



the compassion to care, the leadership to conquer

Alzheimer's Disease

An On-line Course

“Alzheimer’s Disease: The Journey Continues” is the second of a four part series for caregivers.

“Alzheimer’s Disease: In The Beginning” - discusses topics important in the early stages of the disease, such as defining Alzheimers, the warning signs, getting a diagnosis, medications, early stage behaviors and interventions, financial and legal issues.

“Alzheimer’s Disease: The Journey Continues” – discusses topics relevant to the middle stages, such as middle stage behaviors and interventions (including medications), alternative living decisions, stress and the caregiver, respite care, and spirituality.

“Alzheimer’s Disease: The River’s End” – discusses topics pertinent to the late stages of Alzheimers, such as late stage behaviors and interventions, end-stage issues and decisions, grief, and planning final arrangements.

“Alzheimer’s Disease: Life Goes On” – discusses topics important to life after Alzheimer’s disease, such as estate settlement, grief, and lifestyle changes and adaptations.

“Alzheimer’s Disease: The Journey Continues” -
online seminar sponsored by



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Introduction

“Alzheimer’s Disease: The Journey Continues” discusses topics relevant to the middle stages, such as middle stage behaviors and interventions (including medications), alternative living decisions, stress and the caregiver, respite care, and spirituality. This online course is designed to allow caregivers who might not be able to attend a three-hour seminar in person an opportunity to receive vital information. It is set up to allow the person to read only the parts that are immediately pertinent. It includes a bibliography and additional resources.

The stories that are included in this course are a result of years of experience with Alzheimer’s disease. They are not unique. The situations described have occurred many times and do not represent a single incident. Certain facts have been altered to protect the identity of any individual.

The Alzheimer's Association is partnering with Midland College Health Science Continuing Education to provide professional CEUs such as type II for nursing, social workers, activity directors and other healthcare professionals that accept online training as professional CEU. This seminar has been approved for 3 hours of CEU. In order to receive CEUs, the Midland College Registration form (in order to register, Midland College must have social security number and date of birth), Certificate Request, Evaluation and the post-test must be completed and payment received. The fee is \$25 and may be paid by credit card or check (made out to Alzheimer’s Association).

If you are taking this seminar and need a certificate of completion for personal use, you must take the post-test at the end of the seminar. There is a \$10.00 fee for a certificate of completion. The fee may be paid either by credit card (information on credit card payment is available following the post-test) or check (made out to the Alzheimer’s Association). Payment must be received before the certificate of completion will be given. The completed post-test(s) must be submitted to Janet Cross, Program Coordinator, Alzheimer's Association STAR Chapter – Midland Region. The completed post-test may be submitted via email to janet.cross@alz.org, by fax to 432-683-2345, or by mail to:

Janet Cross, Program Coordinator
Alzheimer's Association STAR Chapter – Midland Region
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Welcome to **Alzheimer's Disease: The Journey Continues.**



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*Alzheimer's Disease: The Journey Continues
A Conference for Caregivers*

OUTLINE

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*Alzheimer's Disease: The Journey Continues
A Conference for Caregivers*

Course Objectives

I. [Alzheimers – The Middle Stage](#)

Participants will be able to –

- *Describe the difference between the early stage and middle stage of Alzheimer's disease.*
- *List five changes common to the middle stage.*

II. [Communication](#)

Participants will be able to –

- *List three strategies for communicating with a person with dementia.*

III. [Challenging Behaviors](#)

Participants will be able to –

- *Identify and describe five challenging behaviors.*
- *List three interventions to diffuse a difficult situation.*

IV. [MedicAlert+Safe Return](#)

Participants will be able to –

- *Define the Safe Return program.*
- *Identify how people with Alzheimer's disease may wander.*

V. Choosing a New Home

Participants will be able to –

- *List three reasons for making the decision to place someone with dementia in long term care.*
- *Describe two options for placement.*
- *List four things to consider when making the decision for placement.*

VI. Stress and the Caregiver

Participants will be able to –

- *Define stress.*
- *Identify three methods of stress management.*

VII. Respite Care

Participants will be able to –

- *Define respite.*
- *Identify two options for respite care.*

VIII. Spirituality and the Caregiver

Participants will be able to –

- *Define spirituality in relation to caregiving.*

Alzheimers – The Middle Stage

As the journey through Alzheimer's disease continues, the individual will transition into the middle stages. There is not a definitive time line for the transition to occur nor are the stages of Alzheimer's disease clearly defined. Behaviors that are identified as occurring in a specific stage may in fact occur at any time or not at all. The Alzheimer's journey is unique to each individual.

The middle stage of Alzheimers is possibly the most difficult and challenging for the individual and their family. It may last from eight to ten years. A term used to describe the Alzheimer's journey is "retrogenesis" meaning "back to birth. As the disease progresses capabilities are lost and the developmental process may be reversed.

There is a new medication that one might use in middle and late stage Alzheimer's disease designed to improve functional abilities. Namenda has been available since early 2004 and can be used as a stand alone drug or in conjunction with one of the cholinesterase inhibitors. It appears to impact the person's ability to perform activities of daily living, thus enhancing their quality of life. This may result in their ability to live independently for a longer period of time.

At some point in the disease process the person may not recognize familiar people. They may think their son is their brother or their spouse is a stranger. It is not unusual for the police to be called to the home of a person with Alzheimers who thinks there is an intruder in the home. When the police arrive, they discover the intruder is in fact the person's spouse.

“There’s an intruder in my house. Please help me!” This frantic call to the police is a common occurrence in homes of people with Alzheimer’s. When the police arrive, the caller points to the “stranger” in their home and asks the police to take them away. The family member is horrified and tries to reason with their loved one. “Honey, I’m your husband / wife. We’ve been married for over fifty years.” “You are not my husband / wife. My husband / wife doesn’t look like you.” They don’t recognize this older person as their spouse. If they remember being married, they may recall their spouse as a young person and not recognize the older version.

As short term memory is among the first abilities to be destroyed, recent events are lost. The individual with Alzheimers may not be able to recognize people as they are in the present, but instead thinks of them as they were many years ago. They may remember they have sons or daughters but think of them as children not middle aged adults. They may not recognize their own image since they have no memory of themselves being older.

