



the compassion to care, the leadership to conquer

Alzheimer's Disease: The River's End ***An On-line Course***

“Alzheimer's Disease: The River's End” is the third 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 River's End” -
online seminar sponsored by



Foundation

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Revised 2/08

Introduction

“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. 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 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
4400 N. Big Spring, Suite C-32
Midland TX 79705

Welcome to **Alzheimer’s Disease: The River’s End”**.



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*Alzheimer's Disease: The River's End
A Conference for Caregivers*

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*Alzheimer's Disease: The River's End
A Conference for Caregivers*

Course Objectives

I. The Late Stages of Alzheimer's

Participants will be able to –

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

II. The Many Faces of Grief

Participants will be able to –

- A. Identify and describe five emotions common in grief.*
- B. Identify three methods of stress management.*
- C. List two interventions to cope with grief.*

III. Living Until Death

Participants will be able to –

- A. List two documents utilized in making end-of-life decisions.*
- B. Discuss three decisions common during end-of-life care.*

IV. The Final Arrangements

Participants will be able to –

- A. Describe two options for funeral services.*
- B. List four things to consider when making the decision regarding final arrangements.*

V. Spirituality and the Caregiver

Participants will be able to –

- A. Define spirituality in relation to end-of-life.*

Alzheimers – The Late Stage

The journey has progressed into the late stage of Alzheimer's disease. This is a difficult time for the caregiver. For the person with Alzheimer's, whose memory is disappearing, this may be a time of little or no stress and a simplified lifestyle. In the final stage of the disease, the person with Alzheimers will probably need total care for activities of daily living. Because this is highly likely to occur, the caregiver will need to have previously made arrangements and decisions about the care of their loved one. There are many aspects to consider: financial, legal, availability of resources, personal choice. There is no way to gauge the length of the final stage. It may last days, weeks, months, or years.

“In the last stage of Alzheimer's disease, a person usually:

- *Has difficulty eating and swallowing*
- *Needs assistance walking and eventually becomes bed-ridden or chair-bound*
- *Needs full-time help with personal care, including toileting*
- *Is vulnerable to infections and pneumonia*
- *Loses the ability to communicate with words”*

*From the Alzheimer's Association brochure
Steps to Caring for a person with Late-Stage Alzheimer's
disease: Responding to the Individual's Increasing Needs*

Information that may help families provide for their loved one's basic care and comfort as well as maintain a connection with their loved one is important. The focus should be on preserving quality of life and dignity. The Alzheimers journey is a difficult one but it can also be filled with compassion and respect.

Food and liquid intake is often an important issue for the caregiver providing care for a loved one with dementia. Someone with late-stage Alzheimer's disease may develop difficulty swallowing food or liquids. This can lead to aspiration into the airway and lungs resulting in pneumonia. There are some things the caregiver might

try in order to assist their loved one eat and drink safely. Eliminate distractions and chaos during meals. Keep the environment as quiet and calm as possible. Simplify the meal process. Serve one food item at a time with only the essential items (plate, bowl, cup, utensils) available. Do not rush or force the person. It may take them a long time to finish the meal. They may prefer and respond better to several small meals or snacks rather than large meals. Make sure the individual is comfortable. The food items may need to be soft so that they can be swallowed easily. Finger foods might be appropriate. Offer the food slowly and make sure it is being swallowed. Utilize small bites of food followed by a drink of liquid. Liquid intake is important. The person with dementia may not realize they are thirsty or forget to drink. Try to determine the easiest and most effective manner of promoting food and liquid intake. Monitor their weight. Most important of all – know what to do in the event of choking.

During the late-stage of Alzheimer's disease, the individual may become bed-ridden or chair-bound. This is not because their bodies are incapable of movement but rather because they have forgotten how to sit, stand, or walk. Much as a child has to learn how to make these movements, the person with Alzheimer's disease will forget how to make the movements and can not re-learn. When a person has limited mobility, the skin may break down, leading to bedsores, or the muscles may contract. When the individual can no longer initiate body movement, it is important that their position be changed at least every two hours. This will relieve pressure and improve the moisture in the skin. The skin may tear or bruise easily. Keeping it clean and dry is essential. Utilize pillows or pads to protect bony areas. To protect against contractures, carefully (and slowly) move arms and legs two to three times a day, preferably when the person's skin and muscles are warm (such as after bathing). A physical therapist or home health provider can demonstrate proper technique.

