

<b>Project</b>	Newsletter
<b>Objective</b>	Information and support
<b>Solution</b>	Tips and resources

*CONCEPT : CLOCK/TIME*

Magazine format

Front Cover:

[pic of hands clasped]

Head: The Hands of Time : How Symptoms Progress

Box: In this issue: The Ten Commandments of Effective Caregiving  
Tips on how to handle everyday challenges

Inside pg 2/3:

Head: The Hands of Time : How Symptoms Progress

[illus pic: clock with person struggling to hold back the hands of time]

Alzheimer's disease is progressive, which means that symptoms worsen over time. How fast the disease progresses, and what pattern symptoms might follow, varies based on each individual.

Researchers and doctors use a number of scales to measure the progression of symptoms over time, which may define as many as seven distinct stages of the disease. For general purposes, three broad phases are typically recognized: mild, moderate and severe. The symptoms commonly seen in each state follow, but it's important to realize that there may be some overlap among the stages, and that people may not experience all of these symptoms.\*

Subhead: Symptoms by State of Disease

Bullet Head: Mild Symptoms

Confusion and memory loss

Disorientation; getting lost in familiar surroundings

Problems with routine tasks

Changes in personality and judgment

Bullet Head: Moderate Symptoms

Difficulty with activities of daily living, such as eating and bathing

Anxiety, suspiciousness, agitation

Sleep disturbances

Wandering, pacing

Difficulty recognizing family and friends

Bullet Head: Severe Symptoms

Loss of speech  
Loss of appetite; weight loss  
Loss of bladder and bowel control  
Total dependence on caregiver

- Source: Gwyther LP. Care of Alzheimer's Patients: A Manual for Nursing Home Staff, Chicago: AHCA and AA, 1985

[new section: New Hope book]

According to Porter Shimer, in his new book entitled, *New Hope for People with Alzheimer's and Their Caregivers*, Shimer says, it's usually best if only one person assumes the role of primary caregiver. This is the person whose job it is to make the day-to-day decisions, as well as, do most of the day-to-day work of caring for someone with AD.

[insert photo of book]

Caption: *New Hope for People with Alzheimer's and Their Caregivers* by Porter Shimer is available online at [www.amazon.com](http://www.amazon.com) and at most bookstores.

Trying to make a person's life as meaningful and rewarding as possible can be a daunting task. This is an even bigger challenge when that person is someone close to you: It is a personal commitment that is ongoing. As a caregiver, you are faced with challenges every day. To help prepare, review the following Ten Commandments of Effective Caregiving.

#### The 10 Commandments of Effective Caregiving

Taken from *New Hope for People with Alzheimer's and Their Caregivers* by Porter Shimer

##### 1. Be Ready to Improvise

This is no such thing as a 'typical' care of Alzheimer's disease because there is no such thing as a 'typical' human brain. The illness affects every person differently, and even the same person can be affected differently on different days. Do not expect, in other words, to come up with a single game plan capable of handling any given situation for very long. The person with AD is like a moving target, ever changing, so you need to improvise as you go – finding new solutions to new problems at the very moment they arise.

##### 2. Expect the Unexpected

As AD progresses, it does increasingly more damage to parts of the brain responsible for personality and the control of the inhibitors. As a result, people with this illness may behave in ways that are out of sync – not only for them – but with what society considers acceptable. Such behaviors may include disrobing in public, using inappropriate sexual gestures, displaying seemingly unwarranted emotional outbursts, and making scathing remarks to loved ones or even strangers. Care givers need to see these behaviors purely as symptoms of the disease, the result of certain neurological connections 'shorting-out' in the brain.

##### 3. Be sensitive to Sensibility

Although these ‘short-outs’ may impair a person’s ability to realize the sensibilities of others, people with AD can be left with their own sensibilities well intact. This can be easy to overlook, especially if the person with AD appears to be particularly out of touch. You and your family may need to be more careful than you realize when conversing in your loved one’s presence.