“I just had the nicest conversation with that elderly lady. She was quiet and didn’t have much to say but she was such a good listener.” This woman had just spent the last hour talking to her own image in the mirror. She no longer recognized herself or realized that she was seeing an image in the mirror.

“Common Changes in Moderate Alzheimer’s Disease

- Changes in behavior, concern for appearance, hygiene and sleep become more noticeable.
- Mixes up identity of people, such as thinking a son is a brother or that a wife is a stranger.
- Poor judgment creates safety issues when left alone – may wander and risk exposure, poisoning, falls, self-neglect or exploitation.
- Has trouble recognizing familiar people and own objects; may take things that belong to others.
- Continuously repeats stories, favorite words, statements or motions like tearing tissues.
- Has restless and repetitive movements in late afternoon or evening, such as pacing, trying doorknobs or fingering draperies.
- Cannot organize thoughts or follow logical explanations.
- Has trouble following written notes or completing task.
- Makes up stories to fill in gaps in memory. For example might say, “Mama will come for me when she gets off work.”
- May be able to read, but cannot formulate the correct response to a written request.
- May accuse, threaten, curse, fidget or behave inappropriately, such as kicking, hitting, biting, screaming or grabbing.
- May become sloppy or forget manners.
- May see, hear, smell or taste things that are not there.
- May accuse spouse of an affair or family member of stealing.
- Naps frequently or awakens at night believing it is time to go to work.
- Has more difficulty positioning the body to use the toilet or sit in a chair.
- May think mirror image is following him or television story is happening to her.
- Needs help finding the toilet, using the shower, remembering to drink, and dressing for the weather or occasion.
- Exhibits inappropriate sexual behavior, such as mistaking another individual for a spouse. Forgets what is private behavior, and may disrobe or masturbate in public.”

From the *fact sheet “Alzheimer’s disease: Progression”*

Retrogenesis*

“Back to Birth”

<i>Child Development</i>		<i>Alzheimer's disease</i>	
Age	Acquired Ability	Stage	Lost Ability
1 – 3 months	Can hold up head	Mild	No difficulty at all
2 – 4 months	Can smile		Some memory trouble begins to affect job / home
6 – 10 months	Can sit up without assistance		Much difficulty maintaining job performance
1 year	Can walk without assistance	Moderate	Can no longer hold a job, prepare meals, handle personal finances, etc.
1 year	Can speak one word		Can no longer select proper clothing for occasion or season
15 months	Can speak 5 – 6 words		Can no longer put on clothes properly
2 – 3 years	Can control bowels		Can no longer adjust bath water temperature
3 – 4.5 years	Can control urine		Can no longer use toilet without assistance
4 years	Can use toilet without assistance		Urinary incontinence
4 – 5 years	Can adjust bath water temperature		Fecal incontinence
4 – 5 years	Can put on clothes without assistance	Speech now limited to six or so words per day	
5 – 7 years	Can select proper clothing for occasion or season	Severe	Speech now limited to one word per day
8 – 12 years	Can handle simple finances		Can no longer walk without assistance
12+ years	Can hold a job, prepare meals, etc.		Can no longer sit up without assistance
			Can no longer smile
			Can no longer hold up head

*From “The Forgetting”, pages 122-123

Resources utilized for this section include:

An Overview of Alzheimer's disease and Related Dementias

fact sheet "What is Alzheimer's disease?"

fact sheet "Alzheimer's disease: Approaches to Care"

fact sheet "Alzheimer's disease: Progression"

For more information, go to www.alz.org.

Communication

As the disease progresses, the individual with Alzheimer's disease will start to struggle with words. They may substitute or make up words. They may say "no" when they mean "yes". They may interject part of one story into the middle of another when they lose their train of thought. The person may not be able to follow a conversation as words lose meaning or he/she can not remember the beginning. They may withdraw from social situations in an attempt to conceal their struggle with language. The individual may stop reading or watching television as it becomes more difficult to understand the content or follow the storyline.

"My wife is losing weight. She says she's not hungry." When preparing his own meal, her husband would ask her if she wanted to eat. She kept saying no. When the suggestion was made that he prepare her something to eat anyway and put it in front of her, he found that she was indeed hungry.

It is important when dealing with an individual with Alzheimer's disease to understand their reality. Do not argue with them – they are in their world, their reality.

Her husband called the office five times one Saturday morning. "My wife says she's going to Uncle Joe's funeral today. She's dressed and ready to go. There is no funeral." Her husband kept insisting that Uncle Joe had died many years before and there was no funeral. He wanted her to be like she used to be, to understand reality. Finally, on the fifth call, he accepted the suggestion that he stop arguing with her and tell her that "Bill" will be by to pick them up and take them to the funeral (knowing that "Bill" wasn't coming by). This calmed her down and eased his frustration.

Events of the immediate past are forgotten. Recognition of people and places as they appear in the present may not be possible. The Alzheimer's world exists in a time warp with things as they were many years ago. The caregiver's responsibility is to try to and understand the Alzheimer's world. The Alzheimer's world is confusing and frightening. This is the reality the person with the disease lives with. It is their reality and the caregiver needs to find a way to enter their world. Focus on the emotions that are expressed, not behaviors. Validate and respond to the feelings. By staying calm and patient the caregiver has a better chance of communicating with someone with Alzheimer's.

There are some simple tips for communicating with an individual with Alzheimer's disease –

- Approach from the front. This provides the individual with a visual cue that someone is communicating with them. They do not have to guess where the sound is coming from and it allows them to see the conversation is directed toward them.
- Call the person by name. Terms of endearment do not reinforce their identity.
- Identify yourself by name.
- State the purpose of the interaction.

“Hi, Mrs. Jones, it's Janet. I'm here to help you get dressed.”

Resources utilized for this section include:

Steps to Enhancing Communication: Interacting with Persons with Alzheimer's disease

For more information, go to www.alz.org.

Challenging Behaviors

The middle stage can last eight to ten years. This stage of Alzheimer's disease can be a difficult and challenging time for the individual and their caregivers. As the person experiences the progression into the Alzheimer's world, the caregiver has to find a way to understand the Alzheimer reality.

