

ALZHEIMER'S CAREGIVER HANDBOOK

On behalf of our professional caregivers, our local team in your communities, and our corporate team who work together in caring for our Alzheimer's patients, I am pleased to make this [ALZHEIMER'S CAREGIVERS HANDBOOK](#) available at no charge to you and your loved ones.

We gratefully acknowledge the work of the Alzheimer's Association and other sources in assembling and allowing us to share this vital information with you.

Accessible supports the continued quest to provide and increase the research funding and clinical studies that is required to ultimately find the cure for this devastating disease.

Mirella Salem, President
Accessible Home Health Care

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What Is Alzheimer's Disease?

Introduction

Alzheimer's (*AHLZ-high-merz*) disease is a progressive brain disorder that gradually destroys a person's memory and ability to learn, reason, make judgments, communicate and carry out daily activities. As Alzheimer's progresses, individuals may also experience changes in personality and behavior, such as anxiety, suspiciousness or agitation, as well as delusions or hallucinations.

Although there is currently no cure for Alzheimer's, new treatments are on the horizon as a result of accelerating insight into the biology of the disease. Research has also shown that effective care and support can improve quality of life for individuals and their caregivers over the course of the disease from diagnosis to the end of life.



Photo courtesy of ONEgeneration Day Care

Dementia

Alzheimer's is the most common form of dementia, a group of conditions that all gradually destroy brain cells and lead to progressive decline in mental function. Vascular dementia, another common form, results from reduced blood flow to the brain's nerve cells. In some cases, Alzheimer's disease and vascular dementia can occur together in a condition called "mixed dementia." Other causes of dementia include frontotemporal dementia, dementia with Lewy bodies, Creutzfeldt-Jakob disease and Parkinson's disease..

Progression of Alzheimer's disease

Alzheimer's disease advances at widely different rates. The duration of the illness may often vary from 3 to 20 years. The areas of the brain that control memory and thinking skills are affected first, but as the disease progresses, cells die in other regions of the brain. Eventually, the person with Alzheimer's will need complete care. If the individual has no other serious illness, the loss of brain function itself will cause death.

Causes

Introduction

Alzheimer's disease has no known single cause, but in the last 15 years scientists have learned a great deal about factors that may play a role.

Biology of Alzheimer's disease

Scientists believe that whatever triggers Alzheimer's disease begins to damage the brain years before symptoms appear. When symptoms emerge, nerve cells that process, store and retrieve information have already begun to degenerate and die. Scientists regard two abnormal microscopic structures called "plaques" and "tangles" as Alzheimer hallmarks. Amyloid plaques (*AM-uh-loyd plaks*) are clumps of protein that accumulate outside the brain's nerve cells. Tangles are twisted strands of another protein that form inside cells. Scientists do not yet know whether plaques or tangles cause Alzheimer's or are a byproduct of some other process. Clinical trials of experimental drugs targeting amyloid are under way and should help clarify the role plaques play.

Risk factors

Scientists have learned that Alzheimer's disease involves the malfunction or death of nerve cells, but why this happens is still not known. However, they have identified certain risk factors that increase the likelihood of developing Alzheimer's and discovered clues about possible strategies to reduce risk.

Age

The greatest known risk factor is increasing age, and most individuals with the illness are 65 and older. The likelihood of developing Alzheimer's approximately doubles every five years after age 65. After age 85, the risk reaches nearly 50 percent.

Family history and genetics

Another risk factor is family history. Research has shown that those who have a parent or sibling with Alzheimer's are two to three times more likely to develop the disease than those who do not. The more individuals in a family who have the illness, the greater the risk.

Scientists have so far identified one gene that increases risk of Alzheimer's but does not guarantee an individual will develop the disorder. Research has also revealed certain rare genes that virtually guarantee an individual will develop Alzheimer's. The genes that directly cause the disease have been found in only a few hundred extended families worldwide and are thought to account for a tiny percentage of cases. Experts believe the vast majority of cases are caused by a complex combination of genetic and non-genetic influences.

Genes and environment

Age, family history and genetics are all risk factors we can't change. Scientists worldwide are looking for other risk factors that may provide opportunities for treatment or prevention. Some of our best information about the relative importance of risk factors we can and can't control comes from studies of identical twins, who are the same age and have the same genes but have different life experiences.

Several twin studies have shown that when one twin develops Alzheimer's, the other twin is at increased risk but does not always develop the disease. Other studies suggest that even in cases where both twins develop Alzheimer's, the age where symptoms appear can differ significantly. These results suggest that even when there is a strong genetic influence, other factors can play a major role.

Head injury

Research is beginning to reveal clues about some potentially controllable risk factors. There appears to be a strong link between serious head injury and future risk of Alzheimer's. It's important to protect your head by buckling up your seat belt, wearing your helmet and fall-proofing your home.

Overall brain health

One promising line of research suggests that strategies for overall healthy aging may help keep the brain healthy and may even offer some protection against Alzheimer's. These measures include eating a healthy diet, staying socially active, avoiding tobacco and excess alcohol, and exercising both body and mind.

Heart/head connection

Some of the strongest evidence links brain health to heart health. The risk of developing Alzheimer's or vascular dementia appears to be increased by many conditions that damage the heart and blood vessels, including heart disease, diabetes, stroke and high blood pressure or cholesterol. You should work with your doctor to monitor your heart health and treat any problems that arise.

Autopsy studies provide additional evidence for the heart-head connection. These studies suggest that plaques and tangles are more likely to cause Alzheimer symptoms if strokes or damage to the brain's blood vessels are also present.

10 Warning Signs of Alzheimer's Disease

Some change in memory is normal as we grow older, but the symptoms of Alzheimer's disease are more than simple lapses in memory. People with Alzheimer's experience difficulties communicating, learning, thinking and reasoning — problems severe enough to have an impact on an individual's work, social activities and family life.

The Alzheimer's Association believes that it is critical for people with dementia and their families to receive information, care and support as early as possible. To help family members and health care professionals recognize the warning signs of Alzheimer's disease, the Association has developed a checklist of common symptoms.



Photo courtesy of ONEgeneration Day Care

- 1. Memory loss.** One of the most common early signs of dementia is forgetting recently learned information. While it's normal to forget appointments, names or telephone numbers, those with dementia will forget such things more often and not remember them later.
- 2. Difficulty performing familiar tasks.** People with dementia often find it hard to complete routine tasks that are so familiar we usually do not think about how to do them. A person with Alzheimer's may not know the steps for preparing a meal, using a household appliance or participating in a lifelong hobby.
- 3. Problems with language.** Everyone has trouble finding the right word sometimes, but a person with Alzheimer's often forgets a simple word or substitutes an unusual word, making his or her speech or writing hard to understand. If a person with Alzheimer's is unable to find his or her toothbrush, for example, the individual may ask for "that thing for my mouth."
- 4. Disorientation to time and place.** It's normal to forget the day of the week or where you're going. But people with Alzheimer's disease can become lost on their own street. They may forget where they are and how they got there, and may not know how to get back home.
- 5. Poor or decreased judgment.** No one has perfect judgment all of the time. Those with Alzheimer's may dress without regard to the weather, wearing several shirts on a warm day or very little clothing in cold weather. Those with dementia often show poor judgment about money, giving away large sums to telemarketers or paying for home repairs or products they don't need.
- 6. Problems with abstract thinking.** Balancing a checkbook is a task that can be challenging for some. But a person with Alzheimer's may forget what the numbers represent and what needs to be done with them.
- 6. Misplacing things.** Anyone can temporarily misplace a wallet or key. A person with Alzheimer's disease may put things in unusual places, like an iron in the freezer or a wristwatch in the sugar bowl.

8. Changes in mood or behavior. Everyone can become sad or moody from time to time. Someone with Alzheimer's disease can show rapid mood swings — from calm to tears to anger — for no apparent reason.

9. Changes in personality. Personalities ordinarily change somewhat with age. But a person with Alzheimer's can change dramatically, becoming extremely confused, suspicious, fearful or dependent on a family member.

10. Loss of initiative. It's normal to tire of housework, business activities or social obligations at times. The person with Alzheimer's disease may become very passive, sitting in front of the television for hours, sleeping more than usual or not wanting to do usual activities.

If you recognize any warning signs in yourself or a loved one, the Alzheimer's Association recommends consulting a physician. Early diagnosis of Alzheimer's disease or other disorders causing dementia is an important step to getting appropriate treatment, care and support services.

Getting a Diagnosis

A physician should be consulted about concerns with memory, thinking skills and changes in behavior. For people with dementia and their families, an early diagnosis has many advantages:

- time to make choices that maximize quality of life
- lessened anxieties about unknown problems
- a better chance of benefiting from treatment
- more time to plan for the future

It is also important for a physician to determine the cause of memory loss or other symptoms. Some dementia-like symptoms can be reversed if they are caused by treatable conditions, such as depression, drug interaction, thyroid problems, excess use of alcohol or certain vitamin deficiencies.

Common Tests

There is no one diagnostic test that can detect if a person has Alzheimer's disease. The process involves several kinds of tests and may take more than one day. Diagnostic tools and criteria make it possible for physicians to make a diagnosis of Alzheimer's with an accuracy of about 90 percent.

Evaluations may include the following steps:

- Consultation with a primary care physician and possibly a neurologist or other specialists.
- A medical history, which collects information about current mental or physical conditions, prescription and nonprescription drug use, and family health history
- A mental status evaluation to assess sense of time and place; ability to remember, understand, and communicate; and ability to do simple math problems
- A series of evaluations that test memory, reasoning, vision-motor coordination, and language skills
- A physical examination, which includes the evaluation of the person's nutritional status, blood pressure, and pulse
- An examination that tests sensation, balance, and other functions of the nervous system
- A brain scan to detect other causes of dementia such as stroke
- Laboratory tests, such as blood and urine tests, to provide additional information about problems other than Alzheimer's that may be causing dementia
- A psychiatric evaluation, which provides an assessment of mood and other emotional factors that could cause dementia-like symptoms or may accompany Alzheimer's disease

Understanding a Diagnosis

A diagnosis of Alzheimer's usually falls into one of the following categories:

- A diagnosis of **probable Alzheimer's** indicates that the physician has ruled out all other disorders that may be causing dementia and has come to the conclusion that symptoms are most likely the result of Alzheimer's disease.
- A diagnosis of **possible Alzheimer's** means that Alzheimer's disease is probably the primary cause of dementia but that another disorder may be affecting the progression of symptoms.

It is important that you discuss the diagnosis with your physician. Some questions to ask:

- What does the diagnosis mean?
- Are additional tests needed to confirm the diagnosis?
- What changes in behavior or mental capacity can be expected over time?
- What care will be needed, and what treatment is available?
- What else can be done to alleviate symptoms?
- Are there clinical trials being conducted in my area?

Treatment Options

There is no cure for Alzheimer's disease. However, there are several drug treatments that may improve or stabilize symptoms and several care strategies and activities that may minimize or prevent behavioral problems. Researchers continue to look for new treatments to alter the course of the disease and other strategies to improve the quality of life for people with dementia.



