but one we did not fore- see. We did not realize all this information was creating a significant amount of fear along with the increased awareness. We all see the warning signs in publications on tv and on the internet frequently. Articles about Alzheimer's Disease appear everywhere as well.

Although Alzheimer's Disease is the most common dementia, it is not the only reason for the symptoms experienced. Many medical conditions with similar symptoms are now going undiagnosed.

The community is now afraid to tell anyone, including their physicians, that they are experiencing these symptoms for fear the reason might be Alzheimer's Disease.

Confusion and memory loss can have many causes. Alzheimer's Disease is only one reason for this type of condition. That is why a proper examination and interview and family history are so vital. Many conditions and illnesses can have memory loss and confusion as one of their symptoms.

We'll begin with a few simple explanations.

Stress:

Any interference that disturbs a person's healthy mental and physical well-being. Continued exposure to stress often leads to mental and physical symptoms such as anxiety and depression. Stress can also cause memory loss.

We will refer to this type of stress induced memory loss as lapses. We all have lapses. Haven't you ever walked into a room and forgotten why you were there? Be Honest Now!

A professor of psychology was discussing the possibility of lapses in our every day stressful lives. There was one student who raised his hand to proclaim that he never has lapses. He claimed to be in complete control of his mental faculties at all times. Isn't there always one in the group?

The professor congratulated him on his ability. He requested that the student do a test to reinforce his un-

usual ability and asked that he share the results with the class when they next met. The student was to keep a record of each time he entered a room and forgot why he was there, each time he misplaced his keys, glasses, his car in a large parking lot, when he finds the sugar in the refrigerator, arrived late for an appointment or forgot the appointment all together. The student assured the professor these things never happen to him. The professor asked the student to please humor him and try the test anyway.

The next time the class met, the professor asked the student to share the results of the exercise with the class. The student had three pages of lapses he had experienced.

I might add that this particular student was very attentive for the remainder of the discussion on stress and how it affects our lives. That's one for all the teachers out there.

Delirium:

An acute state of confusion in which the activity of the brain is affected by fever, drugs, poisons or injury. The elderly are particularly prone to acute confusional states from certain drugs, such as barbiturates, tranquilizers or alcohol. Many older persons can have delirium after surgery, due to the mixture of sedatives, anesthesia and pain relievers. This delirium can take several days or even weeks to clear.

Confusion:

A disorganized mental state in which the abilities to remember, think clearly and reason are impaired. Confusion does not always indicate dementia.

Many disorders can cause dementia-like symptoms:

Medication reactions:

Many medications can have side effects that mimic the symptoms of dementia.

While presenting a workshop on handling medication with a group of seniors who were attending a day center, one of the participants told me she puts all of her medications in a bowl in her dining room and takes a handful once a day. I really thought she was joking; unfortunately, she wasn't.

Although her behavior is not common, many people do not take medications seriously. Most often they mix their prescribed medications with over the counter purchases. They have a tendency to share their medications with others. Not realizing that their friend's reaction to their medication can be very different.

Many people also have a tendency to keep medications after their expiration date, as well. I was discussing medication reactions with a group of health care professionals, which luckily included a Pharmacist. I asked him, as an example to the group, if he could assure us that medications that have expired have the same chemical structure. He said he could not.

Most people also assume all of their doctors know all the medications they are taking. They don't! The best thing to do is take a list of all the medications that you are taking, including the over the counter medication you have prescribed for yourself, to each physician you visit. The reaction of many of these medications can be the very reason you felt bad enough to make the appointment with your physician in the first place.

Dehydration:

Older persons dehydrate more rapidly. We all have an indicator in our brains that trigger our thirst when we need water. In the elderly, this trigger slows down. You can see how this can be a severe problem for the Alzheimer's disease sufferer. Not only is their natural alert system not working, their ability to recognize the problem and initiate the drinking of a glass of water is diminished as well.

When we do not get enough water the chemicals in our body concentrate and cause symptoms similar to those caused by dementia. Interestingly, taking too much water can dilute these same chemicals and cause just as serious a reaction.

Hypoglycemia:

Not having enough sugar in the blood stream can cause confusion and personality changes. It is not uncommon for a diabetic who is experiencing low blood sugar to initially be accused of being inebriated because of their reaction to low blood sugar.

Hypothyroid Disease:

An underactive thyroid can cause confusion, memory loss and personality changes. When discovered, the treatment is to replace the thyroxin that has been diminished by the disorder. The symptoms gradually disappear.