Aggression – The world can be a terrifying place for someone with Alzheimer's disease. Friends and family become strangers. Familiar places and items become unfamiliar. Words may be meaningless. The individual with Alzheimers can transition into the Alzheimer's world in a moment, without warning. Suddenly they are in a strange place, surrounded by strange people making sounds they do not understand. In this situation, they may become defensive and try to protect themselves.

He was a kind, gentle, soft-spoken man. He remained at home with his spouse of over sixty years. He had been diagnosed with Alzheimer's disease about four years ago but seemed to be doing fairly well. Then one night his wife was awakened when he started hitting her. She looked up and he was standing over her, hitting her again and again. He had never raised his voice to her before, much less his hand. She was confused and frightened by this total change in her partner of sixty some odd years. The next morning, he was mortified by his actions.

It can happen in a moment - a sojourn into the Alzheimer's world that leaves the family and friends reeling. Maybe she had rolled over in bed, or he had. For whatever reason, he had awakened, looked over and saw a stranger in his bed. At that moment, he did not recognize his wife of many years. If you had asked him, he might have remembered he was married but his wife was a young woman, not this older person sleeping in his bed. He lashed out, in fear and confusion, defending himself.

Suspicious – When surrounded by strange people, strange environment, strange sounds, it is reasonable to become suspicious. A person with Alzheimers may feel the need to hide perceived valuables from the strangers in their home. Once they have hidden the item, they forget where they placed it. In their world that translates to someone stole it. The logical conclusion is that the person in their house took it. They end up accusing their loved ones of theft.

“My wife is accusing me of having an affair and hiding the women behind the dresser in our bedroom! I love my wife and I’ve never been unfaithful. Why is she doing this?” *Her husband of over fifty years was distraught and did not understand why his loving companion was accusing him of having an affair. A gentle exploration of the situation revealed that the wife spent most of her time in bed in their bedroom. At the foot of the bed was a dresser with a mirror. When the wife was sitting up, she saw the image of an elderly woman, an image she did not recognize as her own (or as an image in a mirror – she thought it was a real person). When she lay down, the image dropped down. In her mind, the elderly woman was in her bedroom and hiding behind the dresser. The solution was to cover or get rid of the mirror.*

Bathing - Taking a shower or bath may become a frightening experience for a person with Alzheimers. They may become upset, cry, or resist when their caregiver tries to get them to bathe. Disrobing is a private matter, something most people aren’t comfortable doing in front of “strangers”. Without clothing, a person may feel vulnerable. Plumbing becomes a mystery. “Where is the water coming from? Where is it going? If the water can go through the drain, can I? Am I going to drown? Am I safe?” It may take several tries over a period of time, maybe even days, before a bath or shower can be completed. One step at a time may be the answer – bathing one arm today, another tomorrow. The need to feel safe is very important to the person with Alzheimers. They need some control over the situation.

Eating – The individual with Alzheimers may struggle with eating. They may eat a meal and then forget they have eaten and want to eat again. They may forget what to do with the utensils and not know how to get the food in their mouth. They may not recognize that a food item is too hot. The person may use sugar instead of salt. There may be too many choices so they may not eat anything. They may eat off of other people’s plates. Food may be placed in the mouth without chewing or swallowing. Putting one item of food on the plate at a time or using finger food may be helpful.

Safety concerns – As the sojourn into the Alzheimer’s world continues, once familiar items and tasks become mysteries. The caregiver should be aware of potentially dangerous situations. Items that may be risky can include the stove, hot water, electrical outlets, power tools, weapons, etc. Possible safety measures are similar to those taken with a young child. Remove the knobs from the stove. Turn the temperature down on the hot water heater. Remove or lock weapons away so that they are not accessible. These safety precautions are to protect the caregiver and family members as well as the person with Alzheimer’s disease.

Driving – At some point in the disease process, the person with Alzheimer’s disease will be unable to continue driving. Traffic signs and lights may cease to have meaning. The individual may get lost even though traveling along previously familiar routes. Brakes, accelerator, turn signals, and rules of the road no longer register. Traffic is not recognized as a potential hazard.

The family had decided it was time to take the car keys away. Dad was not safe to drive any more. He got lost and had trouble with traffic signs, lights, and other vehicles. So one day, without telling him, they took the keys. The next day, they discovered the car was gone...dad was driving. When he got back home, they took this set of car keys away. The next day, the same thing happened. They decided that dad had a few extra sets of keys so they searched the house. Some 76 sets of keys later, they were pretty sure they had them all. To be safe, they also disabled the car.

Depression – The world is turned upside down. Previously familiar tasks become confusing. The loss of ability to function or recognize people or places happens more and more frequently. The individual with Alzheimer’s recognizes these losses on some level. Grief and depression are not unusual for someone experiencing significant loss.

Sleep – It is unknown why people with Alzheimer’s disease experience sleep disturbances. Some possible reasons for this behavior may be due to napping during the day, lack of activity, restlessness, medications, etc.

The phenomenon referred to as “**sundowning**” is a fairly common behavior for people with Alzheimers. For some unknown reason they may become very active and agitated. It is possible as the light diminishes visual cues that aided their ability to function are no longer recognized. Leaving a light on during this time may have a calming influence.

Shadowing – People with Alzheimers may feel the need to stick close to their caregiver. As the world becomes more and more confusing, the caregiver gives them a sense of security. With short term memory loss, the individual may not remember that their loved one will come back so they want to keep them in sight.

Incontinence – At some point the person with Alzheimers may become incontinent of bladder and bowel. Initially, they may not remember where the bathroom is and not make it in time. They may look for the closest place that resembles a toilet or bathroom, such as a trash can, plant pot, or closet. Eventually, they will not recognize the physical sensations that tell them they need to use the bathroom. Taking the individual to the bathroom on a regular schedule may prove useful.

Wandering – There is no way to predict who will wander or when. Wandering may occur by foot, car, or other means of transportation. Once a person wanders, the behavior is likely to be repeated.