Prescription Drugs

There numerous prescription drugs on the market you must consult with the treating physician and follow their advice and take the drugs prescribed by the physician.

Herbal Treatment

Do not self administer these over the counter products without discussing with your physician.

Behavioral and Psychiatric Symptoms

Definition

When Alzheimer's disrupts memory, language, thinking and reasoning, these effects are referred to as "cognitive symptoms" of the disease. The term "behavioral and psychiatric symptoms" describes a large group of additional symptoms that occur to at least some degree in many individuals with Alzheimer's. In early stages of the disease, people may experience personality changes such as irritability, anxiety or depression. In later stages, other symptoms may occur, including sleep disturbances; agitation (physical or verbal aggression, general emotional distress, restlessness, pacing, shredding paper or tissues, yelling); delusions (firmly held belief in things that are not real); or hallucinations (seeing, hearing or feeling things that are not there).

Many individuals with Alzheimer's and their families find behavioral and psychiatric symptoms to be the most challenging and distressing effects of the disease. These symptoms are often a determining factor in a family's decision to place a loved one in residential care. They also often have an enormous impact on care and quality of life for individuals living in long-term care facilities.

Medical evaluation

A person exhibiting behavioral and psychiatric symptoms should receive a thorough medical evaluation, especially when symptoms come on suddenly. Treatment depends on a careful diagnosis, determination of the possible causes, and the types of behavior the person is experiencing. With proper treatment and intervention, significant reduction or stabilization of the symptoms can often be achieved.

Symptoms often reflect an underlying infection or medical illness. For example, the pain or discomfort caused by pneumonia or a urinary tract infection can result in agitation. An untreated ear or sinus infection can cause dizziness and pain that affect behaviors. Side effects of prescription medication are another common contributing factor to behavioral symptoms. Side effects are especially likely to occur when individuals are taking multiple medications for several health conditions, creating a potential for drug interactions.

Non-drug interventions

There are two distinct types of treatments for agitation: non-drug interventions and prescription medications. Non-drug interventions should be tried first. In general, steps to managing agitation include (1) identifying the behavior, (2) understanding its cause, and (3) adapting the caregiving environment to remedy the situation.

Correctly identifying what has triggered symptoms can often help in selecting the best environment.

- Change in caregiver
- Change in living arrangements
- Travel
- Hospitalization
- Presence of houseguests
- Bathing
- Being asked to change clothing

A key principle of intervention is redirecting the affected individual's attention, rather than arguing, disagreeing, or being confrontational with the person. Additional intervention strategies include the following:

- Simplify the environment
- Simplify tasks and routines
- Allow adequate rest between stimulating events
- Use labels to cue or remind the person
- Equip doors and gates with safety locks
- Remove guns
- Use lighting to reduce confusion and restlessness at night

Medications to treat agitation

Medications can be effective in the management of some symptoms of agitation, but they must be used carefully and are most effective when combined with behavioral or environmental changes. Medications should target specific symptoms so that improvement can be monitored. People with Alzheimer's disease are susceptible to serious side effects that require close observation. In general, it is best to begin treatment with a single medication and with low doses.

Alternative Treatments for Alzheimer's

Introduction

Several herbal remedies and other dietary supplements are promoted as effective treatments for Alzheimer's disease and related disorders. Claims about the safety and effectiveness of these products, however, are based largely on testimonials, tradition, and a rather small body of scientific research. The rigorous scientific research required by the U.S. Food and Drug Administration for the approval of a prescription drug is not required by law for the marketing of dietary supplements.

Concerns about alternative therapies

Although many of these remedies may be valid candidates for treatments, there are legitimate concerns about using these drugs as an alternative or in addition to physician-prescribed therapy:

- **Effectiveness and safety are unknown.** The maker of a dietary supplement is not required to provide the U.S. Food and Drug Administration (FDA) with the evidence on which it bases its claims for safety and effectiveness.
- **Purity is unknown.** The FDA has no authority over supplement production. It is a manufacturer's responsibility to develop and enforce its own guidelines for ensuring that its products are safe and contain the ingredients listed on the label in the specified amounts.
- **Bad reactions are not routinely monitored.** Manufacturers are not required to report to the FDA any problems that consumers experience after taking their products. The agency does provide voluntary reporting channels for manufacturers, health care professionals, and consumers, and will issue warnings about products when there is cause for concern.
- **Dietary supplements can have serious interactions** with prescribed medications. No supplement should be taken without first consulting a physician.

Stages of Alzheimer's Disease

Experts have documented common patterns of symptom progression that occur in many individuals with Alzheimer's disease and developed several methods of "staging" based on these patterns. Progression of symptoms corresponds in a general way to the underlying nerve cell degeneration that takes place in Alzheimer's disease. Nerve cell damage typically begins with cells involved in learning and memory and gradually spreads to cells that control every aspect of thinking, judgment, and behavior. The damage eventually affects cells that control and coordinate movement.

Staging systems provide useful frames of reference for understanding how the disease may unfold and for making future plans. But it is important to note that all stages are artificial benchmarks in a continuous process that can vary greatly from one person to another. Not everyone will experience every symptom and symptoms may occur at different times in different individuals. People with Alzheimer's live an average of 8 years after diagnosis, but may survive anywhere from 3 to 20 years.

The framework for this section is a system that outlines key symptoms characterizing seven stages ranging from unimpaired function to very severe cognitive decline. This framework is based on a system developed by Barry Reisberg, M.D., Clinical Director of the New York University School of Medicine's Silberstein Aging and Dementia Research Center.

Within this framework, we have noted which stages correspond to the widely used concepts of mild, moderate, moderately severe, and severe Alzheimer's disease. We have also noted which stages fall within the more general divisions of early-stage, mid-stage, and late-stage categories.

Stage 1: No impairment (normal function)

Unimpaired individuals experience no memory problems and none are evident to a health care professional during a medical interview.

Stage 2: Very mild cognitive decline (normal age-related changes)

Individuals may feel as if they have memory lapses, especially in forgetting familiar words or names or the location of keys, eyeglasses or other everyday objects. But these problems are not evident during a medical examination or apparent to friends, family or co-workers.

Stage 3: Mild Decline

Friends, family or co-workers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview. Common difficulties include:

- Word- or name-finding problems noticeable to family or close associates
- Decreased ability to remember names when introduced to new people
- Performance issues in social or work settings noticeable to family, friends or co-workers
- Reading a passage and retaining little material
- Losing or misplacing a valuable object
- Decline in ability to plan or organize

**Stage 4: Moderate cognitive decline
(Mild or early-stage Alzheimer's disease)**

At this stage, a careful medical interview detects clear-cut deficiencies in the following areas:

- Decreased knowledge of recent occasions or current events
- Impaired ability to perform challenging mental arithmetic-for example, to count backward from 100 by 7s
- Decreased capacity to perform complex tasks, such as marketing, planning dinner for guests or paying bills and managing finances
- Reduced memory of personal history
- The affected individual may seem subdued and withdrawn, especially in socially or mentally challenging situations

**Stage 5: Moderately severe cognitive decline
(Moderate or mid-stage Alzheimer's disease)**

Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential. At this stage, individuals may:

- Be unable during a medical interview to recall such important details as their current address, their telephone number or the name of the college or high school from which they graduated
- Become confused about where they are or about the date, day of the week, or season
- Have trouble with less challenging mental arithmetic; for example, counting backward from 40 by 4s or from 20 by 2s
- Need help choosing proper clothing for the season or the occasion
- Usually retain substantial knowledge about themselves and know their own name and the names of their spouse or children
- Usually require no assistance with eating or using the toilet

**Stage 6: Severe cognitive decline
(Moderately severe or mid-stage Alzheimer's disease)**

Memory difficulties continue to worsen, significant personality changes may emerge and affected individuals need extensive help with customary daily activities. At this stage, individuals may:

- Lose most awareness of recent experiences and events as well as of their surroundings
- Recollect their personal history imperfectly, although they generally recall their own name
- Occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces
- Need help getting dressed properly; without supervision, may make such errors as pajamas over clothes or shoes on wrong feet

- Experience disruption of their normal sleep/waking cycle
- Need help with handling details of toileting (flushing toilet, wiping and disposing of tissue properly)
- Have increasing episodes of urinary or fecal incontinence
- Experience significant personality changes and behavioral symptoms, including suspiciousness and delusions (for example, believing that their caregiver is an impostor); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviors such as hand-wringing or tissue shredding
- Tend to wander and become lost

**Stage 7: Very severe cognitive decline
(Severe or late-stage Alzheimer's disease)**

This is the final stage of the disease when individuals lose the ability to respond to their environment, the ability to speak and, ultimately, the ability to control movement.

- Frequently individuals lose their capacity for recognizable speech, although words or phrases may occasionally be uttered
- Individuals need help with eating and toileting and there is general incontinence of urine
- Individuals lose the ability to walk without assistance, then the ability to sit without support, the ability to smile, and the ability to hold their head up. Reflexes become abnormal and muscles grow rigid. Swallowing is impaired.

Dispelling Myths about Alzheimer's

Myth 1: Memory loss is a natural part of aging.

Reality: In the past people believed memory loss was a normal part of aging, often regarding even Alzheimer's as natural age-related decline. Experts now recognize severe memory loss as a symptom of serious illness.

Whether memory naturally declines to some extent remains an open question. Many people feel that their memory becomes less sharp as they grow older, but determining whether there is any scientific basis for this belief is a research challenge still being addressed.

Myth 2: Alzheimer's disease is not fatal.

Reality: Alzheimer's is a fatal disease. It begins with the destruction of cells in regions of the brain that are important for memory. However, the eventual loss of cells in other regions of the brain leads to the failure of other essential systems in the body. Also, because many people with Alzheimer's have other illnesses common in older age, the actual cause of death may be no single factor

Myth 3: Drinking out of aluminum cans or cooking in aluminum pots and pans can lead to Alzheimer's disease.

Reality: Based on current research, getting rid of aluminum cans, pots, and pans will not protect you from Alzheimer's disease. The exact role (if any) of aluminum in Alzheimer's disease is still being researched and debated. However, most researchers believe that not enough evidence exists to consider aluminum a risk factor for Alzheimer's or a cause of dementia.

Myth 4: Aspartame causes memory loss.

Reality: Several studies have been conducted on aspartame's effect on cognitive function in both animals and humans. These studies found no scientific evidence of a link between aspartame and memory loss.

Aspartame was approved by the U.S. Food and Drug Administration (FDA) in 1996 for use in all foods and beverages. The sweetener, marketed as Nutrasweet® and Equal®, is made by joining two protein components, aspartic acid and phenylalanine, with 10 percent methanol. Methanol is widely found in fruits, vegetables and other plant foods.

Myth 5: There are therapies available to stop the progression of Alzheimer's disease.

