

# 2014

## A Year with Alzheimer's

A calendar for those caring for and living with Alzheimer's disease



*“A strong person knows they have strength enough for the journey, but a person of strength knows that it’s in the journey where they’ll become strong.” -Unknown*

# January 2014

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## 7 Sings of Alzheimer’s:

- Asking the same question over and over again.
- Repeating the same story, word for word, again and again.
- Forgetting how to cook, or how to make repairs, or how to play cards - activities that were previously done with ease and regularity.
- Losing one’s ability to pay bills or balance one’s checkbook.
- Getting lost in familiar surroundings, or misplacing household objects.
- Neglecting to bathe, or wearing the same clothes over and over again, while insisting that they have taken a bath or that their clothes are still clean.
- Relying on someone else, such as a spouse, to make decisions or answer questions they previously would have handled themselves.

(Alzheimer’s Disease Health Center, 2005)

## Dealing with diagnosis:

- Ask the doctor questions, knowing and learning more will only benefit you and your loved ones.
- Contact organizations such as Alzheimer’s Association and the Alzheimer’s Disease Education and referral.
- find a support group in which you can express your feelings with and possibly get advice from. The power of communication is endless.
- studies behaviors and notice different behavior changes at different times of the day and modify your schedule to improve conditions
- begin to plan for the future, financially, mentally, emotionally, and physically for you or your loved one.

(Caregiver Guide: Tips for Caregivers of People with Alzheimer’s Disease, 2010)

## Caregivers:

During the early stage, both the caregiver and the individual with AD will want to take time to adjust to the diagnosis and make plans for the future.

(Alzheimer’s Disease & Caregiving)



*“Life is ten percent what happens to you  
and ninety percent how you respond to it.”  
-Lou Holtz*

# February 2014

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## Early-stages: What to expect

- Trouble remembering recent events or conversations
- Asking the same question over and over or repeating stories
- Withdrawal from social situations and general apathy; trouble initiating an activity
- Cooking and shopping become more difficult
- Poor judgment - difficulty making wise decisions; may be easily swayed by others
- Tendency to lose things or forget where they are when they are "put away carefully"
- May become disoriented in familiar surroundings or get lost easily
- Denial that anything is wrong

(Alzheimer's Disease & Caregiving)

## Learning:

The more you know about AD, the easier it will be for you as a caregiver. One of the most difficult things to learn is to differentiate between the disease and your loved one. Particularly in the early stage, caregivers may find themselves thinking, "He's doing this to spite me!" or "She is just being lazy." In these cases, the behavior that is upsetting to the caregiver is usually a result of the disease process, not an attempt by the person with AD to hurt or frustrate the caregiver.

(Alzheimer's Disease & Caregiving)

Research has shown that the average person has symptoms for several years before a clinician diagnoses Alzheimer's. (David Snowdon, 2001, p. 88)



*“Strive for progress, not perfection.”  
-Unknown*

# March 2014

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### Emotional Support:

A diagnosis of AD can be a heart-wrenching experience for both the person diagnosed and the caregiver. The person with AD may not remember or may not admit to having the disease or ever being told they had Alzheimer's. The goal is to establish a system of emotional support that will grow and change with you as your caregiving role and the emotional challenges change.

(Alzheimer's Disease & Caregiving)

We want to retain our ability to reason, to remember, to express our thoughts, to read a new novel or the newspaper. We want, as much as possibly, to remain independent of others and when it comes to moving about, dressing, eating, and using a bathroom. We want to be spared the suffering cause by chronic illnesses. We want to live in communities with people we and love and people who love us. (David Snowden, 2001, pp. 197-198)

A disease that quickly causes a severe illness in one person may take years or even decades to cause symptoms in another. Some people develop symptoms, while others hardly show any typical symptoms at all. (David Snowden, 2001, p. 87)





*“What you do every day matters more than what you do every once in a while.” -Unknown*

# April 2014

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## Family Roles:

As the disease progresses, it will be harder for the person with AD to fulfill the roles they have typically played in the family. Focusing on these issues early will allow the person with AD to help the caregiver prepare for the future.

(Alzheimer's Disease & Caregiving)

The most important component of my health investment portfolio is eating a wide variety of fresh fruits and vegetables. More and more promising nutrients are being discovered in plants-well beyond the standard vitamins and minerals. Some of these are new antioxidants, while some are other phytochemicals that have a wide variety of health-promoting effects. As with many things that affect our health, it now appears that these nutrients work synergistically. (David Snowdon, 2001, p. 181)

There is evidence, but no documented proof, that mental stimulation (brain games), exercise (like walking, swimming, yoga), social activities, and a healthy diet (fruit, vegetables and foods high in antioxidants) may help.