Tips for coping with challenging behavior –

- Look for triggers – what is causing the behavior? It could be too much noise or chaos, a confusing situation or environment, or frustration with a task or interaction.
- Stay calm
- Be patient
- Don't argue
- React to the feelings, not the behavior
- Don't take it personally

Resources utilized in this section include:

Steps to Understanding Challenging Behavior: Responding to Persons with Alzheimer's disease

Steps To Assisting With Personal Care: Overcoming Challenges and Adapting to the Needs of Persons with Alzheimer's disease

Steps to Ensuring Safety: Preventing Wandering and Getting Lost Safe Return™

FACTS: About Agitation and Alzheimer's disease

FACTS: About Depression and Alzheimer's disease

FACTS: About sleep changes and Alzheimer's disease

For more information, go to www.alz.org.

Wandering is one of the most challenging and life-threatening behaviors exhibited by people with dementia. Approximately 60% of individuals with Alzheimer's disease will wander and many will do so repeatedly. If not found within 24 hours, 46% of those individuals who are lost may die.

He was last seen getting in his red car to go two blocks to the store. This was a trip he had made many times without any problems. His family alerted law enforcement and the media for assistance in finding him when he did not return home. Almost twenty four hours later he was located 300 miles away in a major metropolitan city. He had gotten lost on the way to the store and couldn't remember how to get home. He just kept driving.

Imagine finding yourself in an unfamiliar location, not knowing where you are or how to get home. Confused and frightened, the person with dementia may not ask for assistance. They may be dressed inappropriately for the weather and not recognize that they are getting dehydrated or hypothermic. They may continue to search for familiar landmarks and just keep going until they succumb to the elements.

There is no way to determine who will wander or when the behavior will occur. The Alzheimer's Association's **Safe Return™ Program** is the only nationwide system designed to help identify, locate and return individuals with dementia who wander and become lost. Regardless of where the individual is when they get lost, Safe Return™ may provide necessary information to law enforcement that will assist in reuniting the person with Alzheimers with their family.

Safe Return™ provides:

- a national, 24-hour, toll free number to contact when someone is lost or found.
- identification products for the memory-impaired, including a bracelet or necklace, clothing labels, and wallet card. These products alert others that the individual is memory-impaired and may need assistance and also list the **Safe Return** 24-hour crisis number.
- registration in a national database including important information that can be accessed quickly when someone wanders and gets lost. This information can be critical in helping law enforcement agencies and others in their search.
- connection to community-based Alzheimer's Association chapters across the country that offer assistance and support. Some chapters have scholarship programs to help pay for the registration fee.
- Safe Return is now partnered with MedicAlert and includes a personal health record.

To register:

Complete a **MedicAlert + Safe Return** registration form. To obtain a copy, contact your local Alzheimer's Association at (800) 272-3900, contact MedicAlert + Safe Return at (888) 572-8566 or download the form from the Association's Web site at www.alz.org or www.medicalert.org/safereturn. ”

Resources utilized in this section include:

Steps to Ensuring Safety: Preventing Wandering and Getting Lost
Safe Return: Fact Sheet.
Safe Return: Registration Form.

For more information, go to www.alz.org.

Choosing a New Home

“When should I place my loved one in a nursing home?” is probably one of the most frequently asked questions from caregivers calling the Alzheimer’s Association. There may be several reasons for starting to think about placing a loved one in long term care. The reasons may include incontinence, wandering, safety issues, or the health of the caregiver. The time to make this important decision is not when there is a crisis but should be made before the need is imminent. There are financial and legal preparations that need to be addressed. If there is a crisis, the decision may be made on immediate availability rather than considering where the individual can receive the best care.

The first call that morning was from a daughter whose father had been diagnosed with Alzheimers approximately a year ago. She lived far away and was in town for a visit with her parents. “Do you really think he has Alzheimers? I think he’s doing fine. He’s still driving (even though the doctor has said he can’t). Tell me more about this disease because I don’t think he has it.”

About twenty minutes later, the daughter called back. She was going to be accompanying her father to the doctor in a few minutes and wanted to know what questions to ask.

A short time later, she called for the third time. She said she didn’t realize her father was as bad as he was. She requested the name and phone number for local certified Alzheimers care facilities.

It is not unusual for the person with Alzheimers to be able to function fairly well for brief periods of time. In fact, sometimes they can behave in such a way that it convinces the caregiver that they are the ones with a problem.

The primary decision to be made is what kind of facility will best meet the needs of the person with dementia. Two of the options available are assisted living or a nursing home. Assisted living will provide food and activities with minimal assistance. Typically assisted living facilities are private pay and are not covered by Medicare or Medicaid.

When selecting a nursing home, some criteria to consider –

- location
- size
- atmosphere
- safety – secure unit, wandergard
- certified Alzheimer's facility
- adequately trained staff
- financial (Medicaid / Medicare / insurance / private pay)

Tips for making a decision –

- Visit facility at different times of day / week
- Ask to see state inspection records
- Talk to residents / staff / families
- Rely on your eyes, ears, and nose
- Ask for references

Many people express guilt when making the decision for placing their loved one in long-term care. They may have promised this would never happen. The promise was made before the reality of Alzheimers. In actuality the promise was to provide the best possible care.

Be sure the facility can handle the increasing needs as the disease progresses. If at all possible try to make only one move.

“When should I place my loved one in a nursing home?” Answer:
When you ask the question. Be sure to contact the Alzheimer's
Association for other local resources.

Resources utilized in this section include:

Residential Care: A Guide For Choosing A New Home

Steps To Understanding Legal Issues: Planning for the Future

Steps To Understanding Financial Issues: Resources for Caregivers

For more information, go to www.alz.org.

Stress and the Caregiver

Stress is a physiological response to an unusual and intense situation. The body reacts to stress by shutting down non-essential functions such as the immune system and blood flow to the extremities. It concentrates oxygen and blood flow to the heart and lungs. When stress is alleviated the systems return to normal. With caregiving the stress is ongoing and in fact increases, leaving the caregiver susceptible to health concerns such as heart disease, cancer, and infections. It is not unusual for the caregiver to die first.

Caregiving is a twenty four hour a day, seven day a week responsibility. As the disease progresses the needs of the individual increase as do the demands on the caregiver. As a result the caregiver becomes socially and emotionally isolated. It is extremely important that the caregiver recognize the impact of this ever increasing responsibility.

