



the compassion to care, the leadership to conquer

Alzheimer's Disease: Life Goes On An On-line Course

“Alzheimer’s Disease: Life Goes On” is the fourth 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 Goes On disease, such as estate settlement, grief, and lifestyle changes and adaptations.

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Introduction

“Alzheimer’s Disease: Life Goes On” discusses topics important to Alzheimer’s disease, such as estate settlement, grief, and lifestyle changes and adaptations. 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. Most documents are available for reviewing and printing either by using the link at the end of each section or going to the bibliography / additional resources section and clicking on the title of the document.

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

Welcome to **Alzheimer's Disease: Life Goes On**".



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*Alzheimer's Disease: Life Goes On
A Seminar for Caregivers*

OUTLINE

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***Alzheimer's Disease: Life Goes On
A Conference for Caregivers***

Course Objectives

I. The Many Emotions of Grief

Participants will be able to –

- A. Describe one intervention to cope with grief.*
- B. Identify and describe three emotions common to grief.*

II. Stress Management

Participants will be able to –

- A. Identify three methods of stress management.*
- B. Name one complication to long-term stress.*

III. Life After Loss

Participants will be able to –

- A. Identify a common difficulty for the caregiver following the loss of their loved one.*
- B. Discuss one common reaction to loss.*

IV. Settling the Estate

Participants will be able to –

- A. List four documents necessary to settle the estate.*
- B. Define “executor”.*
- C. Identify the most important consideration in settling an estate.*

The Many Emotions of Grief

The journey is over...but it isn't. It is difficult to watch someone struggle and disappear, the person they once were gone long before their physical death. After months or years of watching a loved one with Alzheimer's disease travel this devastating journey, the end has finally come. Death has been long awaited, even hoped for. And yet, after all this time, emotions are mixed and confused.

Grief begins when there is some kind of change in life. When there is an anticipated loss, mourning begins. With Alzheimer's disease, the grieving process probably began with the diagnosis or with the realization that something was wrong. While Alzheimer's disease is a terminal illness, it typically is a slow process, lasting many months or even years. The focus has been on making sure the person with Alzheimer's disease is well-cared for and treated with dignity and respect. The role of caregiver may be so overwhelming that emotions are denied or ignored. Now death has occurred and the feelings can no longer be ignored.

Conflicting emotions are normal yet difficult to deal with. There may be anger – anger that the person left. Family and friends left behind may be angry at their loved one for leaving, at dreams unrealized, a future forever altered, and personal affairs not finished. They may be angry at themselves for things left unsaid or not done, for things said and things done. There may even be anger at God for allowing this awful, devastating illness to take someone so dear from this earth. This is normal and natural.

Maybe the feeling is one of relief. It has been a long and difficult journey that is finally over. Family and friends may feel relief that their loved one is no longer suffering, that they do not have to watch the disappearance of the person they once were. The relief may be because the role of caregiver has ended at last. Life can resume some sense of normalcy.

There may be an overwhelming sense of loss, of a tremendous void in the lives of family and friends. A once overwhelming, all-consuming role of caregiver is at an end. Where once there was not enough time in the day to get everything done, now there is too much time with nothing to fill the void. The sense of loneliness and sadness may be overpowering. An important relationship is gone. Family and friend, especially the primary caregiver, may experience depression. It may be difficult to eat, concentrate, or sleep. Withdrawal from social activities, friends, hobbies and interests may have occurred during the journey and continue after the death of the person.

There may be a myriad of feelings which seem confusing. It is difficult to re-enter that other world, the world without Alzheimer's disease. The world has gone on, ever changing, always moving while the family has been consumed with the Alzheimer's journey.

“I felt that I had faced the Alzheimers and dealt with the grief every day along the journey. I was surprised to find that Mother's death was so hard for me. I was working with families every day helping them to face the challenges of Alzheimer's disease and thought I was through grieving and yet I was not really prepared to lose her. I found myself grieving two people, the mother that I knew and the sweet person I cared for in the end. The grief seemed double. I encourage those who find themselves in the same situation to be very gentle with themselves and allow their grief to run its course.”



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

Grieving does not end with death but continues forever after. It may diminish in intensity with time as the focus shifts from despair and sadness to one of peace and acceptance, gratitude for time spent together. Memories of pain, heartache, and loss fade as memories of joy, laughter, and love take over.