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. This is a safety and health issue. If it has not already happened, this behavior often leads to placing the individual in a nursing facility. Some suggestions for coping with incontinence include utilizing a toileting schedule, eliminate caffeinated drinks which may act as diuretics, limit liquids late in the day while ensuring adequate intake during the day, and using absorbent and protective products.

The lack of mobility and movement during the late stage of the disease may lead to increased vulnerability to infections. Oral hygiene is important to eliminate bacteria in the mouth. Make sure all soft tissue in the mouth is cleaned daily. Any cuts or scrapes need to be cleaned immediately and professional assistance sought if the cut is deep. A yearly flu vaccine or even a pneumonia vaccine may help reduce the risk of flu or pneumonia.

One of the focuses in the late stage of Alzheimer's disease is to keep the individual comfortable and pain-free. Because people at this stage of the disease have difficulty communicating their pain or needs, the caregiver needs to be observant and vigilant. There are other indicators of discomfort besides words. There may be physical signs such as pale or flushed skin, vomiting, feverish skin, or swelling that indicates illness. Gestures, facial expressions (wincing, eyes shut, etc.), crying, or agitation may indicate discomfort or even pain. Any change in behavior, whether it is sleep pattern, shouting, or anxiety, might indicate some kind of physical discomfort. The physician might decide pain medication is appropriate.

“Common Changes in Severe Alzheimer’s Disease

- Doesn't recognize self or close family.
- Speaks in gibberish, is mute or is difficult to understand.
- May refuse to eat, chokes or forgets to swallow.
- May repetitively cry out, pat or touch everything.
- Loses control of bowel and bladder.
- Loses weight and skin becomes thin and tears easily.
- May look uncomfortable or cry out when transferred or touched.
- Forgets how to walk or is too unsteady or weak to stand alone.
- May have seizures, frequent infections, falls.
- May groan, scream or mumble loudly.
- Sleeps more.
- Needs total assistance for all activities of daily living.

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

As cognitive abilities are lost, the individual with Alzheimer’s disease continues to experience the world around them through their senses. Verbal communication may not be possible but there are ways to demonstrate love and security. It is important to the person and their caregiver that their connection to each other remains.

“As my mother’s Alzheimers progressed our communication changed. She had long forgotten my name and yet she seemed to know I was someone who loved her. When I walked into the room she would raise her hands and reach for me. She could no longer speak but we would sit and hold hands for long periods of time. The communication changed from talking to the experience of learning to be..... We sat together without words and held hands. Mother would raise my hand and kiss it over and over. This experience of communication was stronger and deeper than any words could ever be.”



This was one of the last pictures of mother with some of her grandchildren and great grandchildren.

*Denese Watkins, daughter and CEO
Alzheimer's Association STAR Chapter*

What is said isn't as important as how something is said. The tone and volume of speech can help the individual feel safe and loved. Reading a favorite story or scripture can be reassuring and calming. Music from the past can be calming and enjoyable.

She had difficulty walking, leaning against her loved one for support. When she spoke, it was mainly gibberish, with only a word or two that was understandable. She called everyone by the same name. However, when she was sitting in front of a piano, she played beautifully and knew the words to all the songs.

Husband recalling wife's journey

Find ways to stimulate the senses, whether it is the smell of flowers or food, touching, holding hands, or looking at family pictures. Reminiscing about family events, interests, favorite activities, or friends can be a special time for the person and the caregiver.

His only sounds were gibberish – words that had no meaning. There was a vacant look in his eyes. He didn't respond to anyone – except his sister, who sat by his side lovingly singing long-forgotten songs from their childhood. Then his eyes would smile and he would giggle with joy.

Family caregiver

When the final stage of Alzheimer's disease is reached, the journey has likely been ongoing for many years. As their cognitive and physical abilities decline, the need for increased care becomes overwhelming. The family may be unable to meet the needs of their loved one. If it has not already occurred, the decision may be made to place the individual in a long term care facility. This is a

difficult decision and hopefully one which the family has prepared for prior to the actual move.