Tips for stress management –

- Take a break
- Utilize resources (friends / family / community / adult day care / home health agencies / church / neighbors)
- Educate yourself
- Go to a movie
- Exercise and eat healthy
- Read a book
- Listen to music
- Take a hot bath
- Massage
- **ATTEND A SUPPORT GROUP**

In order for the caregiver to provide the continuous care their loved one requires as the disease progresses, it is essential that they take care of themselves by learning how to manage stress.

Caregiver Stress- Middle Stage

“Oh my gosh.....

He just called the sitter fat!”

She got outside without me knowing-luckily it was just as my husband was coming home—what if it had been some other time!”

She won’t bathe or change clothes!”

“I am so STRESSED OUT!!!”

“I never sleep or rest well! I can never get it all done or done the way I want it!”

Let’s talk about caregiver stress and what to do to relieve it!

- 1) Find somebody to share with and SHARE what’s going on
 - A. Support group
 - B. Phone a friend
 - C. Exercise and talk to somebody
- 2) Find humor in the situation!! Got to laugh or cry or go crazy!
- 3) Find the rules, then check and re-check the rules or expectations that we put on ourselves.
 - A. Find the rules—we all set rules or expectations on ourselves and we need to explore and list these rules we have set for ourselves. Here are some examples of the rules/expectations:
 1. “I will do it all myself and not ask anyone for help.”
 2. “He/she cared for me as a child and I will care for them”
 3. “I can’t or won’t ask for help.”
 4. “I will handle the role reversal gracefully.”
 5. “I will not get angry if my family/siblings don’t help or don’t do it the way I want.”
 6. “Things have to be done my way!”
 7. “I will not allow old relationship issues to come up and affect me.”
 8. “I will not allow them to manipulate me.”
 9. “I will feel guilty if I ask for help.”
 10. “I will feel guilty if I don’t do it perfect.”
 11. “I will feel guilty and like I have broken the sacred trust if I talk to anyone about it.”
 12. “I will feel guilty if I become exasperated, frustrated, resentful, or angry.”
 13. “I will have my feeling and actions in control at all times!!”

Continued

B. Check and Re-Check the rules /expectations

1. Ask yourself what Dr. Phil would ask-“How’s that working for you?”
2. Ask yourself, “Who said that is the rule?” Would I hold a friend in this situation to this rule? If I made the rule, then I can cut myself some slack!
3. As we look at the rules and each situation ask yourself, “Will it really matter 3 or 6 months from now.” “Who will know if I followed this rule (besides me) in 3 or 6 months?”
4. “Am I carrying all this GUILT for a reason or can I put it down, cut myself some slack?” You know you wouldn’t hold a friend to this high a standard, so why hold yourself there.
5. Re-Check the rules again and again, as each thing changes in your life and every 6 months or so.
6. Learn to laugh at your rules, your situation and what is happening around you.

STRESS BUSTERS:

Talk to someone

Laugh with someone

Exercise: Walk, swim, dance, move the tight muscles

Make time for Rest

Follow good nutrition

Use Relaxation Techniques

Deep Breathing, Progressive relaxation, relaxation mini-vacation, or meditation
Vacation (short or long), Time Away and PUT AWAY the GUILT!!

Build a resource list (community & personal)

Community-agencies to help (meals on wheels, respite care, etc.)

Personal - jot down all the folks that offer to help. When there is laundry, or need of transportation, etc. Call them and keep calling them to find help each time!



*Written by Susan Jones, RN, LPC
Instructor, Midland College*

Resources utilized in this section include:

Especially for the Alzheimer Caregiver
Caregiver Stress – Signs to Watch for ... Steps to Take

fact sheet “Alzheimer’s disease: Impact on the Care Partner”

For more information, go to www.alz.org.

Respite Care

Care giving for an individual with Alzheimer's disease is a twenty-four hour a day, seven day a week responsibility. As the person with Alzheimers journeys deeper into the world of Alzheimers, he/she requires more and more care. For the caregiver, the world becomes compressed and the job of care giving becomes all consuming. They may become isolated as it becomes too difficult to get away or take time away from their responsibilities.

There are several options that may be available. The individual with Alzheimers may be able to remain in the home if the caregiver has some assistance. Family and friends may be able to assist with routine chores such as mowing the lawn, running errands, or preparing meals. When someone calls offering help it may be useful to have a list in advance of ways people may help.

Staying with the person with dementia for an hour or a day can provide much needed respite for the caregiver. A home health agency may be able to assist with personal care needs or sitting with the person. Adult day care provides an essential service to families caring for people with Alzheimer's disease.

Resources utilized in this section include:

Especially for the Alzheimer Caregiver
Caregiver Stress – Signs to Watch for ... Steps to Take

fact sheet “Alzheimer’s disease: Impact on the Care Partner”
Services You May Need

For more information, go to www.alz.org.

Spirituality and the Caregiver

An inner strength, belief in self, faith, values – that is spirituality. Spirituality is a belief in something other than you, that there is a higher power in control of the universe. For caregivers dealing with the devastation of the Alzheimer's journey, spirituality can be a source of tremendous strength or extreme confusion. Caregivers may turn to their belief system to find the courage to continue, to face the challenges of the journey. Spiritual and religious beliefs may enable the family and the individual with Alzheimers to deal with their grief and the many changes they have experienced in their lives. For others, there may be enormous confusion and anger. They may question the existence of a higher power. “Why has God brought this horrible disease into our lives?” “Has He forsaken me?” Spirituality can be a difficult issue for people dealing with Alzheimer’s disease.

Spirituality is unique to each person. Beliefs are individual and every person must look to their own values, faith, and feelings. This section is not intended to convert anyone. Alternative views are offered as a resource for those who choose to use them. Answers are found within yourself.

“Finding Your Heart

- Scan your body from head to toe with your awareness.
- Just observe. Don't analyze. Don't judge.
- Notice any pockets of sensation, emotion, feeling, tension.
- Notice any tiredness, weariness, boredom.
- Notice any agitation, restlessness, resistance.
- Notice your thoughts. Identify the main one(s).
- What is your heart most wanting? Not wanting?