(Caregiver Guide: Tips for Caregivers of People with Alzheimer's Disease, 2010)



*A whole stack of memories never equal  
one little hope. -Charles M. Schulz*

# May 2014

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## Activities



What to do all day? Finding activities that the person with Alzheimer's disease can do and is interested in can be a challenge. Building on current skills generally works better than trying to teach something new.

Mentally stimulating activities strengthen brain cells and the connections between them, and may even create new nerve cells.

(Alzheimer's Disease Health Center. 2005)

- Don't expect too much. Simple activities often are best.
- Help the person get started on an activity. Break the activity down into small steps and praise the person for each step he or she completes.
- Watch for signs of agitation or frustration with an activity. Gently help or distract the person to something else.
- Incorporate activities the person seems to enjoy into your daily routine and try to do them at a similar time each day.
- Try to include the person with Alzheimer's in the entire activity process. For instance, at mealtimes, encourage the person to help prepare the food, set the table, pull out the chairs, or put away the dishes. This can help maintain functional skills, enhance feelings of personal control, and make good use of time.
- Take advantage of adult day services, which provide various activities for the person with Alzheimer's, as well as an opportunity for caregivers to gain temporary relief from tasks associated with caregiving.

(Caregiver Guide: Tips for Caregivers of People with Alzheimer's Disease, 2010)



*Attitude is a little thing that makes a big difference. -Winston Churchill*

# June 2014

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**Middle stage:**

-Difficult behaviors emerge often, but not always. Common examples include:

-Anger, suspicion, overreacting and paranoia (e.g., believing that family members are stealing money or a spouse is having an affair)

-More repetition of questions or statements

-Wandering or sundowning (i.e., restlessness or agitation in the late afternoon and evenings)

-Fear of bathing

-Eating problems, table manners decline

-Incontinence

-Hoarding belongings

-Inappropriate sexual behavior

-Violent behavior - hitting, shouting, arming themselves for protection

-Will go from needing help choosing clothes and remembering to change clothes to needing help getting dressed

-Will progress from needing reminders regarding personal care to needing help bathing, taking medication, brushing teeth, shaving, brushing hair, toileting, etc?

-Increased difficulty with verbal expression and comprehension, particularly when trying to name items

-Spatial problems (e.g., having trouble finding their way, sometimes even at home)

-Loss of reading, writing and arithmetic abilities; difficulty following the story line of a television show

-Loss of coordination often leading to shuffling feet or gait problems

-May lose the ability to recognize family and friends at times

(Alzheimer's Disease & Caregiving)

During the middle stage of AD, the caregiver's role will expand to full time. Keeping the person with AD safe will become a priority. Both the person with AD and the caregiver will need help and support.

(Alzheimer's Disease & Caregiving)



*We must free ourselves of the hope that the sea will ever rest. We must learn to sail in high winds. -Aristotle Onassis*

# July 2014

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## Dealing With Challenging Behaviors:

We often use intuition to help us decide what to do. Unfortunately, dealing with Alzheimer's disease and other dementias is counter-intuitive; i.e., often the right thing to do is exactly opposite of what seems like the right thing to do.

(Alzheimer's Disease & Caregiving)

During Alzheimer's the insides of the brain, specifically the neurons are at constant war with many different chemicals and proteins acting much like the immune system. When neurons fail to void off predators, this causes the formation of amyloid plaques. This may be hard to imagine for our brain is home to billions of neurons. This visual may help:

The endless formation of amyloid plaques is like a school dance gone wrong. Imagine a cell "prom." Most of the time, protein molecules swirl about in specific steps. Cells even have special proteins called chaperones that try to keep order. Chaperones perform various roles in helping proteins fold into and maintain their normal forms. One large chaperone complex, for example, can completely surround a protein that's unfolding, shield it from other proteins that might stick to it, and help it to properly refold. All's well at the molecular dance until a grisly, amyloid-forming protein shows up. Scientists have learned that even one molecule of these proteins can cause healthy copies of the same protein to misfold and build gluey plaques. Too many amyloid proteins can overwhelm the chaperones, causing plaque formation to outpace the protective activities.

There is no doubt that treating depression in Alzheimer's patients can result in improvements in their mental, social, and physical functioning. (David Snowdon, 2001, p. 82)





*Wake up every morning with the thought that something wonderful is going to happen. -Unknown*

# August 2014

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## Emotional Support:

People caring for loved ones with AD frequently feel isolated, and feelings of grief and loss surface as the person they are caring for changes (see FCA fact sheet, Caregiving and Ambiguous Loss). Getting emotional support from professionals, family, friends and/or a support group as well as taking periodic breaks from the responsibilities of caregiving is crucial to the mental and physical health of caregivers. Be sure to speak to your physician if you feel depressed or anxious.

