

Module 10: Maintaining Caregiver Health

Purpose: To provide caregivers with positive information regarding things they can do to help maintain their health and endurance

Intended use: All caregivers

Introduction

When you are a caregiver it seems as if your whole focus is on the care, supervision, and maintaining quality of life for the person with dementia. It may seem like your life has become so focused on meeting the needs of the person with dementia, your needs become a last thought. Yet without the caregiver, the person with dementia would be lost.

Research shows us that caregiving is a very complex activity: draining yet rewarding; demanding yet fulfilling; boring yet challenging, and intimate yet lonely. Caregivers often suffer from guilt, fatigue and depression as their responsibilities may span decades. The effect can also be physical as caregivers may neglect their own health suffering from stress-related illnesses. A surprising number die from the prolonged stress. Caregiving stresses are compounded when caregivers must continue other responsibilities such as raising children, grandchildren, or being employed. Moreover, families are often conflicted about how caregiving should be accomplished or how much participation should be expected from each member.

Caregiving responsibilities do not end when the person with dementia is admitted to a care setting. Families/caregivers must monitor care continuously, balancing expectations with the realities of long-term-care environments, continue to provide certain aspects of care, and advocate

In America, family caregivers save the government billions by avoiding or postponing long term care placement. It is, therefore important from both governmental and personal perspectives to help caregivers stay healthy and find their roles satisfying and fulfilling. Most Americans want to care for family members, but they can not do it alone. This module focuses on maintaining health and well-being of family caregivers.

What I Love Best About Caregiving

The following exercise is to help you focus on your caregiving responsibilities.

1. On an average-to-good day, list three things you like best about caring for your person with dementia. Some suggestions might include statements like “It makes me feel capable,” “It is a way to express my love,” “My family/friends have a new respect for how capable I am,” “I am amazed at how much I get done each day,” or “I find I am good at solving problems.” Next rank them from 1-5 with 1 being the least important and 5 being the most important to you.

Things I love about being a caregiver	
1	
2	
3	

2. On an average-to-bad day, list three things you like least about caring for your person with dementia. Some suggestions might include statements like “I miss our conversations,” “He/she never says ‘thank you,’” “I feel like I’ve disappeared,” “His/her temper is awful,” or “I’m lonely.” Next rank them from 1-5 with 1 being the least disliked and 5 being the most disliked to you.

Things I like least about being a caregiver	
1	
2	
3	

3. Do these things balance out? If not, what do you do each day that you be willing to accept help in order to feel more fulfilled? Yes = I would be willing to give that up; No = I want this responsibility; N/A = I don’t help with this.

Task	Yes	No	N/A	Task	Yes	No	N/A
Managing finances &				Cleaning			
Driving, providing transportation, filling the car with gas				Cooking			
Planning all activities				Bathing			
Yardwork				Selecting clothing, dressing, and helping with grooming			
Setting limits (driving, safety, credit cards)				Toileting and/or changing soiled garments			
Laundry				Feeding my person			
Shopping for groceries				Providing night-time supervision			
Supervising/giving medications				Trying to communicate and be therapeutic			
Managing the telephone				Entertaining and making holidays			
Other				Other			

You now have a brief overview of your role as a caregiver that you can use to begin to modify in order to take care of you in addition to your person with dementia.

Taking Care of Yourself

Caregivers often experience a terrible time planning for their own needs. As the symptoms of their loved ones' illness become more pronounced and more demands made on their time, caregivers often neglect social relationships, physical and emotional health. This experience can produce depression, anger, guilt, isolation, and physical illness. Moreover friends and families may expect this degree of self-sacrifice as a part of the marriage vows or their perception of familial obligations.

The Adult Child's Lament: "But Mom/Dad, we're busy right now!"

Often adult children decline to participate in helping with care because they are "busy" with their own families or career. While we are all busy these days, this should not be an excuse to avoid all family responsibilities for care. Part of being included as a member of a family is taking both the good times and not-so-good. Common concerns of adult children include the following:

- "I don't want to remember mom/dad that way!" – Neither do you, but life doesn't really give us a choice about what we want to remember. It is the troubling experiences in life that help us to grow the most. No one chose to have a loved one develop dementia and refusing to visit and/or help is seen as abandonment. Moreover the adult child who refuses to visit is teaching his/her children about how they want to be treated by their children should they become ill in late life.
- "I'm afraid" – This is a good statement because it gives you the opportunity to share the fear. Everyone with dementia and those who care for them are afraid. Talking about it helps to make the disease less frightening, more real in day to day terms. While the person with dementia may not be able to dress himself in a few years, there are a lot of good times between now and then. Some of the more common fears include the following:
 - Fear of violence – less than 10% of people with dementia become violent
 - Fear of getting the disease – While dementing illnesses are frightening, knowing the course rather than just the lowest points can reassure that there is still quality of life.
 - Fear of being rejected by the person with dementia – especially if asked to help with placement or removing the car
 - Fear of conflict with family members about how to provide care
 - Fear of being asked to provide more care than the adult child can handle
 - Fear that the caregiving experience might threaten a job or marriage
 - Fear of traumatizing grandchildren by exposing them to someone who "is not normal" or is frightening – Care must be taken to help young and adolescent children understand that the person has an illness
 - Fear of the stigma of mental illness in the family – very few professionals feel that dementias should be categorized as a "mental illness" due to its obvious pathology in the brain.