Voicing your Heart

- Try to summarize what you noticed earlier:
 - Your main feeling(s)
 - Your main thought(s)
 - Your heart's desire at present
- Boil it all down to one clear sentence, or a phrase or two.
- If an image or mental picture occurs, include it.
- Go through the process of expressing all this content to yourself, to God, (or handle it as you wish).
- Sit with it a moment; just be in your heart, now that you have expressed it.

Listening from your Heart

- Sit up, very still, eyes downcast.
- Become aware of breathing, naturally; feel it at the nostrils.
- Count your out-breaths (exhalations), from 1 to 10, and start over. Focus on each breath as it happens. Forget all else. When distracted, start over at 1.”

***Written by Jim Chaumont, Chaplain
VistaCare Hospice
San Angelo Texas***

“Spiritual Action Plan

I. Keys to preparing for spiritual help and support

Be spiritually and emotionally present

Acknowledge your needs, concerns, fears

Speak what you feel

II. Receiving spiritual help, support and encouragement

Your attitude is important, but don't let a poor attitude keep you from seeking help. God can and will help you change a poor attitude so that you can once again have spiritual peace, strength, confidence and hope.

Prayer – don't give up! Don't give in! Take it to God!”

*Excerpts taken from material written by
Walter McCall, Chaplain
Odyssey Hospice, Big Spring Texas*

“SPIRITUALITY AND THE CAREGIVER

Spirituality is deeply and richly tied to a sense of meaning, competence, and connection to values that transcend this moment, this place, and these circumstances.

When dealing with Alzheimer’s care givers and their loved ones, both face tremendous obstacles in body and soul to these sensations of meaning, competence and connection. If you are a care giver, you may have tried mightily to balance the demands of caring, of holding down a job, and of meeting obligations to friends and family. There probably seems to be little left at the end of the day in terms of esteem and well-being. You are tired, your soul is tired, both often beyond measure. The dynamics of the load you are trying to balance seem to be constantly shifting.

There are no “bumper sticker sayings” that provide relief. All that can sometimes be offered is spirituality and compassion!

There is a profound relationship between spirituality and compassion, for wherever genuine spirituality is manifested the other, compassion, is also present.

Matthew Fox addressed this connection in a most inspirational and challenging manner. Compassion is a heavenly plant – transplanted to earth, and wherever it is manifested, God is there. “Whoever does good is from God; whoever does evil has not seen God” (3 John 11). Compassion is a rare commodity in the world today. Compassion is not the same as sympathy. There is a vast difference. Sympathy (meaning to sorrow with) is an emotional response of sorrow toward another human being with loving, caring concern, in an endeavor to alleviate suffering and remove the pain.

Continued

Three couplets illustrate the difference between the two.

1. Sympathy looks down with teary-eyed pity and says,
“Oh, I am so sorry.”

Compassion *comes down* with loving concern and declares “How can I be of help?”

That’s spiritual!

2. Sympathy remains in the real of *affection*.

Compassion always moves from affection to *action*.

That’s spiritual!

3. Sympathy is sometimes motivated out of *self-interest* in a pious cloak.

Compassion is motivated out of a *genuine concern* for others with no strings attached.

The essence of Compassion is *taking the role of the other* and viewing life from the Other’s perspective, out of the Other’s situation of need, as a motivation for action.

That’s spiritual!”



***Written by Richard Edwards, Senior Pastor
St. Luke’s United Methodist Church, Midland TX***

Conclusion

Alzheimer's disease is a devastating terminal illness that impacts a significant portion of the world's population. By the year 2025 the United States will see an approximate 44% increase in the number of people with Alzheimer's disease. In the state of Texas the increase is expected to be 74%. Few families will escape unscathed.

The Alzheimer's Association is a leader in providing information and education about this devastating disease. There are support groups throughout the country to provide assistance and encouragement to those affected by Alzheimer's. The Alzheimer's Association is the leading private funder of Alzheimers research in the world. This has lead to great strides being made in the diagnosis, treatment, medications, and understanding of the disease.

For assistance and information contact the Alzheimer's Association at 1-800-272-3900 or www.alz.org. The STAR Chapter address is www.alz.org/txstar .

Resources utilized in this section include:

fact sheet "About the Alzheimer's Association"

fact sheet "Alzheimer's Association: Chapter Network"

fact sheet "Alzheimer's Association: Our Commitment to Research"

fact sheet "Changing the Way Americans Think About Alzheimer's disease"

fact sheet "Alzheimer's disease growth: U.S. will see average 44 percent increase in Alzheimer's disease by 2025"

For more information, go to www.alz.org.

Bibliography

BOOKS -

1. Mace, Nancy L., and Peter V. Rabins. *The 36 – Hour Day*. New York: Warner, 1999.
2. Shenk, David. *The Forgetting: Alzheimer’s: Portrait of an Epidemic*. New York: Doubleday, 2001.
3. *Alzheimer’s disease: Unraveling the Mystery*. U.S. Department of Health and Human Services. National Institutes of Health. NIH Publication Number: 02-3782. October 2002.

Alzheimer’s Association FACT SHEETS -

4. Alzheimer’s Association. fact sheet “About the Alzheimer’s Association”. 2004.
5. Alzheimer’s Association. fact sheet “Alzheimer’s disease: Approaches to Care”. 2004.
6. Alzheimer’s Association. fact sheet “Alzheimer’s Association: Chapter Network”. 2004.
7. Alzheimer’s Association. fact sheet “Alzheimer’s disease: Impact on the Care Partner”. 2004.
8. Alzheimer’s Association. fact sheet “Alzheimer’s Association: Our Commitment to Research”. 2004.
9. Alzheimer’s Association. fact sheet “Alzheimer’s disease: Progression”. 2004.
10. Alzheimer’s Association. fact sheet “Alzheimer’s disease growth: U.S. will see average 44 percent increase in Alzheimer’s disease by 2025”. 2004.
11. Alzheimer’s Association. fact sheet “Safe Return. 2004.

12. Alzheimer's Association. fact sheet "What is Alzheimer's disease?". 2004.

13. Alzheimer's disease and Related Disorders Association, Inc. FACTS: About Agitation and Alzheimer's disease. 11/01.

14. Alzheimer's disease and Related Disorders Association, Inc. FACTS: About Depression and Alzheimer's disease. 2/10/03.