Anemia:

Chronic alcoholism can deplete vitamin B-1, which can severely impair mental abilities. Severe deficiencies in vitamin B-6 can lead to a neurological illness with features of dementia. Pernicious anemia, an impaired

ability to absorb vitamin B-12, can also cause personality changes. The symptoms of confusion, memory loss and weakness disappear with treatment.

Urinary Tract Infection:

Especially devastating in the elderly. It may have manifestations that are hard to identify. Classically one experiences burning, spasms, foul odor of the urine, an elevated temperature and sometimes, in a severe urinary tract infection, blood may appear in the urine. However, the symptoms can be disguised, as they were in an elderly man I cared for. The only indication that he had a urinary tract infection was when he suddenly fell forward while walking across the room. A large gash on his forehead and an emergency trip to the hospital clarified his sudden loss of balance as a very severe urinary tract infection.

Depression:

Confusion, apathy and forgetfulness are associated with depression and sometimes mistaken for dementia, especially in the elderly.

Many years ago, I had the privilege of meeting a physician in Houston who was in the process of researching depression. Again, one of the times I was honored to be in the presence of an incredible professional who allowed me to see this Alzheimer's Disease process so clearly.

He shared with me his concern that so many times, too many times, the symptoms of depression can mimic the aspects of Alzheimer's Disease. This includes confusion, memory loss, personality changes, reclusive behavior, mood swings and the loss of the ability to continue one's personal care. If diagnosed early and

the needed medication, started the person will begin to recover, usually in about four to six weeks. If left undiagnosed, the person will sink deeper into the depression, never to recover. It is usually in the elderly that the symptoms of depression go undiagnosed more frequently.

Sadly, we as a society had a tendency to believe an elderly person showing up at the emergency room in a confused state was to be expected. This situation might not have alarmed the staff several years ago. Luckily we have improved our knowledge of elder care immensely since then.

Most often these disease processes, if diagnosed early, are reversible. The person many times returns to normal functioning. That is why a thorough evaluation is so very important when any of these symptoms appear.

Dementia:

A brain disorder caused by the progressive degeneration and death of brain cells.

The following information describing the different types of dementia was taken from information obtained from *Dementia: Not Always Alzheimer's*, published by the Mayo Clinic. I found it very clear and understandable, without becoming too clinically complicated.

Dementia is a neurological disorder that affects a persons ability to think, speak, reason, remember and move. While Alzheimer's disease is the most common dementia, many other conditions can cause these symptoms.

The three most common forms of dementia are Alzheimer's disease, Vascular dementia and Lewey Body dementia. Sometimes the person can have more than one of these problems at the same time.

Vascular Dementia:

Vascular dementia occurs when arteries feeding the brain become narrowed or blocked. The onset of symptoms is abrupt, frequently occurring after a stroke.

Some forms of vascular dementia progress slowly, making them difficult to distinguish from Alzheimer's Disease.

Vascular dementia often causes problems with thinking, language, walking, bladder control and vision. Preventing additional strokes by treating underlying diseases, such as high blood pressure, may halt the progression of vascular dementia.

Lewey Body Dementia:

In this form of dementia, abnormal round structures (Lewey bodies) develop within the cells of the midbrain, beneath the cerebral hemispheres. Lewey Body dementia shares characteristics with both Alzheimer's disease and Parkinson's disease. Like Alzheimer's disease, it causes confusion and impaired memory and judgement. It also produces physical signs typical of Parkinson's disease, shuffling gait and flexed posture. Lewey Body dementia can also cause hallucinations.

Lewey bodies contain a protein associated with Parkinson's disease and Lewey bodies are often found in the brains of people who have Alzheimer's disease. This suggests the three ailments are related, or that Lewey Body dementia and Alzheimer's Disease or Parkinson's Disease sometimes co-exist. Some people with Lewey Body dementia have experienced dramatic improvements in symptoms when treated with Alzheimer's Disease and Parkinson's Disease medications. Several less common brain disorders can also result in dementia.

Frontotemporal Dementia:

Because it affects the lobes of the brain that are responsible for judgement and social behavior, Frontotemporal dementia can result in impolite and socially inappropriate behavior. Symptoms of this form of dementia usually appears between the ages of 40 and 65. The disease seems to run in families.

Pick's Disease:

Pick's Disease is one form of Frontotemporal dementia (FTD). FTD's are a group of rare disorders that affect primarily the frontal and temporal lobes of the brain, which control speech and personality. In Pick's disease, affected areas of the brain contain abnormal brain cells called Pick's bodies. The disease usually occurs in adults between the ages of 40 and 60. The cause is not known.

Unlike Alzheimer's disease in which memory loss usually is the first sign of the problem, people with FTD often show personality changes first. They may become more impulsive and uninhibited, causing them to be socially inappropriate and to make poor decisions. As the disease progresses, they can lose language skills. The disease varies greatly in the way it affects individuals.