Reality: At this time, there is no medical treatment to cure or stop the progression of Alzheimer's disease. FDA-approved drugs may temporarily improve or stabilize memory and thinking skills in some individuals.

Statistics about Alzheimer's Disease



Alzheimer's disease is not a normal part of aging. It is a devastating disorder of the brain's nerve cells that impairs memory, thinking, and behavior and leads, ultimately, to death. The impact of Alzheimer's on individuals, families and our health care system makes the disease one of our nation's greatest medical, social and economic challenges.

- An estimated 4.5 million Americans have Alzheimer's disease. The number of Americans with Alzheimer's has more than doubled since 1980.¹
- The number of Americans with Alzheimer's disease will continue to grow – by 2050 the number of individuals with Alzheimer's could range from 11.3 million to 16 million.¹
- Finding a treatment that could delay onset by five years could reduce the number of individuals with Alzheimer's disease by nearly 50 percent after 50 years.²
- In a Gallup poll commissioned by the Alzheimer's Association, 1 in 10 Americans said that they had a family member with Alzheimer's and 1 in 3 knew someone with the disease.³
- Increasing age is the greatest risk factor for Alzheimer's. One in 10 individuals over 65 and nearly half of those over 85 are affected.⁴ Rare, inherited forms of Alzheimer's disease can strike individuals as early as their 30s and 40s.⁵
- A person with Alzheimer's disease will live an average of eight years and as many as 20 years or more from the onset of symptoms as estimated by relatives.⁶ From the time of diagnosis, people with Alzheimer's disease survive about half as long as those of similar age without dementia. Average survival time is affected by age at diagnosis and severity of other medical conditions.⁷
- National direct and indirect annual costs of caring for individuals with Alzheimer's disease are at least \$100 billion, according to estimates used by the Alzheimer's Association and the National Institute on Aging.⁸
- Alzheimer's disease costs American business \$61 billion a year, according to a report commissioned by the Alzheimer's Association. Of that figure, \$24.6 billion covers Alzheimer health care and \$36.5 billion covers costs related to caregivers of individuals with Alzheimer's, including lost productivity, absenteeism and worker replacement.⁹

- More than 7 out of 10 people with Alzheimer's disease live at home, where almost 75 percent of their care is provided by family and friends.⁶ The remainder is "paid" care costing an average of \$19,000 per year. Families pay almost all of that out of pocket.¹⁵
- Half of all nursing home residents have Alzheimer's disease or a related disorder.¹¹
- The average cost for nursing home care is \$42,000 per year¹⁰ but can exceed \$70,000 per year in some areas of the country.¹²
- The average lifetime cost of care for an individual with Alzheimer's is \$174,000.⁸
- Medicare costs for beneficiaries with Alzheimer's are expected to increase 75 percent, from \$91 billion in 2005 to \$160 billion in 2010; Medicaid expenditures on residential dementia care will increase 14 percent, from \$21 billion in 2005 to \$24 billion in 2010, according to a report commissioned by the Alzheimer's Association.¹³
- The Alzheimer's Association has awarded more than \$165 million in research grants since 1982, according to our audited annual financial statements.
- The federal government estimates spending approximately \$647 million for Alzheimer's disease research in fiscal year 2005.¹⁴

References

For questions or further information on statistics, please contact the Alzheimer's Association Benjamin B. Green-Field Library and Resources by calling 1.800.272.3900 or 1.312.335.9602 or by e-mailing greenfield@alz.org.

¹ Hebert, LE; Scherr, PA; Bienias, JL; Bennett, DA; Evans, DA. "Alzheimer Disease in the U.S. Population: Prevalence Estimates Using the 2000 Census." *Archives of Neurology* August 2003; 60 (8): 1119 – 1122.

² Brookmeyer, R; Gray, S; Kawas, C. "Projections of Alzheimer's Disease in the United States and the Public Health Impact of Delaying Disease Onset." *American Journal of Public Health* 1998; 88(9): 1337 – 1342.

³ 1992 Gallup survey of 1,015 individuals. For more information, please contact our Green-Field Library.

⁴ Evans, DA; Funkenstein, HH; Albert, MS; et al. "Prevalence of Alzheimer's Disease in a Community Population of Older Persons: Higher than Previously Reported." *JAMA* 1989; 262(18): 2552 – 2556.

⁵ Bird, TD; Sumi, SM; Nemens, EJ; Nochlin, D; Schellenberg, G; et al. "Phenotypic Heterogeneity in Familial Alzheimer's Disease: A Study of 24 Kindreds." *Annals of Neurology* 1989; 25(1): 12 – 25.

⁶ *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias*. U.S. Congress Office of Technology Assessment; U.S. Government Printing Office, 1987; p. 14.

⁷ Larson, EB, Shadlen, M-F, et al. "Survival after Initial Diagnosis of Alzheimer Disease." *Annals of Internal Medicine*, 6 April 2004; pp. 501 - 509.

⁸ Ernst, RL; Hay, JW. "The U.S. Economic and Social Costs of Alzheimer's Disease Revisited." *American Journal of Public Health* 1994; 84(8): 1261 – 1264. For the \$100 billion annual cost, this study cites figures based on 1991 data, which were updated in the journal's press release to 1994 figures. Cited in *2001 – 2002 Alzheimer's Disease Progress Report*. National Institutes of Health publication number 03-5333, July 2003; p. 2.

⁹ Koppel, R. *Alzheimer's Disease: The Costs to U.S. Businesses in 2002*. Washington, D.C.: Alzheimer's Association; 2002.

¹⁰ Rice, DP; et al. "The Economic Burden of Alzheimer's Disease." *Health Affairs*, Summer 1993; 12(2): 164 – 176.

¹¹ *National Nursing Home Survey*. National Center for Health Statistics, 1985; p. 49.

¹² Unpublished data reported by Alzheimer's Association chapters in some regions.

¹³ *Saving Lives, Saving Money: Dividends for Americans Investing in Alzheimer Research*. A report from the Lewin Group, commissioned by the Alzheimer's Association. Washington, D.C.: 2004.

¹⁴ Unpublished analysis of federal budget documents by Alzheimer's Association senior public policy staff.

¹⁵ Fox, PJ; Kohatsu, N; et al. "Estimating Costs of Caring for People with Alzheimer's Disease in California: 2000 - 2040." *Journal of Public Health Policy* 2001; 22(1): 88 - 97.

Care with Confidence

No two people experience Alzheimer's disease in the same way. People with the disease can maximize their ability to function in daily life with drug treatments and adjustments to daily routines. As time goes on, the need for care assistance will increase.

Because of the disease's unpredictable course, there is no way to predict what a caregiver's role will involve. Responsibilities can include making important legal decisions, managing changes in a loved one's behavior and helping him or her maintain hygiene.

Day-to-Day Care

As Alzheimer's progresses, it can affect an individual's personality, abilities and moods. There is no exact way to deal with these changes. The information in the following sections provides creative approaches to managing a person's daily routine and safeguarding his or her safety.



Activities

Introduction

Activities are the things that we do, including getting dressed, doing chores and even paying bills. They can represent who we are and what we're about. For the person with Alzheimer's, they can mean the difference between feeling loved and needed and unloved and unnecessary.

When planning activities and daily tasks to help the person with Alzheimer's organize the day, think about:

- What skills and abilities does the person have?
- What does the person enjoy doing?
- Does the person begin activities without direction?
- Does the person have physical problems?

Your approach

- Make the activities part of your daily routine.
- Focus on enjoyment, not achievement.
- Determine what time of day is best for the activity.
- Offer support and supervision.
- Be flexible and patient, and stress involvement.
- Help the person remain as independent as possible.
- Simplify instructions.
- Establish a familiar routine.

The environment

- Make activities safe.
- Change your surroundings to encourage activities.
- Minimize distractions that can frighten or confuse the person.

Structuring the day

When structuring the day, consider the following activities:

Morning activities

- Wash up, brush teeth and get dressed.
- Prepare and eat breakfast.
- Discuss the newspaper or reminisce about old photos.

Afternoon activities

- Prepare and eat lunch, read mail and clear and wash dishes.
- Listen to music or do a crossword puzzle.
- Take a walk.

Evening activities

- Prepare and eat dinner.
- Play cards or watch a movie.
- Read a book or magazine.

Communication

People with Alzheimer's disease often find it difficult to express themselves and understand others. They may:

- Have difficulty finding the right words.
- Use familiar words repeatedly.
- Invent new words to describe familiar objects.
- Frequently lose their train of thought.
- Experience difficulty organizing words logically.
- Revert to speaking in a native language.
- Curse or use offensive words.
- Speak less often.
- Rely on nonverbal gestures.



Tips for enhancing communication

- Show that you are listening and trying to understand what is being said.
- Maintain eye contact.
- Encourage the person to continue to express thoughts even if he or she is having difficulty.
- Be careful not to interrupt.
- Avoid criticizing, correcting and arguing.
- Be calm and supportive.
- Use a gentle, relaxed tone of voice.
- Use positive, friendly facial expressions.
- Always approach the person from the front, identify yourself and address him or her by name.
- Speak slowly and clearly.
- Use short, simple and familiar words.

- Break tasks and instructions into clear, simple steps.
- Ask one question at a time.
- Allow enough time for a response.
- Avoid using pronouns and identify people by their names.
- Avoid using negative statements and quizzing (e.g., “You know who that is, don’t you?”).
- Use nonverbal communication such as pointing and touching.
- Offer assistance as needed.
- Don’t talk about the person as if he or she wasn’t there.
- Have patience, flexibility and understanding.

Depression

Introduction

Depression is a common cause of “reversible” dementia in older adults. Depression is four times more likely to strike those over age 65 than younger individuals.

It is found in 20 percent of persons with Alzheimer’s disease, in up to 50 percent of Alzheimer caregivers and in 15 percent of adults over age 65. Sadly, most people never get help for this treatable illness.

Those with Alzheimer’s disease commonly exhibit symptoms of depression in the early stages of the disease, while they are still aware. Because depression and dementia share common symptoms, the two are sometimes confused, with the result that depression often goes untreated in persons with Alzheimer’s disease. Alzheimer symptoms, however, are more progressive than the symptoms of depression and include profound memory loss. While their depression can be treated through medications, the cognitive abilities of persons with dementia will continue to decline.

Symptoms of depression

Persons with depression may lose interest or pleasure in activities that were once fulfilling, have difficulty concentrating or experience feelings of hopelessness and worthlessness. They may exhibit such physical symptoms as changes in appetite, weight, energy and sleeping patterns.

The presence of at least four of the following symptoms over a two-week period may indicate depression:

- Depressed or irritable mood
- Feelings of worthlessness or excessive guilt
- Suicidal thinking or attempts
- Motor retardation or agitation
- Disturbed sleep
- Fatigue and loss of energy
- Loss of interest or pleasure in usual activities
- Difficulty thinking or concentrating
- Changes in appetite and weight

Source: American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders

Treatment is available

If symptoms of depression are present, it is important for you to obtain a complete medical evaluation to rule out any other physical causes. Medications or an unrecognized disorder may cause depression.