15. Alzheimer's disease and Related Disorders Association, Inc. FACTS: About sleep changes in Alzheimer's disease. 4/15/02.

16. Alzheimer's disease and Related Disorders Association, Inc. Services You May Need. 1999. Reprinted 2001. ED210Z

Alzheimer's Association BROCHURES -

17. Alzheimer's disease and Related Disorders Association, Inc. An Overview of Alzheimer's disease and Related Disorders. 1997. Reprinted 2003. ED616Z.

18. Alzheimer's disease and Related Disorders Association, Inc. Caregiver Stress – Signs to Watch for ... Steps to Take. 1995. Reprinted 2002. PR200Z.

19. Alzheimer's disease and Related Disorders Association, Inc. Especially for the Alzheimer Caregiver. 2001. ED230Z.

20. Alzheimer's disease and Related Disorders Association, Inc. Steps To Assisting With Personal Care: Overcoming Challenges and Adapting to the Needs of Persons with Alzheimer's disease. 1999. Reprinted 2001. ED318Z.

21. Alzheimer's disease and Related Disorders Association, Inc. Steps To Enhancing Communication: Interacting with Persons with Alzheimer's disease. 1996. Reprinted 2003. ED301Z.

22. Alzheimer's disease and Related Disorders Association, Inc. Steps To Ensuring Safety: Preventing Wandering and Getting Lost. 1999. Reprinted 2001. ED319Z.

23. Alzheimer's disease and Related Disorders Association, Inc. Steps To Understanding Challenging Behaviors: Responding To Persons With Alzheimer's disease. 1996. Reprinted 2001. ED311Z.

24. Alzheimer's disease and Related Disorders Association, Inc. Steps To Understanding Financial Issues: Resources for Caregivers. 1999. Reprinted 2003. ED315Z.

25. Alzheimer's disease and Related Disorders Association, Inc. Steps To Understanding Legal Issues: Planning for the Future. 1997. Reprinted 2003. ED314Z.

26. Alzheimer's disease and Related Disorders Association, Inc. Residential Care: A Guide For Choosing A New Home. 1998. Reprinted 2001. PF110Z.

ADDITIONAL RESOURCES

Alzheimer's Association FACT SHEETS -

27. Alzheimer's Association. fact sheet "Alzheimer's disease: Statistics". 2004.
28. Alzheimer's Association. fact sheet "Changing the Way Americans Think About Alzheimer's disease". 2004.
29. Alzheimer's Association. fact sheet "Maintain Your Brain". 2004.
30. Alzheimer's disease and Related Disorders Association, Inc. Medications. 1992. Revised 2002. ED247ZP.
31. Alzheimer's Association. fact sheet "Alzheimer's disease: Diagnosis". 2004.
32. Alzheimer's Association. fact sheet "Alzheimer's disease: The 10 Warning Signs". 2004.
33. Alzheimer's disease and Related Disorders Association, Inc. Ethical Considerations: Issues in Diagnostic Disclosure. 1997. ED231Z.
34. Alzheimer's disease and Related Disorders Association, Inc. FACTS: About Aluminum and Alzheimer's disease. 6/20/02.
35. Alzheimer's disease and Related Disorders Association, Inc. FACTS: About AN – 1792, the "Alzheimers vaccine". 5/22/03.
36. Alzheimer's disease and Related Disorders Association, Inc. FACTS: About Chronic Wasting Disease. 4/11/03.
37. Alzheimer's disease and Related Disorders Association, Inc. FACTS: About COGNISHunt and Alzheimer's disease. 1/03.
38. Alzheimer's disease and Related Disorders Association, Inc. FACTS: About CX516 (Ampalex™), a Drug under Investigation for Treating Alzheimer's disease. 4/18/03.

39. Alzheimer's disease and Related Disorders Association, Inc. FACTS: About dementia screening tests marketed to consumers. 3/8/02.
40. Alzheimer's disease and Related Disorders Association, Inc. FACTS: About Dental Fillings and Alzheimer's disease. 10/01.
41. Alzheimer's disease and Related Disorders Association, Inc. FACTS: About health claims for drugs and dietary supplements. 01/02.
42. Alzheimer's disease and Related Disorders Association, Inc. FACTS: About hormone replacement therapy and Alzheimer's disease. 1/27/03.
43. Alzheimer's disease and Related Disorders Association, Inc. FACTS: About Leteprinin Potassium (Neotrofin[®]) and Alzheimer's Disease. 5/2/02.
44. Alzheimer's disease and Related Disorders Association, Inc. FACTS: About Mild Cognitive Impairment. 5/2/02.
45. Alzheimer's disease and Related Disorders Association, Inc. FACTS: About Nonsteroidal Anti-Inflammatory Drugs. 6/03.
46. Alzheimer's disease and Related Disorders Association, Inc. FACTS: About statins and Alzheimer's disease. 3/13/02.
47. Alzheimer's disease and Related Disorders Association, Inc. FACTS: About the CATIE trial for psychiatric Alzheimer symptoms. 1/28/03.
48. Alzheimer's disease and Related Disorders Association, Inc. FACTS: About Vitamin E in the Treatment of Alzheimer's Disease. 02/03.

Alzheimer's Association BROCHURES -

49. Alzheimer's disease and Related Disorders Association, Inc. Is It Alzheimers? Ten Warning Signs You Should Know. 2002. Reprinted 2003. PR301Z.
50. Alzheimer's disease and Related Disorders Association, Inc. Steps To Enhancing Your Home: Modifying the Environment. 1996. Reprinted 2001. ED313Z.