Resources utilized in this section include:

fact sheet “About grief, mourning and guilt”

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

Especially for the Alzheimer’s Caregiver

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

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

Stress Management

The person with Alzheimer's disease has died. The stress should have reached its end. Life should be returning to normal. But it isn't.

Alzheimer's disease is a long and difficult journey for all involved. The impact on the caregiver is extraordinary. For months and years on end, the focus has been on providing quality care for the individual with the disease. The caregiver has to deal with tremendous physical, emotional and financial stress. Just because their loved one has passed away does not mean that the stress is over.

The physical response to stress is similar to the "fight or flight" reaction to a crisis situation. The body shuts down non-essential functions while concentrating on the important systems such as heart and lung capacity. Circulation to the extremities is diminished and the focus is on the heart and lungs. The immune system temporarily shuts down. When the crisis is over, the body returns to normal function.

In caregiving for a person with Alzheimers, the crisis is ongoing and long-term. There is no relief to the impact on the body. The caregiver may experience symptoms such as blurred vision, stomach irritation, high blood pressure or behavioral changes such as irritability, lack of appetite, or inability to concentrate. This continuous stress leaves the human body susceptible to illness. It is not unusual for the caregiver to succumb to catastrophic illness or even death before the person with Alzheimer's disease. While their loved one has died, coping with the aftermath and loss is devastating. The stress is ongoing.

It is essential that family and friends learn how to manage stress. Learn about and utilize relaxation techniques. These can include things like a massage or going to a spa. Exercise is important. Swimming, dancing, walking, yoga or water aerobics are some types of exercise. Start slow and consult a physician before beginning any exercise regime. Join a club such as a service organization, reading, dance, church or bridge group. Pursue interests and hobbies. Getting involved in the community and socializing are vital to recovering from grief and stress.

Acknowledging feelings and loss are an important part of the grieving process. While losing someone to Alzheimer's disease is devastating, life does go on. Family and friends may find it difficult to accept that it is okay to laugh and smile again; it's alright to joke and enjoy life. This is a normal part of moving on. Humor is healthy and natural.

An important aspect of stress management is taking care of physical health (nutrition / exercise / social activity). Reconnect with old friends and make new ones. Family and friends need to allow themselves to live life to the fullest.

Resources utilized in this section include:

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

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

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

Life After Loss

How does someone move on after a loved one has died? For so many months and years, life has been about Alzheimers. Continuing with the pursuit of life can be hard for caregivers.

“I thought that when he finally died, I would be relieved. It had been such a long, sad journey. I hoped and prayed that he would die quickly and peacefully, yet it seemed forever. Yet when he died, what I really felt was despair and regret. There are so many things I wish I had said and done differently. I wish I could still take care of him. I’m sorry I ever wished he would die. What do I do now?”

Family caregiver

Starting over is difficult for anyone, young or old. While being in the role of caregiver, many of life’s interests and activities have been put aside. The focus has been the care giving responsibilities. When that role ends, caregivers are faced with having to redefine themselves. They often feel lost, empty, and without purpose.

Finding a way to fill the void is vital to returning to some sense of normalcy. This can be accomplished by getting involved in the community. Start a new project – maybe something that has been a long-time interest that there’s never been time to pursue. Start anew.

Beginning life over again without a loved one is not easy. But it is the greatest testament to the relationship that a person can make. Life does go on.

Resources utilized in this section include:

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

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

Settling The Estate

There are so many things to take care of when someone dies. Probably one of the most important is to settle the estate. If there is a will, it will need to be probated.

*“A will is a document created by an individual that names an **executor** – the person who will manage the estate – and the **beneficiaries** – the person or persons who will receive the estate-at the time of death. Wills are effective only when the individual who created and executed the will dies. An executor named in a will has no authority to act during the lifetime of the individual making the will.”*

*From the Alzheimer's Association brochure
Steps to Understanding Legal Issues: Planning for the Future*

If there is insurance, either medical or life, the companies need to be notified and death certificates provided. Is there a retirement fund? Who is the beneficiary of insurance and retirement? Banks, mortgage companies, credit companies, and others will require proof of death in order to conduct business.