If there are no other underlying causes, consult a psychiatrist to obtain a diagnosis. Geriatric psychiatrists specialize in recognizing and treating depression in older adults.

There is no one test to identify depression. The diagnosis involves an assessment of medical history, interviews with the person with Alzheimer's and family members and a mental status examination.

Treatment for depression can include some combination of medicine, therapy, psychosocial support and activities.

Driving

Introduction

Driving is a complex activity that demands quick reactions, alert senses and split-second decision making. For a person with Alzheimer's, driving inevitably becomes difficult.

A diagnosis of Alzheimer's disease does not mean the person has lost all ability to drive. Caregivers should evaluate the person regularly to determine if it is safe for him or her to drive.

Warning signs of unsafe driving

- Forgetting how to locate familiar places
- Failing to observe traffic signals
- Making slow or poor decisions
- Driving at an inappropriate speed
- Becoming angry and confused while driving

For many, restricting driving privileges signifies a loss of independence and mobility, often forcing people with the disease to rely on friends, family and community services for transportation. This sense of dependence may prevent people with dementia from giving up the car keys.

Tips to limit driving

- Ask a doctor to write the person a "do not drive" prescription
- Control access to the car keys
- Disable the car by removing the distributor cap or battery
- Park the car on another block or in a neighbor's driveway
- Have the person tested by the Department of Motor Vehicles
- Arrange for other transportation
- Substitute the person's driver's license with a photo identification card (in addition to making the car inaccessible)

Home Safety

Introduction

When caring for an individual with Alzheimer's disease at home, safety and accessibility are important concerns. There are simple steps you can take to make the home safe for the person with Alzheimer's.

Make potentially dangerous places less accessible

- Lock or disguise hazardous areas.
- Install door locks out of sight.
- Use special safety devices, such as child-proof locks and door knobs, to limit access to places where knives, appliances, equipment and cleaning fluids are stored.

Accommodate for visual changes

- Diffuse bright light by removing or covering mirrors and glass-top furniture, and cover windows with blinds, shades or sheer draperies.
- Add extra lighting in entries, outside landings, areas between rooms, stairways and bathrooms because changes in levels of light can be disorienting.
- Place contrasting colored rugs in front of doors or steps to help the individual anticipate staircases and room entrances.

Avoid injury during daily activities

- Monitor the temperature of water faucets and food because the person may have a decreased sensitivity to temperature.
- Install walk-in type showers , grab bars and decals to slippery surfaces in the bathroom to prevent falls.
- Supervise the person in taking prescription and over-the-counter medications.

Beware of hazardous objects and substances

- Limit the use of certain appliances and equipment such as mixers, grills, knives and lawnmowers.
- Supervise smoking and alcohol consumption.
- Remove objects, such as magazine racks, coffee tables and floor lamps, to create safe wandering areas and reduce the possibility of injury.
- Clean out the refrigerator regularly and discard inedible food.
- Lock firearms in a cabinet or drawer, or remove them from the house. Don't allow unsupervised access to firearms.

Be prepared for emergencies

- Keep a list of emergency phone numbers and addresses for local police and fire departments, hospitals and poison control help lines.
- Check fire extinguishers and smoke alarms and conduct fire drills regularly.
- Enroll the person with Alzheimer's disease in the Alzheimer's Association Safe Return® program, a nationwide system designed to identify, locate and return to safety persons who are memory impaired. To learn more about Safe Return.

Hygiene and Personal Care

Introduction

People with Alzheimer's disease may need help with routine activities related to grooming and hygiene. The need for assistance can be very difficult for them because it signifies a loss of independence and privacy.

It is also difficult for caregivers, especially when they assist with activities that interfere with the individual's privacy. On this page, you will find tips on handling grooming and hygiene tasks for an individual with Alzheimer's disease.

Bathing

Bathing is often the most difficult personal care activity that caregivers face. Because it is such an intimate experience, the person with Alzheimer's may perceive it as unpleasant, threatening or painful and, in turn, exhibit disruptive behaviors such as screaming, resisting and hitting. These behaviors often occur because the person doesn't know what bathing is for or doesn't have the patience to endure such unpleasant aspects as lack of modesty, being cold or experiencing discomfort. Try the following:

- Do everything you can in advance to make the process easier, such as increasing the room temperature and having bath towels nearby.
- Make the person feel in control. Involve and coach him or her through each step of the process. You may need to experiment to determine if the individual prefers showers or tub baths and what time of day is best.
- Create a safe and pleasing atmosphere. Place non/slip adhesive on the floor surface and grab bars in the bathtub to prevent falls. Test water temperature in advance to prevent burns.
- Respect the person's dignity. Some individuals may be self-conscious about their nakedness. Allowing the person to hold a towel in front of their body, both in and out of the shower, may ease anxiety.
- Don't worry about the frequency of bathing. It may not be necessary to bathe every day. Sponge baths can be effective between showers or baths.
- Be gentle. The person's skin may be very sensitive, so avoid scrubbing and pat skin dry instead of rubbing.
- Be flexible. You may experience the most difficulty when attempting to wash the person's hair. Use a washcloth to soap and rinse hair to reduce the amount of water on the person's face.

Using the bathroom

It is common for persons with Alzheimer's disease to experience loss of bladder and/or bowel control. This can be caused by many factors, including medications, stress, a physical condition, the environment, and the person's clothing. If incontinence is a new problem, consult your doctor to rule out potential causes such as a urinary tract infection, weak pelvic muscles or medications. If the problem continues, try to:

- Provide visual cues. Signs may assist an individual in finding the bathroom. Placing colored rugs on the bathroom floor and lid covers on the toilet may help the bathroom stand out. Avoid having items nearby that can be mistaken for a toilet, such as a trash can.
- Monitor incontinence. Identify when accidents occur and plan accordingly. For example, if they happen every two hours, get the person to the bathroom before that time. To help control incontinence at night, limit the intake of liquids after dinner and in the evening.
- Remove obstacles. Make sure clothing is easy for the individual to remove.
- Provide reminders. Because the person with Alzheimer's may forget to use the bathroom, you may need to remind him or her periodically. Also watch for visible cues such as restlessness or facial expressions that may indicate the person needs to use the bathroom.
- Be supportive. Help the person with Alzheimer's retain a sense of dignity despite incontinence problems. A reassuring attitude will help lessen feelings of embarrassment.

Dental care

Good oral hygiene can be a challenge for individuals with Alzheimer's. Brushing is sometimes difficult due to the individual's inability to understand and accept assistance from others. To help the individual:

- Provide short, simple instructions. "Brush your teeth" may be too difficult. Instead try: "hold your toothbrush," "put paste on the brush" and "brush your top teeth," etc.
- Use a mirroring technique. Hold a brush and show the individual how to brush his or her teeth.
- Monitor daily oral care. Brush teeth or dentures after each meal and floss daily. Remove and clean dentures every night, and brush the person's gums and roof of the mouth. If the person refuses to open his or her mouth, try using oral hygiene aids available from your dentist to prop the mouth open. Strained facial expressions during dinner or refusal to eat may indicate oral discomfort.

Caregivers are essential in helping the person maintain oral hygiene, noticing any problems and seeking help from a dentist. Notify the dentist in advance that the person has Alzheimer's, so that an oral care routine can be developed.

Dressing

Physical appearance contributes to everyone's sense of self-esteem. Clothing can be a form of self-expression, so it's important to consider the person's tastes and dislikes. To help the person with dressing:

- Simplify choices. Each morning, offer two choices of shirts and pants for the individual. Keep the closet free of excess clothing.
- Organize the process. Lay out clothing in the order it needs to be put on, or hand the person each piece while giving short, simple instructions. Don't rush the individual; it will only create anxiety.
- Be flexible. If the individual wants to wear the same outfit repeatedly, try getting a duplicate of the outfit or have similar options available.
- Choose comfortable and simple clothing. Cardigans or shirts that button in front are sometimes easier to work than pullover tops. Substitute Velcro™ for buttons, snaps or zippers that may be too difficult to handle. Make sure the individual has comfortable shoes that are not slippery.

With all personal care activities, it is important to incorporate the individual's past routine whenever possible into the current one.

As you assist the person, be patient and creative. An approach that worked one day may not work the next, so be flexible.

Late-Stage Care

Introduction

Comfort, dignity and respect — these are important words for caregivers to remember in ensuring quality of life during the late stage of Alzheimer's disease.

At this point in the disease process, people typically lose the ability to talk and walk and experience difficulties with eating. Families and care providers play a critical role in making tough decisions that ultimately respect the person's end-of-life wishes and at the same time maintain the person's dignity and comfort.

Advance directives

Ideally, discussions about end-of-life issues should take place while the person with the disease still has the capacity to make decisions.

People with Alzheimer's have the legal right to limit or forgo medical or life-sustaining treatment, including the use of mechanical ventilators, cardiopulmonary resuscitation, antibiotics and artificial nutrition and hydration. These wishes can be expressed through advance directives.

Two common forms of advance directives are a living will and a durable power of attorney for health care. A living will states the individual's choices for future medical care decisions. The durable power of attorney allows the person with Alzheimer's to designate a surrogate, usually a trusted family member, to make specific decisions about treatment on his or her behalf.

Family members should not equate the refusal or withdrawal of treatment, including treatment for life-threatening illnesses (infections, hemorrhaging, heart attacks, etc.) as euthanasia or assisted suicide. In fact, aggressive medical treatment may feel like torture to an individual who is in unfamiliar surroundings and does not understand the intentions of the care providers.

If there are no advance directives in place, families and care providers should try to make decisions consistent with what they think the individual's wishes would have been. Typically, nursing homes and hospitals have ethics committees that can facilitate the decision-making process if there is a conflict between family members or with the care provider.

Artificial nutrition and hydration

People with Alzheimer's may also refuse to eat and drink. Such cases should be evaluated to make sure that they are not due to conditions, such as constipation, kidney failure, nausea and fluid and electrolyte imbalance, that could be reversed with medications.

One of the more difficult decisions for families to make is whether or not to withhold nutrition and hydration in response to a patient's refusal to eat or drink. Many families and care providers believe that it is appropriate to do everything in their power to get the person to eat or drink. The use of feeding tubes and intravenous (IV) hydration is often assumed to prolong life when in fact it could be lengthening the dying process. In addition, if these artificial means are used, families will eventually be faced with the tough decision about whether or not to withdraw such treatment.

Treating infections

Pneumonia and urinary tract infections are common in the last stage of Alzheimer's. The person's advance directive should indicate whether preventive measures such as pneumonia vaccines and antibiotics may be used. If the Alzheimer patient does not wish to receive these, care providers can use medications to reduce pain and make the person more comfortable.

If the patient cannot talk, it is important to look for behavioral clues such as depressive or psychotic symptoms, anxiety and sleep and activity disturbances that may indicate he or she is experiencing pain.