“The real meaning of despair is when no facility will take your loved one because they are violent.” Facilities cannot accept someone they can adequately care for or who may be a danger to others.

Spouse

Alzheimer’s disease is a terminal illness. Unless some other illness intercedes, the disease will eventually affect all cognitive and physical functions. When the person can no longer swallow, move, turn, and are bed bound, they often succumb to pneumonia (drowning in bodily fluids) from lack of motion.

One night, two nights before he died, he looked at his daughter, smiled and said “There’s my pretty girl.” Those were the last words he ever spoke but for that one moment, he was truly there again. It was the most precious gift and one never forgotten.

Daughter

“Often, Mary was afraid, a nameless, shapeless fear. Her impaired mind could not put a name or an explanation to her fear. People came, memories came, and then they slipped away. She could not tell what was reality and what was memory of people past. The bathroom was not where it was yesterday. Dressing became an insurmountable ordeal....Mary gradually lost the ability to make sense out of what her eyes and ears told her....She worried about her things: a chair, and the china that had belonged to her mother. They said they had told her over and over, but she could not remember where her things had gone. Perhaps someone had stolen them. She had lost so much....

Mary was glad when her family came to visit. Sometimes she remembered their names; more often she did not. She never remembered that they had come last week, so she regularly scolded them for abandoning her....She was glad when they didn't try to remind her of what she had just said or that they had come last week, or ask her if she remembered this person or that one. She liked it best when they just held her and loved her.”

Excerpt from “The 36-Hour Day”

Taken from the book “Alzheimer’s Disease: Unraveling the Mystery”

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Resources utilized for this section include:

An Overview of Alzheimer's disease and Related Disorders

fact sheet "About Agitation and Alzheimer's disease"

fact sheet "About Depression and Alzheimer's disease"

fact sheet "About feelings"

fact sheet "About holidays"

fact sheet "About sexuality"

fact sheet "About sleep changes in Alzheimer's disease"

fact sheet "Alzheimer's disease: Progression"

fact sheet "What is Alzheimer's disease?".

Helping Children and Teens Understand Alzheimer's Disease: A Guide for Parents

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

Steps To Caring for a Person with Late-Stage Alzheimer's Disease: Responding to the Individual's Increasing Needs

Steps To Enhancing communication: Interacting with Persons with Alzheimer's Disease

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

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

The Many Faces of Grief

Many people believe that grief begins with death and is characterized by sadness and loss. The fact is grief may begin long before the actual death occurs. It may begin with the diagnosis or maybe even with the realization that something is wrong. Long before the physical body is gone, there are numerous losses. It may begin with the loss of a dream – of how the future was supposed to be. Retirement, vacations, family time may all change. As Alzheimer's disease progresses, there is the loss of self, of the person as they have been. Relationships and roles change. Children may become the parent and a parent the child. The person who has always taken care of finances and family affairs may no longer be able to do so, requiring someone else to intervene.

Grief is a normal part of life. When a loved one is near death, it is common to feel loss. It is also normal to feel guilt, anger, sadness, and loneliness.

When faced with the death of a loved one, family and friends may deny the reality of death. They may hope that someone has made a mistake, that their loved one is not really ill. If they are ill, maybe the mistake is the diagnosis – it is not really Alzheimer's disease, it is not really a terminal illness. The family may look for cures and expect the person to get better. Especially in the early stage of Alzheimer's disease, when the symptoms are so innocuous, they may try to normalize the behaviors. At some point, acceptance of the situation and disease process needs to occur. Acceptance allows the caregiver and family to find personal meaning in providing care for someone who is terminally ill.

Fear and anxiety are a normal part of the grieving process. It is okay to be afraid of what the disease is going to do to a loved one. It is alright to fear the future – the loss and void that will occur.