Adult children often need help to understand about dementia and what you would have them do to help. It is a good idea to voice your expectation that they will be needed to provide help. You might generate a written list for them and then have a family meeting to open negotiations. Some things that might be included are in the table below:

Ideas for Helping the Caregiver

From a distance	Living nearby
Send funny greeting cards or flowers regularly	Pick up dry cleaning
Reviewing sources of information on the internet and forwarding them	Take a casserole for dinner once a week
Call at least twice a month and listen – even if it is repetitive or sad. Tell the caregiver and person with dementia how much you care	Call or visit at least twice a month – when you visit, just listen.
Send news of your children and pictures	Help with cleaning and fix-ups
Plan to visit at least 2-3 times a year and stay in a hotel	Take the person with dementia out for a meal
Plan to attend diagnostic appointments	Stay with the person while the caregiver gets a haircut
Remember all birthdays, anniversaries, and holidays	Serve as a sounding board without feeling like you have to “fix” problems
Consult with other family members on specific needs	Take the caregiver to a support group
Send favorite foods occasionally	Help to find local resources, including legal resources
Send theater tickets or perhaps a subscription to a film rental service	Monitor the person’s driving
Keep up-to-date on dementia for your family	Help with legal and financial issues as appropriate
Complement the caregiver on a job well-done, complement nearby relatives on the help they provide	Take the caregiver and person with dementia to church
Plan to provide actual onsite respite 1-2 times a year for 1-2 days at a time.	Stay with person so caregiver can go to a favorite social group
Now, insert three things your children could do to help and support you!	

The most important thing a caregiver must remember is that often adult children need to be asked to help and then told how to help. You must help them to understand that this is an expectation for membership in the family. You must be your own vocal advocate in meeting your needs. This is not selfish.

Taking Care of Yourself

Taking care of yourself is the most important thing you can do to take care of your loved one. Some suggestions:

1. Eat right – make sure you get a balanced diet
2. Get adequate rest
3. Drink plenty of fluids (1 ½ - 2 quarts per day are suggested for good health, but notice we do not advocate just water.)
4. Exercise at least 3 times a week (5 is preferable) for a minimum of 20 minutes
 - a. Walking, especially good if done with a friend
 - b. Dancing with your loved one
 - c. Gardening
 - d. Bowling
 - e. Swimming
 - f. Mall-walking or shopping
 - g. Exercising a pet
5. If you find you are having the following symptoms for two weeks or more call your doctor and ask about treatment with an antidepressant. There is NO SHAME in taking an antidepressant as depression is a common problem for caregivers.
 - a. Low mood, continuing sadness, crying
 - b. Feelings of hopelessness or despair
 - c. Feelings of guilt
 - d. Changes in appetite and/or weight loss
 - e. Changes in sleep patterns
 - f. Inertia, inability to get things started or completed
 - g. Nervousness or anxiety
 - h. Irritability
 - i. Memory loss or confusion
 - j. Unexplained aches and pains anywhere
6. Make sure you get annual health screenings
7. Get flu and pneumonia vaccinations
8. Make sure your tetanus immunization is current
9. Get out with friends and by yourself regularly
10. Make sure you have some time alone each day
11. Pursue a hobby, especially with family or friends
12. Find something that makes you laugh and do it regularly
13. Rent movies you enjoy
14. Attend your spiritual or religious center regularly
15. Use respite services, especially adult day programming as often as possible. With adult day programs 3 days per week is recommended
16. Attend support groups and keep in touch with professionals
17. Do something challenging (crosswords or puzzles)
18. Splurge on yourself on a regular basis, whether clothing, a food treat, a long distance phone call, or whatever makes you happy

19. Always remember that you are doing something special for someone you care deeply about. That makes you very special
20. Once a month go outside after dark, and let the universe know exactly what you are thinking!

Family Conflict

Expect family conflict during this time. Most families argue to create enough energy to cope. Each member will go through stages of grief – at their own pace. Try to keep the arguments fair and seek help from a family therapist if needed.

Support groups

Many people find support groups very helpful, while others feel embarrassed. Look in the telephone book under “Alzheimer’s Association” or go to www.alz.org to find the groups nearest to you. It may take a few tries before you find a group you like, but it is well worth the effort. Sometimes talking with other people who are experiencing similar problems and understand your concerns is invaluable. No one fully understands what it is like to live with someone with memory loss until they have done it.

Many support groups offer services for the patient: respite while the caregiver attends the meeting; support groups for patients; and/or allow patients to attend with their caregiver.

Watch your local newspaper for announcements of special speakers and events. A support group can be an invaluable new resource for making friends and social contacts. Events such as Memory Walks can involve you and your loved one in positive social events that will reduce your sense of isolation and help you to continue to feel engaged in your community..

On-Line Support

For those who have access to a computer, there are numerous home pages and information sites for neurological diseases.