Restraints

Restraints may be used in long-term care settings and hospitals as a means to control Alzheimer-related behavior problems such as wandering, agitation and combativeness. They are also used to prevent patients who are receiving artificial nutrition from pulling out the feeding tube.

Although restraints are intended to protect the safety of the patient, their use can cause harm as well as jeopardize the individual's independence and dignity.

According to the Joint Commission on Accreditation of Health Care Organizations (JCAHO) , an organization that evaluates and accredits health care organizations, studies have demonstrated that effective programming can eliminate the need for restraints.

Physical restraints restrict the person's ability to move and, as a result, can cause incontinence, loss of muscle tone, pressure sores, depression and decreased appetite.

People with Alzheimer's have the right to receive care without the use of physical or chemical restraints that are not needed to treat a medical condition. Care providers have an obligation to try alternatives to restraints, such as diversions for aggressive behavior or safe places to wander.

Hospice care

People with Alzheimer's disease will likely be in and out of nursing homes and hospitals as the disease advances. One unique care option is hospice.

The underlying philosophy of hospice focuses on quality and dignity by providing comfort, care and support services for people with terminal illnesses and their families.

Hospice places an emphasis on maximizing patient comfort and providing counseling and bereavement services to the family before and after their loved one dies.

To qualify for hospice benefits under Medicare, a physician must diagnosis the person with Alzheimer's disease as having less than six months to live.

Support for caregivers

It is important for caregivers to seek support, particularly during this difficult stage of the disease. Local chapters of the Alzheimer's Association have support groups and help lines that allow caregivers to deal with the emotions they may be experiencing, including stress, grief, guilt, anger and depression.

Long-Distance Caregiving

Introduction

Caring for a loved one who lives far away can be emotionally and financially exhausting.

Concerns about your loved one's safety, nutrition, health and care may seem overwhelming. You may also feel guilty and anxious because you cannot be there every day to see how the person is doing.

This page offers advice on coping with long-distance care giving and considerations for when it's time to move your loved one into an assisted living facility.

Determine what services are needed

If the person with Alzheimer's disease lives alone, it is important to monitor his or her ability to manage various daily tasks. Visit the person with Alzheimer's disease to determine what kind of assistance he or she may need. Make the following observations:

- Is there appropriate and adequate food available?

- Is the person eating regular meals?
- What is the condition of the living environment? Has it changed?
- Are the bills paid?
- Is checkbook in order?
- Do friends and relatives visit regularly?
- Is the person maintaining personal care routines such as bathing and grooming?
- Is the person still able to drive safely?

If you are unable to answer these questions, the person's doctor, neighbors, family members and friends can be good sources of information.

Turn to others for help

Establishing an informal support system can help ensure the person's safety and give you peace of mind.

- Family members and friends can provide companionship. Ask them to visit once a week or so, depending on how far away they live.
- Neighbors can check regularly on your loved one. Ask if they will remain alert to anything unusual such as the smell of smoke or the sound of an alarm coming from your relative's home.
- Community organizations, such as churches, synagogues, neighborhood groups and volunteer organizations, often provide companion services.

Make the most of visits

Few long-distance caregivers are able to spend as much time with their loved one as they would like. The key is to make periodic visits and use your time effectively:

- Make appointments with your loved one's physician, lawyer and financial adviser during your visit to facilitate decision making.
- Meet with neighbors, friends and other relatives to hear their observations about how the person is doing. Ask if there have been any behavioral changes, health problems or safety issues.
- Take time to reconnect with your loved one by talking, listening to music, going for a walk or participating in activities you enjoy together.

Consider carefully before moving a loved one into your home

The decision to move the person to your home is influenced by many factors. Here are some things to think about before moving the person into your home:

- Does he or she want to move? What about his or her spouse?
- Is it possible to create an environment similar to their own home using same furnishings and draperies?
- Can accommodations be made for the persons pet?
- Can favorite artwork or pictures be placed on the walls in the new home?
- Is your home equipped for this person?
- Will someone be at home to care for the person?
- How does the rest of the family feel about the move?
- How will this move affect your job, family and finances?
- What respite services are available in your community to assist you?

Moving a person with Alzheimer's disease from familiar surroundings may cause increased agitation and confusion. You may want to talk with your loved one's physician or a social worker or call your local Alzheimer's Association chapter for assistance before making a decision. In some situations, an assisted living or a residential care setting may be a better option for the individual.

Caring for a loved one in a facility

Whether your loved one lives in an assisted living or a residential care facility, it is important to maintain ongoing communication with the care staff and friends who visit regularly.

- Work with the managing nurse and physician. Agree on a time when you can call to get updates on the person's condition and progress.
- Call family, friends or other visitors and ask for their observations.
- When you visit, meet with the staff members who have primary responsibility for your loved one's care.

Resolving family conflicts

Caregiving issues can often ignite or magnify family conflicts, especially when people cope differently with caregiving responsibilities.

Family members may deny what is happening, resent you for living far away or believe you are not helping enough. There may also be disagreement about financial and care decisions.

To minimize conflicts, try to acknowledge these feelings and work through them.

- Have a family meeting. Talking about caregiving roles and responsibilities, problems, and feelings can help ease tensions. You may want help from a professional counselor or clergy.
- Recognize differences. Some family members may be hands-on caregivers, responding immediately to issues and organizing resources. Others may be more comfortable with being told to complete specific tasks.
- Share caregiving responsibilities. Make a list of tasks and include how much time, money and effort may be involved to complete them. Divide tasks according to the family member's preferences and abilities.
- Continue to communicate. Periodic family meetings or conference calls keep the family up-to-date and involved. Discuss how things are working, reassess the needs of both the person with Alzheimer's and the caregiver and decide if any changes in responsibilities are needed.

Many long-distance caregivers feel guilty for living far away from the person with Alzheimer's. This guilt, compounded by the grief related to seeing a loved one's decline, may make it difficult to emotionally recover from a visit. It is important to seek support from family, friends, a counselor, or the Alzheimer's Association to help deal with these feelings.

Monitoring Abuse

Introduction

People with Alzheimer's are vulnerable to abuse by people close to them. They may also fall prey to strangers who take advantage of their cognitive impairment.

Types of abuse

- Physical — causing physical pain or injury
 - Emotional — verbal assaults, threats of abuse, harassment and intimidation
 - Neglect — failure to provide necessities, including food, clothing, shelter or medical care
 - Confinement — restraining or isolating the person
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- Financial — the misuse or withholding of the person's resources to his or her disadvantage or the advantage of someone else
 - Sexual abuse — touching, fondling or any sexual activity when the person is unable to understand, unwilling to consent or threatened or physically forced
 - Willful deprivation — willfully denying the person medication, medical care, food, shelter, or physical assistance, and thereby exposing the individual with Alzheimer's to the risk of physical, mental or emotional harm

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Coping with stress

Caregivers — both family and professionals — are most often the abusers of older people. In many cases, stress and frustration may provoke unintentional violent feelings in caregivers. Family caregivers may feel isolated, depressed and resentful toward their loved as the disease progresses and may become abusive without realizing it. Other issues, such as substance abuse, emotional problems and dependency, may also lead to mistreatment.

If you are having difficulty dealing with stress related to caregiving, it is important to get the support you need through a counselor, clergy or Association-sponsored support group. To contact your local

Music, Art and Other Therapies



Introduction

Music, art, pet and other types of therapies can help enrich the lives of people with Alzheimer's disease. Pets, for instance, have been shown to reduce depression and boost self-esteem. Art provides an outlet for expression. Music stirs memories, emotions and when accompanied by singing, encourages group activity. Create guidelines for all activities in order to ensure their effectiveness.

Music therapy guidelines

- Identify music that's familiar and enjoyable to the listeners.
- Use live music, tapes or CDs; radio programs, interrupted by too many commercials, can cause confusion.
- Use music to create the mood you want.
- Link music with other reminiscence activities; use questions or photographs to help stir memories.
- Encourage movement (clapping, dancing) to add to the enjoyment.
- Avoid sensory overload; eliminate competing noises by shutting windows and doors and by turning off the television.

Art therapy guidelines

- Keep the project on an adult level. Avoid using crayons or anything else that might be demeaning or seem child-like.
- Build conversation into the project. Provide encouragement, discuss what the person is creating and try to initiate a bit of creative storytelling or reminiscence.
- Help the person begin the activity. If the person is painting, you may need to start the brush movement. Most other projects should only require basic instruction and assistance.
- Use safe materials. Avoid toxic substances and sharp tools. Allow plenty of time to complete the art project.
- The person doesn't have to finish the project in one sitting.
- And remember: The artwork is complete when the person says it is.

Pet therapy guidelines

- Studies have shown Alzheimer's patients have fewer anxious outbursts if there is an animal in the home.
- Not everyone will react positively to animals. Those who owned pets previously tend to be more responsive.

Tracking Symptoms

Many caregivers find it useful track their loved ones symptoms in a journal. This record may be helpful when you meet with health care professionals when they ask you if there have been any changes with the person's memory or behavior.

In addition, you may find it helpful to review the journal from time-to-time, reminding yourself of caregiving strategies that have worked.

For each day you are tracking, note the following:

- Problems or changes in the following areas:
 - Memory
 - Behavior
 - Personality
 - Skills (e.g. can get dress and feed themselves)
- Caregiving strategies that worked? Strategies that did not work?
- Activities the person with dementia enjoys.
- Any medications the person took that day (include prescriptions, over-the-counter and herbal remedies):
 - Medication name
 - Dosage
 - When and how many taken daily

Caregiving Challenges

Introduction

Alzheimer's disease can cause a person to exhibit unusual and unpredictable behaviors that challenge caregivers, including severe mood swings, verbal or physical aggression, combativeness, repetition of words, and wandering. These behavioral changes can lead to frustration and tension, for both people with Alzheimer's and their caregivers. It is important to remember that the person is not acting this way on purpose, and to analyze probable causes and develop care adjustments.

Common causes of behavior changes

- Physical discomfort caused by an illness or medications
- Over stimulation from a loud or overactive environment
- Inability to recognize familiar places, faces or things
- Difficulty completing simple tasks or activities
- Inability to communicate effectively

Tips for responding to challenging behaviors

- Stay calm and be understanding
- Be patient and flexible
- Don't argue or try to convince the person
- Acknowledge requests and respond to them
- Try not to take behaviors personally
- Accept the behavior as a reality of the disease and try to work through it

Exploring causes and solutions

It is important to identify the cause of the challenging behavior and consider possible solutions.

Identify and examine the behavior

- What was the undesirable behavior? Is it harmful to the individual or others?
- What happened before the behavior occurred and did something trigger it?

Explore potential solutions

- Is there something the person needs or wants?
- Can you change the surroundings? Is the area noisy or crowded? Is the room well-lighted?
- Are you responding in a calm, supportive way?

Try different responses in the future

- Did your response help?
- Do you need to explore other potential causes and solutions? If so, what can you do differently?

Agitation

Introduction

The term agitation is used to describe a large group of behaviors associated with Alzheimer's disease. As the disease progresses, most people with Alzheimer's experience agitation in addition to memory loss and other thinking symptoms.