Anger is an emotion that causes tremendous difficulty for families. How could they be angry with their loved one? Yet they may be. They may be angry that this disease has devastated their life, their dreams, and their loved one. They may blame God, the doctors, anyone and everyone for this difficult situation. There may be resentment toward family members who cannot or refuse to help provide care. There could be resentment for having to take on the role of caregiver or toward the individual for abandoning their loved ones. Frustration with the person and the situation is normal. So is anger.

Another difficult yet normal emotion is guilt. The caregiver and family may wonder if they did something to cause or deserve the situation. There may be regret for actions taken or not taken before and after the diagnosis. The regret may be due to certain aspects of the relationship. Family and friends may experience guilt because they still find enjoyment in life. Or perhaps the guilt is due to wishing the person would go away or die. There could be unrealistic expectations with thoughts such as “I should have...” “I could have...” “I must visit everyday...” or “I can do more...” This is normal and okay.

Grief and the loss of a loved one are emotionally, mentally, and physically exhausting. It is essential that the caregiver and family members take care of themselves. Accept things beyond control. Make responsible decisions about things over which there is realistic control. Complete any unfinished emotional business – make amends, resolve conflict, give forgiveness, or say good-bye. Remember the good times. Stay involved with others, activities that are enjoyed, and the community. Talk with friends and family. Attend a support group to share with others the feelings of isolation and loneliness experienced during this final stage of the Alzheimer’s journey. It is important to remember that not everyone understands grief. People may think that grief only

happens after a loved one has died. In reality, it is possible to grieve deeply for someone who is fading away.

“Face your feelings

- *Think of all your feelings – positive as well as negative.*
- *Let yourself be as sad as you want.*
- *Accept feelings of guilt – they’re perfectly normal.*
- *Work through your anger and frustration. These are healthy emotions.*
- *Prepare to experience feelings of loss over and over as the person with dementia changes.*
- *Take ownership of your feelings, so you can start healing.*
- *Claim the grieving process as your own – no two people experience grief the same way. Grief hits different people at different times; some people need more time to grieve than others. Your experience will depend on the severity and duration of the person’s illness, on your own history of loss, and on the nature of your relationship with the person who has Alzheimer’s.*
- *Know that it is common to feel conflicting emotions. It’s OK to feel love and anger at the same time.*
- *Consider writing in a journal as a way to help you.”*

*From the Alzheimer's Association fact sheet
About Grief, mourning and guilt*

It is important for the caregiver and family to take care of themselves. Overwhelming stress and grief can have a devastating impact on a person’s health. The best thing a person can do for their loved one with Alzheimer’s disease is to stay healthy by caring for their own physical, mental, and emotional well-being.

At home caregivers deserve a lot of credit and a little respite for giving so much of their love, patience and commitment to their loved one, for giving them the gift of home, family, pets and familiar surroundings for as long as possible. Caregiving for someone with dementia is associated with a higher level of stress than caring for someone with functional impairment from another type of chronic illness. Caregiver burden is an all encompassing term used to describe the physical, emotional and financial toll of providing care. It is very common for caregivers to experience fatigue, anxiety, irritability, anger, depression, frustration, social withdrawal, or health problems. They must recognize these symptoms and seek medical attention and emotional support in order to maintain optimal health and well-being. It is key that caregivers have periodic respite. Respite involves the provision of temporary care to the Alzheimer's patient thus giving the caregiver a reprieve from their caregiving tasks and responsibilities.

Respite care can take several forms: In-home respite provides caregivers with occasional temporary relief from the pressures of continuous caregiving. Some Adult Day Care programs are designed specifically for persons with Alzheimer's. Others provide structured activities to a more heterogeneous group of impaired older persons or other group. Adult Day care provides exercise, activities, recreation, support of daily living skills, and monitoring of the Alzheimer's patient's general health. Such programs can help the person with Alzheimer's maintain some abilities that would otherwise deteriorate more quickly. By utilizing adult day care, caregivers can remain employed, do errands, rest, and have a social life. Respite can also be provided in an institutional setting if needed. All are excellent sources of the provision of care for the Alzheimer's patient and enhances the quality of life for the caregiver.

Respite may also postpone institutionalization of the demented person. Support groups are popular outlets for caregivers giving

them opportunities to network with other caregivers who are experiencing similar stresses. Educational support has proven to be very beneficial to caregivers as well so they can be informed, qualified and effective caregivers.