Documents that are critical include military papers and marriage licenses (if appropriate). A copy of the will and any trust documents will be needed. It would be prudent to get multiple copies of the death certificate from the funeral home.

These are legal matters and it is recommended that an attorney be consulted. Laws vary from state to state.

Resources utilized in 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.

Conclusion

Alzheimer's disease is a long and difficult journey. But there is life after Alzheimers. Find a way to get involved in the community. Pursue personal interests and hobbies. Stay active socially. Volunteer.

The Alzheimer's Association is working to give everyone a reason to hope. There are things anyone can do to help. Learn about Alzheimer's disease and ways to reduce the risk. Take care of body and mind. Speak out for those affected by Alzheimer's. Urge lawmakers at all levels to increase funding for research, care and support. Participate in Memory Walk and help the community become more aware of the impact of this devastating disease.

Make a difference.

“Not long ago, Alzheimer's disease was widely considered a hopeless condition. It was largely unknown by doctors, researchers and policy-makers. People with the disease and their caregivers had few resources for information or support.

Today, a network of scientists, health care professionals and industry leaders is collaborating with the Alzheimer's Association to rapidly uncover the mysteries of the disease; prevent or treat its effects; and find better ways to support and care for those affected by its symptoms. Phenomenal progress in research is being made every day and what was once considered hopeless is now hopeful.”

*From the Alzheimer's Association brochure
“what's being done about alzheimer's?”*

Don't Wait Until It Hits Home

I used to think I had a fairly good understanding of "Alzheimer's Disease". I assumed Alzheimer's disease was the politically correct term for memory loss associated with aging.

My misconception regarding the symptoms, diagnosis and effect on the individual afflicted as well as his family and friends, was not realized until I began to accept the real possibility that my father had Alzheimer's disease.

Before any testing by medical professionals, individuals in my father's hometown had called me with concerns regarding his memory, driving and other cognitive functions. While taking the keys away from a parent is not one of the more memorable events in my life, it was the beginning of an education and realization that this "condition" was much more than something that had affected a strong president named Ronald Reagan; it was a disease that was slowly robbing my lifelong role models' independence.

As I began educating myself regarding this terrible disease I turned to the Alzheimer's Association for support. What I found was an organization of caring staff and volunteers willing to provide me all the necessary information and support I would need to embark on a road I had no choices but to travel.

I learned that the Alzheimer's Association was not only willing to provide me with the emotional support I needed, but it was also an organization that was dedicated to the advancement of research so that the effects of this terrible disease might spare future generations. I also learned that the care and support of the Alzheimer's Association extended to all affected; the afflicted, the family and friends. Finally, by reaching out to the Alzheimer's Association I learned that in addition to the research and support, an ongoing goal was a reduction of the risk of dementia through the promotion of brain health.

Although I initially felt that I was unique in the fears and apprehensions I was experiencing regarding the uncertain course of this disease, I now realize that I am not alone and there are many brave individuals who have paved the road so that the journey shall be easier. I am sure my story is similar to many of those who are reading my words. I am hopeful that those who shall follow will find strength and courage as we all seek to care for our loved ones, make them comfortable and work to eliminate this disease.

The mission of the Alzheimer's Association cannot be achieved or advanced without the dedicated volunteers, community support through donations, memorials/tributes and participation in our fund raisers and special events such as the Memory Walk.

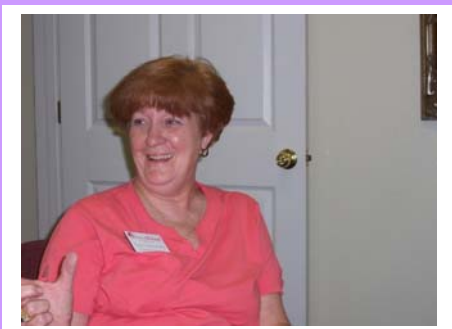
I would encourage all who read these words to continue with your ongoing support of the Alzheimer's Association including recruiting new volunteers, identifying additional sources of funding and finding additional ways to provide support to those affected.

Sincerely,
Mitch Moss
President, Regional Council, El Paso TX

“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”

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

fact sheet “Changing the Way Americans Think About Alzheimer’s disease”

what’s being done about alzheimer’s?

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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