Agitated behaviors

In the early stages of the disease, people with Alzheimer's may experience personality changes such as irritability, anxiety or depression. As the disease progresses, other symptoms may occur, including sleep disturbances, delusions (firmly held belief in things that are not real), hallucinations (seeing, hearing or feeling things that are not there), pacing, constant movement or restlessness, checking and rechecking door locks or appliances, tearing tissues, general emotional distress and uncharacteristic cursing or threatening language.

Possible causes of agitation

Agitation may be caused by a number of different medical conditions and drug interactions or by any circumstances that worsen the person's ability to think. Situations that may lead to agitated behavior include moving to a new residence or nursing home, other changes in the environment or caregiver arrangements, misperceived threats, or fear and fatigue resulting from trying to make sense out of a confusing world.

Treating agitation

A person exhibiting agitated behavior should receive a thorough medical evaluation, especially when agitation comes on suddenly. The treatment of agitation depends on a careful diagnosis, determination of the possible causes and the types of agitated behavior the person is experiencing. With proper treatment and intervention, significant reduction or stabilization of the symptoms can often be achieved.

There are two distinct types of treatments for agitation: behavioral interventions and prescription medications. Behavioral treatments should be tried first. In general, steps to managing agitation include (1) identifying the behavior, (2) understanding its cause and (3) adapting the caregiving environment to remedy the situation.

Preventing agitation

General caregiving strategies to prevent or reduce agitated behaviors include the following:

- Create a calm environment: remove stressors, triggers or danger; move person to a safer or quieter place; offer rest or privacy; limit caffeine use; provide opportunity for exercise; develop soothing rituals; and use gentle reminders.
- Avoid environmental triggers: noise, glare, insecure space and too much background distraction, including television.
- Monitor personal comfort: check for pain, hunger, thirst, constipation, full bladder, fatigue, infections and skin irritation; ensure a comfortable temperature; be sensitive to fears, misperceived threats and frustration with expressing what is wanted.
- Simplify tasks and routines.
- Allow adequate rest between stimulating events.
- Use lighting to reduce confusion and restlessness at night.

Identifying agitation triggers

Correctly identifying what has triggered agitated behavior can often help in selecting the best behavioral intervention. Often the trigger is some sort of change in the person's environment:

- Change in caregiver
- Change in living arrangements
- Travel
- Hospitalization
- Presence of houseguests
- Bathing or changing clothes

During an episode of agitation

- **Do:** Redirect the person's attention, back off and ask permission, use calm positive statements, reassure, slow down, use visual or verbal cues, add light, offer guided choices between two options, focus on pleasant events, offer simple exercise options or limit stimulation.
- **Do not:** Raise voice, take offense, corner, crowd, restrain, rush, criticize, ignore, confront, argue, reason, shame, demand, condescend, force, explain, teach, show alarm or make sudden movements out of the person's view.
- **Say:** May I help you? Do you have time to help me? You're safe here. Everything is under control. I apologize. I'm sorry that you are upset. I know it's hard. I will stay until you feel better.

Safety measures

- Equip doors and gates with safety locks.
- Remove guns and knives from the person's environment.

Combativeness

Introduction

When individuals with dementia are frustrated, scared or unable to communicate, they may become aggressive and even combative.

Possible causes

Combativeness can be caused by many factors including physical discomfort, environmental factors and poor communication. If the person you are caring for is exhibiting combativeness, consider the following:

Physical discomfort

- Is the person tired because of inadequate rest or sleep?

Are medications causing side effects?

- Is the person unable to let you know he or she is experiencing pain?

Environmental factors

- Is the person over stimulated by loud noises, an overactive environment or physical clutter?
- Does the person feel lost or abandoned?

Poor communication

- Are you asking too many questions or making too many statements at once?
- Are your instructions simple and easy to understand?
- Is the person picking up on your own stress and irritability?
- Are you being negative or critical?

Caregiving tips

- Identify signs of frustration. Look for early signs of frustration during activities such as bathing, dressing or eating. Respond in a calm and reassuring tone.
- Don't take the behavior personally. The person isn't necessarily angry with you. He or she may have misunderstood the situation or be frustrated with lost abilities caused by the disease.

- Avoid teaching. Avoid elaborate explanations and arguments. Be encouraging and don't expect the person to do more than he or she can.
- Use distractions. If the person is frustrated because he or she can't unbutton a shirt, distract the person with another activity. After some time has passed you can return to helping the person unbutton the clothing item.
- Communicate directly with the person. Avoid expressing anger or impatience in your voice or physical action. Instead use positive, accepting expressions, such as "don't worry" or "thank you." Also use touch to reassure and comfort the person. For example, put your arm around the person or give him or her a kiss.
- Decrease level of danger. Assess the level of danger — for yourself and the person with Alzheimer's. You can often avoid harm by simply stepping back and standing away from the person. If the person is headed out of the house and onto the street, be more assertive.
- Avoid using restraint or force. Unless the situation is serious, avoid physically holding or restraining the person. He or she may become more frustrated and cause personal harm.

Hallucinations

Introduction

A hallucination is a false perception of objects or events involving the senses. When individuals with Alzheimer's disease have a hallucination, they see, hear, smell, taste or feel something that isn't there. The person may see the face of a former friend in a curtain or may hear people talking.

If the hallucination doesn't cause problems for you, the person or other family members, you may want to ignore it. However, if they happen continuously, consult a physician to determine if there is an underlying physical cause. Also, have the person's eyesight and hearing checked, and make sure the person wears his or her glasses and hearing aids on a regular basis.

Offer reassurance

- Respond in a calm, supportive manner.
- A gentle tap on the shoulder may turn the person's attention toward you.
- Look for the feelings behind the hallucinations. You might want to say, "It sounds as if you're worried" or "I know this is frightening for you."
- Avoid arguing with the person about what he or she sees.

Use distractions

- Suggest that you take a walk or sit in another room. Frightening hallucinations often subside in well-lit areas where other people are present.
- Try to turn the person's attention to music, conversation or activities you enjoy together.

Modify the environment

- Check for noises that might be misinterpreted, such as noise from a television or an air conditioner. Look for lighting that casts shadows, reflections or distortions on the surfaces of floors, walls and furniture.
- Cover mirrors with a cloth or remove them if the person thinks that he or she is looking at a stranger.

Incontinence

Incontinence, a loss of bladder or bowel control, often occurs in people who have Alzheimer's.

Incontinence can be caused by:

- **Medical conditions.** The person may have a urinary tract infection, constipation or a prostate problem. Other illnesses, such as diabetes and stroke, and medication side effects may also trigger incontinence.
- **Fear.** The person may fear that an embarrassing accident may occur. This fear may cause him or her to visit the bathroom more times than necessary.
- **Abrupt movement.** Urine release may be caused by a sneeze, laugh or cough. Weak pelvic muscles in women can also cause uncontrollable loss of urine.
- **Dehydration.** Withholding fluids when a person starts to lose bladder control may compound the problem. Dehydration can create urinary tract infections that lead to incontinence.
- **Diuretics.** Certain beverages, such as coffee, cola and tea, may contribute to incontinence.
- **Environment.** The person may be having trouble finding the bathroom or getting to it in time because it is too far away.
- **Clothing.** Zippers and buttons on clothing could be making it difficult for the person to undress.

You can help by:

- **Providing visual cues.** Signs may assist an individual in finding the bathroom. Placing colored rugs on the bathroom floor and lid covers on the toilet may help the bathroom stand out. Avoid having items nearby that can be mistaken for a toilet, such as a trash can.
- **Monitoring incontinence.** Identify when accidents occur and plan accordingly. For example, if they happen every two hours, get the person to the bathroom before that time. To help control incontinence at night, limit the intake of liquids after dinner and in the evening.
- **Removing obstacles.** Make sure clothing is easy for the individual to remove. Clothing with Velcro™ may be easier for the person to remove than clothing with buttons.
- **Providing reminders.** Because the person with Alzheimer's may forget to use the bathroom, you may need to remind him or her periodically. Also watch for visible cues such as restlessness or facial expressions that may indicate the person needs to use the bathroom.
- **Being supportive.** Help the person with Alzheimer's retain a sense of dignity despite incontinence problems. A reassuring attitude will help lessen feelings of embarrassment.

Sleeplessness and Sundowning

Sleeping problems experienced by individuals with Alzheimer's and caregiver exhaustion are two of the most common reasons people with Alzheimer's are eventually placed in nursing homes. Some studies indicate that as many as 20 percent of persons with Alzheimer's will, at some point, experience periods of increased confusion, anxiety, agitation and disorientation beginning at dusk and continuing throughout the night.

While experts are not certain how or why these behaviors occur, many attribute them to late-day confusion, or "sundowning," caused by the following factors:

- End-of-day exhaustion (mental and physical)
- An upset in the "internal body clock," causing a biological mix-up between day and night
- Reduced lighting and increased shadows
- Disorientation due to the inability to separate dreams from reality when sleeping
- Less need for sleep, which is common among older adults

Tips for reducing evening agitation and nighttime sleeplessness

- **Plan more active days.** A person who rests most of the day is likely to be awake at night. Discourage afternoon napping and plan activities, such as taking a walk, throughout the day.
- **Monitor diet.** Restrict sweets and caffeine consumption to the morning hours. Serve dinner early, and offer only a light meal before bedtime.
- **Seek medical advice.** Physical ailments, such as bladder or incontinence problems, could be making it difficult to sleep. Your doctor may also be able to prescribe medication to help the person relax at night.
- **Change sleeping arrangements.** Allow the person to sleep in a different bedroom, in a favorite chair or wherever it's most comfortable. Also, keep the room partially lit to reduce agitation that occurs when surroundings are dark or unfamiliar.

Nighttime restlessness doesn't last forever. It typically peaks in the middle stages, then diminishes as the disease progresses. In the meantime, caregivers should make sure their home is safe and secure, especially if the person with Alzheimer's wanders. Restrict access to certain rooms or levels by closing and locking doors, and install tall safety gates between rooms. Door sensors and motion detectors can be used to alert family members when a person is wandering.

Once the person is awake and upset, experts suggest that caregivers:

- Approach their loved one in a calm manner
- Find out if there is something he or she needs
- Gently remind him or her of the time
- Avoid arguing or asking for explanations
- Offer reassurance that everything is all right and everyone is safe

Unpredictable Situations

Introduction

People with Alzheimer's disease can act in different and unpredictable ways. It is important to remember that the person is not acting this way on purpose. Whatever the behavior, try to identify the cause and possible solution.

Bold behavior

Individuals with Alzheimer's disease may forget that they are married and begin to flirt or make inappropriate advances toward others.

When there is unusual, inappropriate behavior, try to distract the person with another activity or lead him or her into a private place. Avoid getting angry or laughing at the person.

Inappropriate dressing

The person may forget how to dress or take clothes off at inappropriate times and in unusual settings. For example, a woman may remove a blouse or skirt simply because it is too tight or uncomfortable.