You cannot stop the impact of a chronic or progressive illness or a debilitating injury on someone for whom you care. But there is a great deal that you can do to take responsibility for your personal well being and to get your own needs met. Caregivers of Alzheimer's patients need to be prepared. Find out what community resources are available to help you on your caregiver journey so that you can maintain interests and hobbies that are important to you. Find a way to release negative emotions of caregiving in a healthy way and ask and accept help. Caring for yourself is one of the most important –and one of the most forgotten-things you can do as a caregiver. When your needs are taken care of, the person you care for will benefit as well.



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

Although it is very important for the caregiver to take care of themselves, more often than not, the caregiver dies first. About two-thirds of the time, the caregiver dies before the person with Alzheimer's disease.

Resources utilized for this section include:

Caregiver Stress: Signs to Watch for...Steps to Take

Especially for the Alzheimer's Caregiver

fact sheet "About grief, mourning and guilt"

fact sheet "Alzheimer's disease: Impact on the Care Partner"

Services You May Need

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

Living Until Death

Alzheimer's disease is a terminal illness. At some point, decisions will have to be made regarding end-of-life care. While many decisions and arrangements may have already been made, many decisions still remain. While difficult, the decisions made will have a tremendous impact on the quality of the individual's care and life.

“When individuals with Alzheimer's disease approach the end of life, caregivers and their families must make difficult decisions regarding their care. Ultimately, any end-of-life decisions made on the individual's behalf should respect their values and wishes and maintain their comfort and dignity.”

*From the Alzheimer's Association brochure –
Steps To Facing Late-Stage Care:
Making End-of-Life Decisions*

There are legal documents that may be and should be in place to direct the decision-making. These include a living will which is a document that gives written instructions about the wishes of the person regarding what kind of medical care they want to receive. They may also have a durable power of attorney for health care (recognized by the state where the person resides) that designates a family member or someone to make decisions about their care and treatment if they are unable to do so themselves. These documents should be distributed among appropriate individuals (those involved in the decision making) and placed in a location where they can be easily accessed. It is a good idea to have copies placed with the family physician, care facility, local hospital, and other health care providers. If these documents are not in place, then the family must be prepared to make decisions based on what they believe the individual would want and that would be in their best interest.

Decisions will have to be made about how aggressively to treat the individual with Alzheimer's disease. These may deal with issues such as:

- Respirators to take over breathing
- Feeding tubes and IV hydration when the person is not able to eat or drink
- Antibiotics to treat life-threatening infections
- CPR to resuscitate heart activity and breathing

It is common for people with Alzheimer's disease to develop eating and swallowing difficulties in the late-stage of the disease process. There is no evidence that tube feeding extends life or has any real benefit. While IV hydration may temporarily provide fluids it can not maintain nutritional requirements. It may also cause the individual discomfort because of resultant breathing difficulties and may prolong dying for weeks.

The family may elect to request a DNR (do not resuscitate) order for their loved one. CPR can be painful, traumatic and could even leave the individual in worse condition. If the family decides against CPR, the order should be signed by the physician and placed in the person's medical chart.

“For the person who can no longer swallow, an approach focusing on comfort in dying is most appropriate...”

The absence of hydration is a normal part of the dying process and allows a more comfortable death over a period of days...

CPR is not recommended by many knowledgeable professionals.”

*From the Alzheimer's Association brochure –
Steps To Facing Late-Stage Care:
Making End-of-Life Decisions*

The most important consideration at this time in the disease process is the comfort of the person. The focus should be on quality of life and dignity until life ends naturally. Hospice care may be a consideration at this point in their care. Hospice focuses on comfort and pain control. The emphasis is on dignity and total care – physical, emotional, spiritual – for the individual with Alzheimer’s disease and their family.