51. Alzheimer's disease and Related Disorders Association, Inc. Steps To Planning Activities: Structuring The Day at Home. 1996. ED308Z.
52. Alzheimer's disease and Related Disorders Association, Inc. Steps To Getting A Diagnosis: Finding Out If It's Alzheimer's disease. 1996. Reprinted 2003. ED309Z.
53. Alzheimer's disease and Related Disorders Association, Inc. Steps To Understanding Financial Issues: Resources for Individuals with Alzheimer's disease. 1999. ED316Z.
54. Alzheimer's disease and Related Disorders Association, Inc. If You Have Alzheimer's disease – What you should know, what you should do. 1998. Reprinted 1999. ED312Z.
55. Alzheimer's disease and Related Disorders Association, Inc. Helping Children and Teens Understand Alzheimer's disease – A Guide for Parents. 1997. Reprinted 2001. ED209Z.
56. Alzheimer's disease and Related Disorders Association, Inc. How to be a Long – Distance Caregiver. 1999. ED208Z.
57. Alzheimer's disease and Related Disorders Association, Inc. Living with Early – Onset Alzheimer's disease. 1999. ED206Z.
58. Alzheimer's disease and Related Disorders Association, Inc. The younger Alzheimers patient. 1989. ED223Z.
59. Alzheimer's disease and Related Disorders Association, Inc. You Can Make a Difference – 10 Ways to Help an Alzheimer Family. 1995. PR201Z.

Short List of Alzheimer Web Sites

ALZHEIMER'S DISEASE

Alzheimer's Association – <http://www.alz.org>

The Alzheimer's Association, a national voluntary health organization, provides information and services to people with Alzheimers, caregivers, researchers, physicians, and health care professionals.

Alzheimer's disease: Unraveling the Mystery – <http://www.alzheimers.org/unraveling/index.html>

This on-line booklet from the National Institutes of Health provides basic information about Alzheimer's disease and research and includes numerous graphical representations.

Alzheimer Forum – <http://www.alzforum.org>

A compendium for researchers, physicians and the general public, the site includes news, articles, discussion forums, interviews, diagnostic and treatment guide, directory of drugs and clinical trials, and research advances. It also provides access to such unique tools as directories of genetic mutations, antibodies, patents, and conferences.

ADEAR (Alzheimer's disease Education and Referral Center) – <http://www.alzheimers.org>

ADEAR maintains information on Alzheimer's disease research, diagnosis, treatment, drugs, and clinical trials, and Federal Government programs and resources.

Health Information on AD from the National Library of Medicine -

<http://www.nlm.nih.gov/medlineplus/alzheimersdisease.html>

An all-in-one search site, this page provides links to recent news items, symptoms and diagnosis, research, statistics, clinical trials, coping issues and other resources.

Alzheimer's disease Brain - http://www.pueblo.gsa.gov/cic_text/health/alzheim/brain.gif

The site illustrates degenerative neurons in the brain and the areas responsible for motor, vision, sensory, speech and memory functions.

Alzheimer's disease Process in RealMedia – <http://www.alzheimers.org/rmedia/mediaroom.htm>

In a 2-minute captioned film clip the viewer can learn about neurons, neurotransmitters, tangles and plaques, and the death of nerve cells.

Normal and Alzheimer Brain Comparison –

<http://www.macalester.edu/~psych/whathap/UBNRP/alzheimer/symptoms.html>

Viewable are lateral and overhead scans of a normal brain and an Alzheimer brain with the areas of memory, understanding, hearing, speech, temper, personality, and brain atrophy labeled.

CAREGIVING

Caregiver's Handbook - <http://www.adrc.wustl.edu/alzheimer/care.html>

Although this handbook is not specific to Alzheimers, it is easily applicable to AD, provides good coverage on care for the caregiver and is copyright free - making it an excellent training tool.

Caregiving Tips from the Perspective of the Person with Dementia -

http://www.familycaregiversonline.com/fcgo_text/dementia_perspective.html

An Australian writer who has Alzheimer's disease provides practical advice on how to handle 20 caregiving situations.

Family Caregiver Alliance – <http://www.caregiver.org/caregiver/isp/home/jsp>

Family Caregiver Alliance, National Center on Caregiving offers factsheets, monographs, statistical documents, consumer and training publications on a full range of caregiving topics. Most of the resources are free to download. The site includes a page on Alzheimers with a listing of symptoms by stage of the disease. Information is available in Chinese and Spanish.

Mayo Clinic Alzheimer's disease Center – <http://www.mayoclinic.com/home?id=3.1.2>

The Mayo Clinic site contains articles on driving, caregiving tips, nutrition, communication, stress management, depression, interactive caregiver stress tools and a free e-mail update service.

Planning for Long-term Care – <http://www.alzheimers.org/pubs/longterm.html>

This web site from the National Institute on Aging explores the options for long term care, with articles on planning ahead, making the right choice, and making a smooth transition.

Predicting Time in the Nursing Home - <http://cpmcnet.columbia.edu/dept/sergievsky/predictor.html>

Columbia University has developed a tool to help predict how long it might be until a person with Alzheimers requires nursing home care. See the home page for their methodology.

Rush Manual for Caregivers from Rush Alzheimer's disease Center –

http://www.rush.edu/patients/radc/pdfs/Caregivers_Manual.pdf

Written for family caregivers the manual contains 30 chapters on stages, treatment, communication, intimacy, coping, spiritual needs, legal matters, traveling, driving, exercise, hygiene, incontinence, and nutrition and more. Viewers can download the manual in PDF for free; click Caregiver's Manual.pdf.

The Alzheimers Page from Washington University in St. Louis - <http://www.adrc.wustl.edu/alzheimer>

This site links aging and dementia sites and contains the ALZHEIMER discussion group (an on-line support group for family caregivers and professionals).

OTHER TOOLS

Alzheimer Disease International (ADI) - <http://www.alz.co.uk>

The ADI web site links to fifty-seven Alzheimer's disease associations throughout the world, most in developing countries. It lists information about AD (for the person with AD and the caregiver - in English and in 25+ languages.) It also contains information on the global impact of Alzheimers as well as other activities of ADI.

ClinicalTrials.gov - <http://clinicaltrials.gov>

Persons with Alzheimer's disease, family members and members of the public can find current trials and research. The searchable database provides information on the name of the study, the purpose, eligibility, and contact information. Additionally the site indicates whether the study is recruiting and includes citations from published works.

Manual of Geriatrics - http://www.merck.com/pubs/mm_geriatrics

This Internet version of the manual is intended to help both families and professionals find descriptions and treatment information on conditions prevalent in the elderly. Nineteen sections, averaging ten chapters each cover a wide range of disciplines and geriatric diseases.

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