Help the person dress by laying out clothes in the order they need to be put on. Choose clothing that is simple and comfortable.

Shoplifting

The person with Alzheimer's may not understand or remember that merchandise must be paid for. He or she may casually walk out of the store without paying — unaware of any wrongdoing.

Have your loved one carry a wallet-size card that states that he or she is memory-impaired. This may prevent the person with Alzheimer's disease from feeling embarrassed.

Paranoia

The person may become easily jealous and suspicious. For example, a man may think his wife has a boyfriend if he sees her with their son. A person with Alzheimer's may also misinterpret an unfamiliar face as someone who is a thief.

If the person makes accusations or becomes extremely suspicious, don't waste time arguing. Try to distract the person with another activity or reassure him or her with a hug or touch.

Wandering

Introduction

An individual with Alzheimer's disease or a related dementia is likely to become disoriented and wander at some point. Up to 67 percent of those with dementia will wander. Identifying the cause of the behavior can help eliminate or reduce its occurrence. Awareness of the problem can result in reduced injury and death.

Wandering defined

Persons with dementia have varied movement patterns and trying to identify what qualifies as wandering can be difficult for a caregiver as well as for professionals. Many people with dementia do not fit the textbook definition of wandering, "To move about without a definite destination or purpose." In fact, persons with dementia may have a definite purpose for their actions.

The working definition that best describes wandering is, "aimless or purposeful motor activity that causes a social problem such as getting lost, leaving a safe environment or intruding in inappropriate places."

Is someone I know at risk? Warning signs for wandering

1. Returns from a regular walk or drive later than usual
2. Tries to fulfill former obligations, such as going to work
3. Tries or wants to "go home" even when at home
4. Is restless, paces or makes repetitive movements
5. Has difficulty locating familiar places like the bathroom, bedroom or dining room
6. Checks the whereabouts of familiar people
7. Acts as if doing a hobby or chore, but nothing gets done (e.g. moves around pots and dirt without actually planting anything)
8. Appears lost in a new or changed environment

Causes

Wandering can be caused by several factors, including:

- Medication side effects
- Stress

- Confusion related to time
- Restlessness
- Agitation
- Anxiety
- Inability to recognize familiar people, places and objects
- Fear arising from the misinterpretation of sights and sounds
- Desire to fulfill former obligations, such as going to work or looking after a child

Tips for reducing wandering behavior

- Encourage movement and exercise to reduce anxiety, agitation and restlessness
- Involve the person in productive daily activities, such as folding laundry or preparing dinner
- Place color-matching cloth/paint over doorknobs
- Redirect pacing or restless behavior
- Place a mirror near doorways
- Reassure the person if he or she feels lost, abandoned or disoriented

Tips for protecting a loved one from wandering

- Enroll the person in the [Alzheimer's Association's Safe Return®](#), a nationwide identification system designed to assist in the safe return of people who become lost when wandering
- Inform your neighbors and local emergency responders of the person's condition and keep a list of their names and telephone numbers
- Keep your home safe and secure by installing deadbolt or slide-bolt locks on exterior doors and limiting access to potentially dangerous areas
- Be aware that the person may not only wander by foot but also by car or by other modes of transportation

Tips for preparing for emergencies

- Keep a list of emergency phone numbers of the local police and fire departments, hospitals, and poison control as well as the Safe Return 24/7 incident line 1.800.572.1122
- Keep a list of physicians phone numbers and current medications (with dosages)

- Keep copies of legal documents (living will, power of attorney, etc.)
- Check fire extinguishers and smoke alarms, and conduct fire drills regularly

Coping

Caring for someone who has Alzheimer's disease can be overwhelming, exhausting and stressful. A family caregiver may feel loss over changes in relationships with a loved one with Alzheimer's, other family members and friends. During this time, it is critical that caregivers look after their own physical and mental health.



Your Health

Are you so committed to caregiving tasks that you've neglected your own physical, mental and emotional well-being?

The following questions may help you determine if you are putting your health at risk:

Do you visit your physician annually?

The best thing you can do for the person with Alzheimer's disease is to stay healthy. Respect what your body is telling you. Take exhaustion, stress, sleeplessness and changes in your appetite or behavior seriously. Ignoring these symptoms can cause your physical and mental health to decline.

Do you accept assistance from others?

You can't do everything. Attempting to handle everything yourself will only lead to burnout, depression and resentment toward the person you care for. You are not failing as a caregiver by asking others for assistance. When friends and family offer help, accept it. Also look into community resources that offer respite from caregiving responsibilities.

Do you talk to others about your feelings?

You may think that no one understands what you are going through. Holding in your feelings, however, will only make you feel isolated and emotionally neglected. Sharing your experiences with others may help you put things into perspective.



Take care!

There are six simple steps you can take to ensure that you are a healthy caregiver:

1. See your physician regularly.
2. Get screened for stress and depression.
3. Get plenty of rest.
4. Eat well-balanced meals.
5. Exercise regularly.
6. Accept help from others.

Caregiver Stress

More than 80 percent of Alzheimer caregivers report that they frequently experience high levels of stress, and nearly half say they suffer from depression. Many caregivers don't recognize their needs, fail to do anything about them or simply don't know where to turn for help. Too much stress can be damaging to caregivers and the person with Alzheimer's.



If you are a caregiver who is experiencing stress symptoms on a regular basis, consult your physician. You may also want to seek professional counseling so that you have a safe and private environment to talk about your concerns.

Warning signs of caregiver stress

- Denial
- Anger
- Social withdrawal
- Anxiety
- Depression
- Exhaustion
- Sleeplessness

- Irritability
- Lack of concentration
- Health problems

Ways to reduce caregiver stress

- Know what respite resources are available in your community so that you can take a break.
- Become educated about Alzheimer's disease and caregiving techniques.
- Get help from family, friends, and community resources.
- Take care of yourself — get good nutrition, exercise and plenty of rest.
- Manage your level of stress by using relaxation techniques.
- Accept changes as they occur.
- Plan for legal and financial issues to avoid handling them in a crisis situation.
- Be realistic about what you can do.
- Give yourself credit for what you have accomplished; don't feel guilty if you lose patience or can't do everything on your own.
- Connect with other caregivers by initiating an online community. You can share experiences with others who know exactly what you are going through.

Depression and Caregivers

Introduction

Stress, anger, guilt and grief related to caregiving can lead to depression. Caregivers can experience depression at any point in the disease process. If you are experiencing depression that is affecting both your physical and mental well-being, seek immediate help from your physician.

Symptoms of depression

The presence of at least four of the following symptoms over a two-week period may indicate depression:

- Depressed or irritable mood
- Feelings of worthlessness or excessive guilt
- Suicidal thinking or attempts
- Motor retardation or agitation
- Disturbed sleep
- Fatigue and loss of energy
- Loss of interest or pleasure in usual activities
- Difficulty thinking or concentrating
- Changes in appetite and weight

Source: American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders

Treatment is available

If symptoms of depression are present, it is important for you to obtain a complete medical evaluation to rule out any other physical causes. Medications or an unrecognized disorder may cause depression.

If there are no other underlying causes, consult a psychiatrist to obtain a diagnosis. Geriatric psychiatrists specialize in recognizing and treating depression in older adults.

Changes in Relationships

Introduction

If you are a caregiver, you will experience changes in relationships with your loved one with Alzheimer's, and with family members and friends.

Relationships

You may find yourself taking on a new role in your relationship as your partner's memory worsens. The person with Alzheimer's disease may no longer be able to perform certain tasks, such as balancing the checkbook, doing the taxes, handling financial and legal matters and doing certain household chores. Making important decisions on your own may feel overwhelming.

To be prepared for this role reversal, it is important that you locate financial and legal documents, such as life insurance policies, property deeds and retirement accounts, soon after your loved one is diagnosed. You may need to turn to family, friends, professionals or community resources for assistance.

Intimacy

You may be feeling enormous grief over the changes in your relationship. You are not selfish for experiencing these feelings. Given your partner's cognitive decline, you may no longer be able to have the same emotional or physical intimacy that you once shared.

It is typical that people with Alzheimer's disease experience changes in their sexual drive. Depression can cause a reduced interest in sex. Some caregivers report changes in sexual feelings toward their loved one as a result of providing daily caregiving tasks. A physical illness and reactions to medications can also reduce sexual desire.

Changes caused by the disease may cause the person with the disease to exhibit inappropriate behavior and an increased sexual drive. React to your partner with patience and gentleness. Give your loved one plenty of physical contact with hugs or holding hands. In many cases, he or she may simply be anxious and need reassurance through touch and gentle, loving communication.

Family and friends

You may feel socially isolated because your family and friends may have pulled back from your relationship or you have little time to spend with them. Your family and friends may hesitate to spend time with you and the person with Alzheimer's disease because they worry about not knowing what to do or say. They may also not understand the behavior changes caused by the disease or are not able to accept that the person has the disease.

Take the initiative to contact family and friends and explain that while Alzheimer's disease has changed your lives in some ways, you value their friendship and support. Considering inviting a few friends or family members over. Let them know in advance of any physical or emotional changes in the person with dementia. Provide them suggestions about how to communicate with the person and what activities they might be able to do together.

Resolving family conflicts

Caregiving issues can often ignite or magnify family conflicts, especially when people cope differently when faced with caregiving responsibilities.

Family members may deny what is happening or resent family members who live far away or are not helping enough. There may also be disagreement about financial and care decisions.

To minimize conflicts, try to acknowledge these feelings and work through them.

- **Have a family meeting.** Talking about caregiving roles and responsibilities, problems and feelings can help ease tensions. You may want help from a professional counselor or clergy.
- **Recognize differences.** Some family members may be hands-on caregivers, responding immediately to issues and organizing resources. Others may be more comfortable with being told to complete specific tasks.
- **Share caregiving responsibilities.** Make a list of tasks and include how much time, money and effort may be involved to complete them. Divide tasks according to the family member's preferences and abilities.
- **Continue to communicate.** Periodic family meetings or conference calls keep the family up-to-date and involved. Discuss how things are working, reassess the needs of both the person with Alzheimer's and the caregiver, and decide if any changes in responsibilities are needed.

Loss

If you are a caregiver, you can expect to experience feelings of loss, especially as your life and the person you love are changed by Alzheimer's disease. The natural phases of grieving usually involve denial, anger, guilt, physical symptoms and eventually acceptance. However, it is important to know that everyone grieves differently.