[The Alzheimer List](http://alzheimer.wustl.edu/adrc2/alzheimerlist/) (<http://alzheimer.wustl.edu/adrc2/alzheimerlist/>)

A valuable resource for people with memory loss is the Alzheimer List, run by the Alzheimer’s Disease Research Center at Washington University in St. Louis. This free site is accessed by sending e-mail to the following address:

Address: mj2@lists.biostat.wustl.edu

Title: subscribe ALZHEIMER

Message: subscribe ALZHEIMER

You will receive a confirmation notice with a phrase that must be copied and returned. Once that is done you will belong to a support group staffed by laypersons and professionals. You may simply read the email messages or participate by sending or replying to messages. This support group is available to you 24/7 and is a great resource for practical answers on caregiving.

While you may not have a computer, or may be uncomfortable participating, others in your family might benefit from this free service. Many adult children copy postings from the support group for caregiving parents who are intimidated by computers.

Surfing the World Wide Web:

There are numerous sites for information on Alzheimer's disease and related disorders. As with anything on the World Wide Web, some sites are quite helpful while others may be filled with misinformation and/or products advertised to treat or even cure Alzheimer's disease.

Families must be wary of any claims for treatment or cure, especially when the product claims to be a dietary supplement, ancient treatment, or the producer implies there is a medical conspiracy to hide information. When an advance is made in treating Alzheimer's disease, you will be able to access that information on the following sites. Some helpful websites include the following:

The Alzheimer's Association: (<http://www.alz.org>)

This is a comprehensive site developed to provide families and professionals to locate chapters of the Alzheimer's Association and resources nearest you. The site also provides research update, has a library of reference materials, and caregiver information.

Agelessdesign.com: (www.agelessdesign.com)

Ageless Design is a resource for caregivers and professionals dealing with Alzheimer's disease and related dementias. On this site you will find:

The Alzheimer's Store: A resource for products for people with Alzheimer's disease and their caregivers. Visit the Alzheimer's Store web site or talk with our professional staff at (800) 752.3238 to discuss your needs. Several product categories are available:

- Products for Wandering
- Forgetfulness
- Safety, Falling & Frailty
- Bathing Products, Incontinence and Toileting Issues
- Automatic Medications Dispenser
- Activity Products and Books
- Products for a Healthy Mind
- Sing-a-Long and Respite Videos
- Recommended Reading for caregivers, healthcare professionals, children and spiritual books

The Alzheimer's Daily News: This helps you to keep abreast of the latest developments in Alzheimer's treatment, clinical drug trials, research, caregiving strategies, local/national conferences and much more.

[In Search of the Alzheimer's Wanderer:](http://alzwanderer.com/) (<http://alzwanderer.com/>) A book to help find a person with Alzheimer's once they become lost. For Caregivers, families, healthcare professionals and law enforcement professionals.

[The Alzheimer's Library:](#) A comprehensive list of books relating to Alzheimer's disease and related topics - from educational to personal stories, to caregiving issues, to professional instruction. and much more.

[US National Institutes of Health, Clinical Trials Information](http://clinicaltrials.gov/) (<http://clinicaltrials.gov/>) Families are always concerned if their person with dementia is receiving the latest and best treatment available. This website provides access to consumers to the medications currently being studied for Alzheimer's disease, the location of study sites, type of studies, the status of the study, and whether or not the sites are recruiting subjects. To use the site simply type "Alzheimer's disease" in the search box. If you are interested in participating in a study, type in Alzheimer's disease, and the name of your nearest city in the search box.

[NINDS Alzheimer's Disease Information Page](http://www.ninds.nih.gov/disorders/alzheimersdisease/alzheimersdisease.htm)
(<http://www.ninds.nih.gov/disorders/alzheimersdisease/alzheimersdisease.htm>)
Published by the U.S. Department of Health and Human Services, National Institute on Neurological Disorders and Stroke, this page provides up-to-date information on dementing illnesses and invaluable links to reputable organizations and information.

[The National Institute on Aging ADEAR Center:](http://www.nia.nih.gov/Alzheimers/) (<http://www.nia.nih.gov/Alzheimers/>)
The Alzheimer's Disease Education and Referral (ADEAR) Center Web site will help you find current, comprehensive Alzheimer's disease (AD) information and resources from the National Institute on Aging (NIA).

One service offered by ADEAR is [The Alzheimer's Fact Sheet:](http://www.nia.nih.gov/Alzheimers/Publications/adfact.htm)
(<http://www.nia.nih.gov/Alzheimers/Publications/adfact.htm>). This publication can be copied and distributed to friends and family who do not understand the basics of dementia.

Key Points: Maintaining Caregiver Health

- As a caregiver your mental and physical health can be challenged due to the stress associated with caring for someone with dementia
- Plan to ask adult children and other family members to help regularly regardless of where they live. As a member of your family they have a duty to their family members. Be prepared to ask and have an idea what to ask for.
- Take care of your own physical and mental health
- If you start to have the symptoms of depression check with your doctor about treatment
- Get respite regularly in order to pursue your own interests
- Find a support group or system. There are support groups and information sites online if there are none near your home