There is no cure for Pick's disease. Treatment may include medications and is directed at improving daily function and quality of life. The course of Pick's disease is an inevitable progressive deterioration. The length of progression varies, ranging from less than two years in some to more than 10 years in others. Death is usually caused by infection.

Huntington's Disease:

Symptoms of this hereditary disorder typically begin between the ages of 30 and 50, starting with mild personality changes. As the disorder progresses, a person with Huntington's develops involuntary jerky movements, muscle weakness and clumsiness. Dementia commonly develops in the later stages of the disease.

Parkinson's Disease:

People with Parkinson's disease may experience stiffness of limbs, shaking at rest (tremor), speech impairment and a shuffling gait. Some people with Parkinson's develop dementia late in the disease.

Crutzfeldt-Jacobs Disease:

This extremely rare and fatal brain disorder belongs to a family of human and animal diseases known as the transmissible spongiform encephalopathies. A new variety of Crutzfeldt-Jacobs disease has emerged, particularly in Great Britain. It's believed to be linked to the human consumption of beef from cattle with mad cow disease (bovine spongiform enceopalopathy).

Alzheimer's Disease:

Alzheimer's disease involves a loss of nerve cells in the areas of the brain vital to memory and other mental functions. The loss is associated with the development of abnormal clumps and tangles of protein in brain cells. The first sign of Alzheimer's disease is usually forgetfulness. As the disease progresses, it affects language, reasoning and understanding. Eventually, people with Alzheimer's lose the ability to care for themselves.

The precise cause of Alzheimer's disease is unknown, but risk increases with age. Ten percent of the population over 65 years of age has Alzheimer's disease, while nearly half the population over 85 has the disease.

Alzheimer's disease is the most common form of dementia, affecting about 4.5 million men and women in the United States. Alzheimer's Disease's early symptoms are similar to ones that take place in normal aging. Alzheimer's disease is not a part of normal aging.

TEN WARNING SIGNS

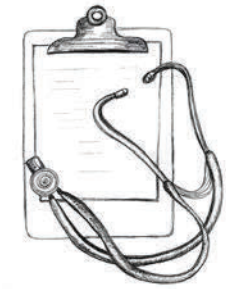
- Recent memory loss affecting job skills
- Difficulty performing familiar tasks
- Problems with language
- Disorientation of time and place
- Poor or decreased judgement
- Problems with abstract thinking
- Misplacing things
- Changes in mood or behavior
- Changes in personality
- Loss of initiative

There is no definitive diagnosis for Alzheimer's disease. The existence of the disease can only be proven at autopsy when the brain tissue can be examined and the plaques and tangles caused by the dead and dying brain cells can be clearly seen.

2

EVALUATION PROCESS

A Diagnosis Of Elimination



Alzheimer's Disease is a diagnosis of elimination. Meaning that we try to find other reasons for the symptoms in hopes that we find one that may be revers- ible. Believe me, any one in the medical community when evaluating a potential Alzheimer's disease suf- ferer prays that they can find something other than the devastating disease of Alzheimer's.

It is very important that the person or family member finds a physician they feel comfortable with. The Neurologist is most likely the usual choice but many family members are more comfortable with their family physicians. Many times the family physician has been seeing this person for years and might be the very one who sees the decline for the first time, Usually as part of their evaluation they will refer you to a Neurologist and maybe even a Psychiatrist.

The Psychiatrist referral is probably the most alarming to the family and the person suspected of having Alzheimer's disease. Sadly there still remains a stigma about mental illness. Some patients are so afraid

that they are going crazy due to the changes in there abilities and memory that they think that others will think the same if they see a Psychiatrist. There is nothing further from the truth. It is usually a combination of physicians that are needed to solve the mystery of these troubling symptoms.

EVALUATION PROCEDURES

Evaluation procedures vary depending on location and available resources. Some are done in a hospital and others done on an out patient basis. Several factors including financial resources have a significant bearing on when, where and to what extent an evaluation is done.

Evaluation components:

Detailed history from someone who knows the person suspected of having Alzheimer's disease and from the person themself to include:

1. Family History of Alzheimer's Disease
2. Education
3. History of Alcohol Consumption
4. Anticholinergic Medications (inhibit acetylcholine action at nerve cell receptors).
5. History of Depression
6. Physical examination
7. Neurological examination
8. Mental status examination
9. Laboratory tests and blood chemistry
10. Thyroid studies
11. VDRL (Venereal Disease Research Laboratories) tests and blood chemistry