Symptoms of grief:

- Denial that your loved one is ill
- Periods of helplessness, despair and depression
- Changes in appetite or sleep patterns
- Feelings of anger or frustration with the person with Alzheimer's and with caregiving tasks
- Withdrawal from social activities, friends, family and the person you care for

Throughout the process of grieving and mourning, guilt is often the most prevalent feelings for caregivers. Guilt can be related to:

- Thinking you could have done something differently
- Being able to enjoy life while your loved one may not
- Feelings that you have failed, especially if your loved has been placed in a nursing home
- Negative thoughts about the person with the disease — wishing that his or her suffering would come to an end
- Conflicts with family members because they are uninvolved or critical of the care that's being provided

In many cases feelings of guilt are linked to unrealistic expectations. To cope with the grieving process, try taking the following action steps:

- Confront your feelings
- Accept guilt as a normal part of loss and grief
- Find ways to forgive yourself

- Share your feelings with a friend, support group, therapist or spiritual leader
- Learn to feel comfortable accepting and celebrating good things in your life

If grieving is so prolonged or severe that your physical and mental well-being are at risk, seek help from your physician. There are ways that you can begin to cope with grief, including:

- Returning to some aspects of your daily routine
- Allowing time for physical exercise, play and rest
- Trying to find humor — even in difficult situations
- Bringing balance to your life by doing things that you enjoy
- Preparing for what the future may entail

Talking to Children and Teens

Introduction

Alzheimer's disease has a large impact on family life. It is important to take the time to talk with the children and teens in your family so they understand what is happening to the person with Alzheimer's.

The degree to which children and teens are affected by the disease depends on who has the disease — a parent or grandparent, relative or friend. Other factors include how close the child or teen is to the person and where the person lives (in the same home, assisted living or nursing home, out-of-state, in close proximity).

Feelings and reactions

Children and teens may feel:

- Sad about changes in a loved one's personality and behavior
- Confused or afraid about why the person behaves differently
- Worried that the disease is contagious and that they will get it
- Worried that their parents might develop the disease
- Angry and frustrated by the need to repeat activities or questions
- Guilty for getting angry or being short-tempered with the person
- Jealous and resentful because of the increased amount of time and attention that is given to the person with Alzheimer's
- Embarrassed to have friends or other visitors to the house

Children and teens may exhibit their emotions in ways you may not easily recognize. They may:

- Verbalize vague physical complaints, such as a stomachache or headache
- Perform poorly in school
- Spend more time away from home
- Stop inviting friends to the house

Ways to help children and teens cope

- Maintain open lines of communication

- Offer comfort and support
- Provide opportunities for them to express their feelings
- Let them know their feelings are normal
- Educate them about the disease and encourage them to ask questions
- Respond honestly to questions

Activities that can help and be done as a family

- Go for a walk
- Do household chores together, such as folding laundry, raking leaves or washing dishes
- Listen to music, dance or sing
- Look at old photographs
- Read a favorite book or newspaper
- Develop a memory book about the person
- Make a family tree
- Watch a movie
- Keep a journal together

Respite Care

Respite care provides caregivers temporary relief from the intensive demands of their daily caregiving responsibilities. Respite also strengthens caregivers to continue to provide on-going care in the home.

Respite care is mainly offered through community organizations or residential facilities. The most common respite care programs are in-home care and adult day services.

In-home services offer a range of options, including companion services, personal care, household assistance and skilled care services to meet specific needs. In-home helpers can be employed privately, through an agency, or as part of a government program.

Adult day services provide the person with Alzheimer's opportunities to interact with others, usually in a community center or facility. Staff lead in various activities such as music programs and support groups. Transportation and meals are often provided.



Planning Ahead

If you are a caregiver, you will be involved in helping to plan for the future legal, financial and care needs of your loved one with Alzheimer's. Legal and financial planning should begin soon after a diagnosis has been made. The earlier you explore care alternatives, the more likely you are to find options that you and your loved one prefer.



Planning for the Future

After a diagnosis of Alzheimer's, you may worry about the impact the disease will have on you and your family. Planning ahead is one way to deal with those fears. By participating in decisions now, you can determine the kind of life you want for the years ahead. In this section, you will find information and tips to help you begin planning.



Choosing Health Care Providers and Facilities

Introduction

You may be able to live independently and safely for some time on your own or with the help of a family member or hired caregiver. As Alzheimer's advances, there may come a time when your day-to-day care will require the skills of a full-time health care staff.

To make sure that your needs and preferences for care are understood, talk about the options available to you with a family member or trusted friend. The sooner you do this, the more likely you are to find those options with services you prefer.

Care services tend to fall into three categories: respite care, residential care and hospice care. The cost for each type of care differs by service and community. Financial assistance may be available through state or federal programs (e.g., Medicaid or the Veterans Administration).

Selecting a care provider

There are important questions to ask when deciding on care providers.

Questions to ask in-home caregivers:

- What is your training and experience in working with people with dementia?
- What times are you available?

- Who would substitute if you can't come?
- Whom can I talk to at the agency if I have a concern?

Concerns when choosing a residential care facility:

- Observe how the environment promotes independence of the residents, provides safety and security, and reflects your own preferences for comfort.
- Ask the care provider if the staff is continually trained on dementia care issues, what kind of programs are offered for people with Alzheimer's, and how they address an increasing need for care.
- Ask the provider if residents and family members can participate in creating and reviewing care and service plans.
- Spend time in a variety of facilities observing what goes on and how people are treated. Talk with residents and visitors about their opinions of the facility and staff. See if the residents look happy, comfortable, relaxed and involved in activities.
- Talk with staff working directly with residents to see if they are competent and content in their jobs. Also, meet with the administrator and directors of nursing and social services.
- Visit a facility more than once before making a decision.

Respite care

Respite care provides your caregiver temporary relief from tasks associated with caregiving. You benefit from opportunities to socialize with others and live in the community longer. Respite care is mainly offered through community organizations or residential facilities. The most common respite care programs are in-home care and adult day services.

In-home services offer a range of options, including companion services, personal care, household assistance and skilled care services to meet specific needs. In-home helpers can be employed privately, through an agency or as part of a government program.

Adult day services provide you with opportunities to interact with others, usually in a community center or facility. Staff lead various activities such as music programs and support groups. Transportation and meals are often provided.

Residential care facilities

The following are types of facilities that may meet your needs, depending on the level of care you require:

- Retirement housing generally provides each resident with an apartment or room that includes cooking facilities. This type of housing usually does not have round-the-clock staff on-site. Staff members may have little or no knowledge about dementia. This setting may be appropriate for persons in the early stage of Alzheimer's who can still care for themselves independently and live alone safely.
- Assisted living facilities (or board and care homes) bridge the gap between living independently and living in a nursing home. Facilities typically offer a combination of housing and meals; supportive, personalized assistance; and health care services.
- Skilled nursing facilities (also known as nursing homes) may be the best choice when a person needs round-the-clock care or ongoing medical treatment. Most nursing homes have services and staff to address issues such as nutrition, care planning, recreation, spirituality and medical care. Many facilities have special care units designed to meet the unique needs of people with dementia.
- Continuing care retirement communities (CCRC) provide all of the different types of options described above. In these facilities, a person may receive all of the different levels of care on one campus but may need to be moved between buildings to receive different services.

Hospice care

Hospice programs provide care to persons in the late stages of Alzheimer's disease. Hospice emphasizes a philosophy of comfort and care at the end of life without using drastic lifesaving measures. This service is available through local hospice organizations and some home care agencies, hospitals and nursing homes.

Insurance Coverage

Introduction

Our national patchwork of insurance programs presents special challenges in reimbursement for dementia care. The Alzheimer's Association advocates before legislative bodies and in other public forums on the need for more equitable coverage and reimbursement of professional care for Alzheimer's disease and related disorders. This section contains a brief overview of Medicare and Medicaid, the two publicly funded programs with significant applicability to dementia care.

Other forms of insurance are available to be purchased privately which will provide varying levels of coverage to patients with long term care needs. Some group health insurance policies may include a home health care benefit. Insurance companies have also developed long term care products specifically providing coverage for individuals with these types of needs.

Medicare

In collaboration with the American Bar Association's Commission on Legal Problems of the Elderly, the Alzheimer's Association has initiated a Medicare Advocacy Project to gather information and identify problems encountered by beneficiaries and providers. The project's director, attorney Leslie Fried, works closely with Alzheimer's Association public policy staff on the identification of Medicare trends, problems and patterns of recurring issues, and assists with the development of appropriate federal policy positions related to Medicare and health care delivery

Coding and reimbursement for Alzheimer care: The most appropriate code for diagnosis and management of Alzheimer's disease is 331, which is reimbursed at the usual Medicare rate of 80 percent. Alzheimer's can also be billed under diagnostic code 290 (pre-senile dementia), an older category that falls under the mental health classification. Because Medicare, like many private health insurance plans, reimburses mental health care at 50 percent, bills submitted under the 290 code are reimbursed at the lower rate. The 331 code should be used to ensure appropriate reimbursement.

Physical, occupational, and speech therapies: In one of its first significant victories, the Medicare Advocacy Project won reversal of a long-standing policy that automatically denied reimbursement for rehabilitative services for beneficiaries who had been diagnosed with dementia. In the fall of 2001, Medicare issued a program memorandum prohibiting denial of these services based exclusively on a dementia diagnosis. The reversal hinged on the recognition that health care professionals now can often diagnose dementia in its earliest stages, when some individuals can derive significant benefit from rehabilitative services. Payment for medical services and procedures will now be determined on a case-by-case evaluation of an individual's needs and capabilities rather than solely on a dementia diagnosis.

Psychiatric and mental health services: Medicare often denies mental health claims for beneficiaries with a primary or secondary diagnosis of dementia. These claims should not automatically be rejected, but should be evaluated and reimbursed on a case-by-case basis.

Individuals with Alzheimer's may develop treatable mental illnesses such as depression that should be covered by Medicare. Medicare pays mental health claims at 50 percent rather than the 80 percent rate for other conditions, so allowable mental health services will be reimbursed at 50 percent.

Home health care: Only Medicare beneficiaries who are "homebound" are eligible for Medicare home health care benefits. Medicare's definition of "homebound" has always been extremely strict, stipulating that leaving the home must involve "considerable and taxing effort." As of December 2000, the application of the definition was broadened to permit some individuals who attend adult day care to qualify as homebound if their day care program meets certain guidelines.

For more information:

- Visit Medicare's Web site at <http://www.medicare.gov>

Medicaid

Because Medicaid is a federal/state collaboration typically administered by each state's welfare agency, eligibility and benefits vary from state to state. Medicaid covers all or a portion of nursing home costs for individuals with Alzheimer's who meet income and asset eligibility guidelines.

Long term care Insurance

Insurance companies have designed products that provide benefits to individuals with long term care needs. These types of policies have been available for private purchase by individuals since the mid 1980s. Known as Long term Care Insurance, the policies vary substantially in benefit levels but most generally provide a benefit stated in dollars per day. The policies may also include annual and/or lifetime caps on utilization. As you might expect the cost for the policy is proportional to the level of coverage benefit purchased.

Health insurance policies

Individual insurance health insurance policies may provide a benefit for home health care services. The Explanation of Benefits section of the policy will provide information as to whether this coverage is available to the insured policy holder. If offered, the level of this coverage may vary greatly and include exclusions and caps on utilization. Therefore, it is always best to verify the coverage particulars directly with a company representative.