(Alzheimer's Disease & Caregiving)

As medical advances and improved living conditions allow ever more people to survive for nine decades (and beyond), the quality of life versus its quantity present a staggering challenge to the so-called oldest old-and those who care for them. (David Snowdon, 2001, p. 197)

Many people still believe that, as we age, our minds wear out, and that if we live long enough, we will inevitably become demented. This is a myth. (David Snowdon, 2001, p. 79)

Being a woman increases the risk of disease. Women as a group live longer than men, but this does not explain the entire difference in risk. It appears that many men who live longer than average for their gender are "hardy" in some ways-they are usually resistant to many diseases, including Alzheimer's. (David Snowdon, 2001, p. 80)



*What we have once enjoyed we can never lose. All that we love deeply becomes a part of us. -Helen Keller*

# September 2014

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## Respite Care:

Caregivers need a regular break or "respite" from providing care and assistance. Respite care includes in-home help (another family member, a neighbor, friend, hired caregiver, or volunteer caregiver), and out of home help (adult day care or a short stay in an assisted care facility). The "Family Care Navigator" on [www.caregiver.org](http://www.caregiver.org) can help you locate the Area Agency on Aging, a source for your local community respite resources. (See FCA's fact sheet Community Care Options and Making Choices About Everyday Care to learn about programs that can help ease the demands placed on the caregiver.)

(Alzheimer's Disease & Caregiving)

## Safety:

Creating a safe and comfortable environment is important. An occupational therapist or physical therapist can provide advice and help in making the home safer for both the caregiver and care recipient. Ask your physician, the local Alzheimer's Association or the Area Agency on Aging for a referral to a professional who is experienced in home modification and assistive devices. For people with AD who are at risk of becoming lost outside of their home, the local police should be advised, and the person should register with the Alzheimer's Association's Safe Return program.

(Alzheimer's Disease & Caregiving)



*It is by acts and not by ideas that people live. -Harry Emerson*

# October 2014

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## Medical Care:

The person with AD will need ongoing medical care both for AD and for any other health problems that might arise. Over time the caregiver will be depended upon to help provide the status update to medical staff. Make sure there is a release of information noted in the medical chart of the patient so that the physician can speak freely with you. It is important to develop a positive relationship with the physician(s) and other health care professionals. You will need them to understand your role as the caregiver, listen to your input and work with you as a team member in providing appropriate medical care.

(Alzheimer's Disease & Caregiving)

We know from the outset that Alzheimer's and longevity often have a harsh relationship: the longer you live the more likely you develop the symptoms of the disease. But we know also that approximately 55 percent of people who live to be eighty-five or older do not develop symptomatic Alzheimer's disease. (David Snowdon, 2001, p. 197)



*It is during our darkest moments that we must focus to see the light.*

*-Aristotle Onassis*

# November 2014

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## Ask for Help

If you feel over-burdened by the responsibility of caregiving, inform the rest of your family (without complaining or blaming others). Your sibling(s) may assume you're doing just fine handling everything on your own unless you tell them what challenges you're facing and specific ways they can help. As the maxim goes, "a burden shared is a burden halved."

(How To Deal with Family Conflict Caused by Alzheimer's, 2012)

The stress of caregiving can affect your health. Be sure to take care of yourself by getting regular medical care for yourself.

(Alzheimer's Disease & Caregiving)

Planning for the Future: Many caregivers wish to keep their loved one at home for as long as possible. However, if more care or a different type of care is needed than what can be provided at home, residential care is often then next best option.

(Alzheimer's Disease & Caregiving)





*The main thing in life is not to be afraid of being human. -Aaron Carter*

# December 2014

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## Late-Stage Alzheimer's Late-Stage Caregiving

- Loss of ability to communicate
- Inability to recognize people, places and objects
- Requires full assistance with all personal care activities
- Loses ability to walk
- Loses ability to smile
- Muscles may become contracted
- May lose ability to swallow

- Seizures may occur
  - Weight loss
  - Majority of time spent sleeping
  - May exhibit a need to suck on items
  - Incontinence of both bowel and bladder
- (Alzheimer's Disease & Caregiving)

## Placement:

Families caring for a loved one with end-stage Alzheimer's should give thoughtful consideration to placement in a skilled nursing facility or dementia care facility, where adequate management and supervision can be provided.  
(Alzheimer's Disease & Caregiving)

24-hour Helpline:  
1.800.272.3900 Anytime day or night, call for reliable information and support.

(Alzheimer's and Dementia Caregiver Center)

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