Important considerations in making informed decisions about end-of-life care include

- Focus on the person’s wishes. What would they want? What is most important to them?
- Reflect on the person’s values and beliefs. Many factors may influence decisions about quality of life and death – cultural, religious, spiritual, and family.
- Weigh the burdens and benefits of treatment. Will the treatment improve their quality of life (and death).
- Make each decision separately. Treatment does not have to be long-term but may be utilized on a trial basis to see if there are benefits.
- Consider the location for care. What is the most appropriate place for the individual? Could the care be best provided at home, in a care facility, or a hospital?
- Do not equate the refusal or withdrawal of treatment as poor care. Death is a natural part of life. Alzheimer’s disease is a terminal illness. The most important consideration is the comfort and dignity of the person.

During the long and difficult journey through Alzheimer’s disease, it is important that the caregiver continue outside interests and support. This is true even during the final stage of the process. The caregiver and family have to go on after the death of the person with Alzheimer’s disease.

Resources utilized for this section include:

Ethical Considerations: Issues in Death and Dying

Steps to Facing Late-Stage Care: Making End-of-Life Decisions

fact sheet “About hospitalization”

fact sheet “About visiting”

fact sheet “Alzheimer’s disease: Progression”

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

The Final Arrangements

The journey is nearing the end or perhaps it is already there. The time has come to plan for the final arrangements, whatever they may be. There are many things to consider – financial, religious, and logistical. Hopefully, at some point in time, a discussion has been held with family members about what is important. The best time to plan is early, when the individual with Alzheimer’s disease can participate and before the actual death, before emotion overrules reason.

What does the person want? Have they already made some arrangements? Is there a funeral plot or burial insurance? Where are those documents? One family utilized an “answer book” where everything was written down – what they wanted and the location of documents. What a wonderful gift to their family!

Funeral arrangements: decisions need to be made about how to handle the body. Is cremation an option? Which funeral home will be used? Is there burial insurance? If yes, what will it pay for? If not, who is paying for the service and how will that be handled? Is there a life insurance policy? How much is it for and how long before it pays? Does the funeral home require a deposit, a copy of the insurance policy, or total payment in advance?

Ceremony: what kind of ceremony is appropriate or preferred? Will it be a big church service, at the chapel of the funeral home, or a graveside service? Who will preside over the ceremony? Will it be a military service or have a flag presentation? Is morning or afternoon better? Will it be hot or cold at that time of day or year? How long do family members need to travel to the location? Will there be pallbearers and who are they? What music is requested?

Burial: Where will the person be buried? Will it be above or below ground? Do they already have a burial plot? What does the cemetery or local law require?

Memorials: will flowers be needed? If so, what kind is available or desired? Who will write the obituary? Which papers should it be placed in? Would the family prefer memorial donations to a particular charitable organization? If yes, which one(s) and what is their address?

Friends and neighbors may wish to help out during this difficult time. Make a list of things they can do to assist so that when they ask, there is something they can do or bring.

I remember finalizing arrangements for my grandmother. It had been a long, difficult illness and the journey was finally over. Out of town relatives went with us to “help”. When they started making suggestions all I could think was where were they when she was ill? There weren’t there when she was sick. How dare they tell us how to do things now!

Family caregiver

There are a lot of decisions to be made. These are some of the issues that the family will have to deal with. It might be a good idea to talk to the funeral home and get an itemized list of services and prices prior to finalizing the arrangements. Death and funerals may be extremely stressful and planning ahead can help alleviate some of the stress. The most important thing to remember is that the funeral is for the survivors. *Do it your way!*

Resources utilized for this section include:

Steps to Understanding Financial Issues: Resources for Caregivers

Steps to Understanding Legal Issues: Planning for the Future

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

Spirituality and Grief

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.

Alzheimer’s caregivers utilize a variety of coping strategies. Some of the most common methods of coping are prayer and talking with friends, relatives, or clergy. 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. Answers are found within each individual.

Acknowledging Endings

Have you ever noticed that “endings” are not what they appear to be? An ending at first seems to be *out there*, totally objective, definite, and final. However, much of what we experience around an ending is in us, and is very much wrapped up in our own subjective opinions, beliefs, and judgments. This is true even in the case of the ending of the life of a loved one, and in the ending of a long period of our having cared for a loved one.

If a situation is judged as bad, then its ending seems good. We await the end with anticipation and longing, and we tend to feel bad until that end comes. If a situation is thought to be good, and we are quite attached to a person or thing, then the end is dreaded, hated, and seems to arrive all too soon, and we gear ourselves up to be miserable. It all seems solid and real, but is it?