#### 4. Assure Security

A defining feature of Alzheimer’s disease is its ability to take what was once familiar to a person and make it threateningly strange. Small wonder, then, that people with the illness benefit from constant reassurance that they’re safe and well loved. This can be done by reaching out emotionally, with lots of hugs, soothing rubs, and verbal communications of love, but also by insuring they feel safe in their physical surroundings and have activities they enjoy doing during the day.

#### 5. Strive for Peace

Attempts to discipline people with AD usually do more harm than good by causing them to become even more frustrated, agitated, guilt ridden, and confused. Your motto, consequently, should be “Make peace, not war” whenever possible. Try to redirect behavior that is problematic rather than reprimand it, or try to get to the bottom of what’s causing the behavior in the first place.

#### 6. Sympathize – Don’t Patronize

This tip can be a hard one for some caregivers, especially as AD advances and their loved one may appear in a progressively more regrettable state. Often people with AD react badly to being talked down to, however, as they still maintain a sense of dignity, regardless of how helpless they may be. It can help to keep your sentences short, however, and to use facial gestures and hand motions to emphasize your points. Remember to be equally helpful as a listener, too. If you communicate in a nonjudgmental manner, he or she is thankful more than hurt.

#### 7. Pacify Using the Past

Even though recent memories are easily lost by people with AD, often they have an amazing ability to reconnect with their past, and they derive a sense of both pleasure and security in doing so. It can be helpful to tap into these archives of good times regularly, especially during periods of inexplicable agitation when there seems to be no discernible cause.

#### 8. Let Less Be More

The urge to want to help our loved ones as much as possible is a natural one—and well intended, of course—but some research suggests we might do better to loosen our grip sometimes and let our loved ones fend more for themselves. This point was shown in a recent study by researchers from the University of Pittsburgh, who found that a group of people with AD in a nursing home learned to dress themselves better and with less fuss when their nurses took a more hands-off approach. This example doesn’t mean setting up our loved ones for frustration and failure by allowing them to wrestle with tasks beyond their abilities; it does mean having the tolerance and patience to let them try things on their own.

#### 9. Make Caregiving a Family Affair

For the sake of efficiency, it’s usually best if one person assumes the role of primary caregiver, whose job it is to make most of the day-to-day decisions as well as do most of the day-to-day work of caring for someone with AD. If this primary caregiver is you, make a list of all the people who

could be available to you, note the ways in which they might be able to help, and keep in regular contact with them about doing just that. Be careful of the trap called 'It's probably easiest if I do it myself.'

#### 10. Know When to Ask for Help

This may be the most important commandment of all, because your well-being is involved as well as your loved one's. If you begin to feel overwhelmed emotionally or physically get help to avoid breaking down entirely. You can start by calling your local chapter of the Alzheimer's Association at 800-272-3900 and simply explain your situation. Many services are available to lend you a hand.

[pic: Alzheimer assn logo]

Caption: The Alzheimer's Association can be one of your most beneficial and helpful resources. The various chapters of this organization are operated by people who are committed to helping anyone affected by Ad, whether that is the person with the disease, his or her caregiver, a family member, or a friend.

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#### For More Information

Alzheimer's Association  
225 North Michigan Avenue  
Suite 1700  
Chicago, ILL 60601-7633  
1-800-272-3900  
<http://www.alz.org>

Alzheimer's Disease Education and Referral Center (ADEAR)  
P. O. Box 8250  
Silver spring, MD 20907-8250  
Tele: 1-800-438-7380  
Fax: 301-495-3334  
<http://www.alzheimers.org>

Children of Aging Parents  
P. O. Box 167  
Richboro, PA 18954  
1-800-227-9294  
<http://www.caps4caregivers.org>

Eldercare Locator  
1-800-677-1116  
<http://www.eldercare.gov>

Family Caregiving Alliance  
180 Montgomery Street

Suite 1100  
San Francisco, CA 94104  
1-800-445-8106  
<http://www.caregiver.org>

The National Institute on Aging Information Center  
P. O. Box 8057  
Gaithersburg, MD 20898-8057  
1-800-222-2225  
1-800-222-4225 (TTY)  
<http://www.nia.nih.gov>

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