Everything that begins also ends. And the goodness or badness is largely a matter of attitude and judgment. Realizing clearly that all things must end can take us in two directions. We can cling stubbornly and fearfully and resist reality, which will mean that even while we still have that loved one, we will not really enjoy them due to our constant, underlying tension. Or, our serene acceptance of “temporariness” will make us free to notice and appreciate each moment, with open mind and open heart, full of gratitude and wonder.

*Written by Richard Edwards
Senior Pastor
St. Luke's United Methodist Church
Midland Texas*



Resources utilized for this section include:

fact sheet “About grief, mourning and guilt”

*Steps to Caring for a Person with Late-Stage Alzheimer’s Disease:
Responding To The Individual’s Increasing Needs*

Who Cares? Families Caring for Persons with Alzheimer’s Disease

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

Conclusion

Alzheimer's disease is a long and difficult journey with a known and certain ending. The incidence of Alzheimer's disease is growing. In the United States, every tenth person has a family member with Alzheimer's disease. Approximately one in three people know someone with the disease. In the state of Texas, a seventy-four percent (74%) increase in the number of people with Alzheimer's disease is expected by the year 2025. This will have an enormous impact on American society and economy. The loss to the families is incalculable.

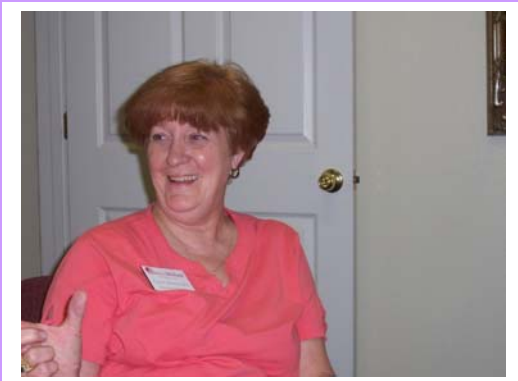
“An estimated 4.5 million Americans have Alzheimer's disease. More than 25 million Americans have a family member with Alzheimer's disease. And, more than 90 million Americans know someone with Alzheimer's disease. Since our founding in 1980, the Alzheimer's Association has been committed to enhancing the quality of life for those affected by Alzheimer's, as well as their families and friends. We will tell their story and the story of the tremendous work being accomplished by our chapter network in providing much-needed care and support. We will also strengthen our commitment to professional caregiving through funding new research into effective models of long-term care, helping to generate standards of care, and educating and training care providers.”

*From the Alzheimer's Association fact sheet
Changing the Way Americans Think About Alzheimer's Disease*

“Memory connects our days. We remember faces of loved ones, the taste of ice cream and the feel of sunshine on our faces. We remember the growing up years, the dating years and the challenges and rewards of starting new projects: marriage, jobs, advanced schooling, and hobbies. We remember other things – almost without thinking about them. We remember how to walk and how to correct our balance if we stumble. We remember how to eat and comb our hair and drink hot coffee. We remember what to do if we don’t feel good and we remember how to access assistance as needed. Memories grow over time until we have a vast bank of recalled experiences that help to guide us day by day in decision making.

Memories grow unless.....we are the victims of Alzheimers. With the diagnosis of Alzheimers the days start to slip away. Memories get tangled and then lost. The person is left without a compass in a sea of faces - the faces of strangers. The loss is so complete that one day the lady looks in the mirror and does not know who is looking at her. Everyone who has witnessed this transformation up close and personal will tell you that the process is heart breaking for everyone. To see the smile disappear and the language go is beyond being sad. Unfortunately, this process happens on a daily basis. This year hundreds of thousands of individuals will be diagnosed with Alzheimers.

Please help us to make a difference. Join the Alzheimers Memory Walk in your community. Gather your friends, family and co-workers. Share a smile and exchange memories as you walk and help to fulfill the vision of the National Alzheimers Association: A world without Alzheimers.”



Carol Armstrong, Chair
Midland Regional Council
Alzheimer’s Association

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”

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

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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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